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Title	The quality of diabetes care in the community: practice, policy and culture
Authors	McHugh, Sheena M.
Publication date	2013
Original Citation	McHugh, S. M. 2013. The quality of diabetes care in the community: practice, policy and culture. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
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Download date	2026-11-08 12:30:57
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The Quality of Diabetes Care in the Community: Practice, Policy and Culture

A thesis submitted to the National University of Ireland, Cork for the degree of Doctor of Philosophy in the Department of Epidemiology and Public Health, School of Medicine.

August 2011

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Table of Contents

Table of Contents i
List of Tables viii
List of Figures x
Glossary xi
Declaration xii
Dedication xiii
Acknowledgements xiv
Thesis Abstract xvi
1 INTRODUCTION 1
1.1 Introduction 2
1.2 Background 2
1.3 Building on Earlier Research and Established Networks 3
1.3.1 Building on previous doctoral research 3
1.3.2 Working with Local Initiatives 4
1.3.3 The National Diabetes Register Project (NDRP) 4
1.4 Context and Terminology 5
1.4.1 Epistemology 5
1.4.2 General Practice in Ireland 7
1.4.3 Terminology for Quality Improvement 8
1.4.4 Terminology for Health Policy Analysis 8
1.5 Aims and Objectives 9
1.6 Thesis Outline 10
2 LITERATURE REVIEW 13
2.1 Introduction 14
2.1.1 Diabetes as a Model for Quality Improvement 14
2.1.2 Burden of Diabetes on Health and the Health System 14
2.1.3 Diabetes Care & the Quality Chasm 17
2.1.4 The Quality Agenda in Healthcare 18
2.1.5 Defining Quality in Health Care 18
2.1.6 Quality Frameworks: from industry to healthcare models 19
2.1.7 Chronic Care Model: Framework for Improvement in Healthcare 21
2.1.8 Improving the Quality of Diabetes Care 23
2.1.9 Reviews of organisational changes within the practice 27
2.1.10 Reviews of changes to the coordination of care 27

2.1.11 Reviews combining organisation and coordination strategies 28
2.1.12 Individual studies of Quality Improvement Interventions 33
2.1.13 Summary of the Evidence 38
2.1.14 Untangling Models of Diabetes Care 41
2.1.15 Diabetes Care in Ireland 43
2.1.16 Summary 48
2.1.17 Overview of Research 49
3 Diabetes Care in Ireland: a Survey of General Practitioners 50
Abstract 51
3.1. Introduction 52
3.1.1 Aims and Objectives 53
3.2 Methodology 54
3.2.1 Design 54
3.2.2 Instrument 54
3.2.3 Sample 54
3.2.4 Procedure 54
3.2.5 Data Management 56
3.2.6 Analysis 56
3.2.7 Ethical Approval 56
3.3 Results 57
3.3.1 Response Rate 57
3.3.2 Practice Profile 58
3.3.3 Practice population 60
3.3.4 Organisation in the Practice 62
3.3.5 Organisation and Delivery of Diabetes Care 65
3.3.6 Guidelines 71
3.3.7 Care Pathways 72
3.3.8 Access to auxiliary services 73
3.3.9 Relationship between having a diabetes register & practice organisation 77
3.3.10 Special Interest in Diabetes 80
3.3.11 Opportunities in Developing Diabetes Care 81
3.4 Discussion 83
3.4.1 Integration between settings 83
3.4.2 Use of strategies to enhance organisation and delivery 83
3.4.3 Strengths and Limitations 85
3.4.4 Conclusion 86

4 Providing Diabetes Care in Irish General Practice; Everyday Experiences and the Barriers and Facilitators to Optimal Delivery 87
Abstract 88
4.1. Introduction 90
4.1.1 Importance of organisation in providing effective diabetes care 90
4.1.2 Importance of integration between settings 90
4.1.3 Aims & Objectives 91
4.2 Methodology 92
4.2.1 Design 92
4.2.2 Participants 92
4.2.3 Sampling Matrix 93
4.2.4 Topic Guide 94
4.2.5 Procedure 95
4.2.6 Analysis 95
4.2.7 Ethical Approval 97
4.3 Results 99
4.3.1 Nature of care delivery: continuum from ad hoc to structured care 101
4.3.2 Balance of Care 105
4.3.3 Extent of sharing care 107
4.3.4 Formal vs. Informal Initiatives 109
4.3.5 GPs' Understanding of Models of Care Terminology 110
4.3.6 Ideal Model of Care: greater sharing, not either/or care 114
4.3.7 Barriers & Facilitators to Optimal Diabetes Care 116
4.3.8 Lack of Financial Incentives & Remuneration 118
4.3.9 Motivations beyond money: "vocational" incentive 124
4.3.10 Barriers & Facilitators to Integration 126
4.3.11 Lack of Coordination at the Primary-Secondary Interface 129
4.3.12 The General Practice setting as a facilitator within the system 137
4.3.13 The HSE: A Help or a Hindrance 137
4.3.14 Auxiliary Services: "Not enough of them and too hard to access" 138
4.3.15 Resources, Time and Workload 142
4.4 Discussion 148
4.4.1 Summary of Findings 148
4.4.2 Barriers to Delivering Optimal Diabetes Care 149
4.4.3 Incentivising Diabetes Care 150
4.4.4 Role of personal and "vocational" incentives 150
4.4.5 Elucidating models of care 152

4.4.6 Strengths & Weaknesses 153
4.4.7 Conclusion 155
5 Attitudes to Engaging in Quality Improvement in General Practice 156
Abstract 157
5.1 Introduction 158
5.1.1 Organisational Culture in Healthcare 158
5.1.2 Role of Health Care Professionals in Quality Improvement 158
5.1.3 Beliefs and Attitudes towards Quality Improvement 159
5.1.4 Improving the Quality of Care in Ireland 159
5.1.5 Aims & Objectives 160
5.2 Methods 161
5.3 Results 162
5.3.1 Enabling change in the practice: ethos, leadership and interest 163
5.3.2 Previous Change in the Irish health system; a cautionary tale 165
5.3.3 Widespread engagement requires remuneration and involvement 170
5.3.4 Learning from previous experience 171
5.3.5 Establishing a National Register: important but not a priority 173
5.3.6 Engaging in Audit- a special interest 179
5.3.7 Audit leading to change and improvement 180
5.3.8 Concerns and Conditions for Audit 181
5.4 Discussion 184
5.4.1 Attitudes influencing interest in future improvement initiatives 184
5.4.2 Participation in the development and implementation of change 185
5.4.3 Developing a quality culture in Ireland 186
5.4.4 Strengths & Weaknesses 188
5.4.5 Conclusions 188
6 The Quality of Primary Care-led Diabetes Management: a Bottom-up Approach to Improvement 189
Abstract 190
6.1 Introduction 191
6.1.1 Increasing the role of primary care in diabetes management 191
6.1.2 Providing Structured Diabetes Care in the Community 191
6.1.3 Reorganising Diabetes Care in Ireland 192
6.1.4 Aims & Objectives 193
6.2 Methodology 194
6.2.1 Design 194
6.2.2 Sample 194

6.2.3 Data Collection 196
6.2.4 Comparators 197
6.2.5 Data Analysis 198
6.3 Results 199
6.3.1 Characteristics of the study participants 199
6.3.2 Recording Processes of Care 200
6.3.3 Outcome Measures 201
6.3.4 Prescribing medications to reduce cardiovascular risk 204
6.3.5 Relationship between quality of care and financial incentives 205
6.4 Discussion 207
6.4.1 The quality of primary care-led diabetes management 207
6.4.2 Financial Incentives and Quality Improvement 207
6.4.3 Role of Special Interest 208
6.4.4 Audit- a special interest activity 209
6.4.5 Prescribing among patients with Type 2 diabetes 209
6.4.6 Comparing Models of Diabetes Care in Ireland 210
6.4.7 Isolating the Improvement Factor 210
6.4.8 Strengths and Limitations 211
6.4.9 Conclusion 212
7 Improving Diabetes Care through Policy Formulation: a Case Study of the Expert Advisory Group for Diabetes. 213
Abstract 214
7.1 Introduction 216
7.1.1 Diabetes; a health system priority 216
7.1.2 Policy as a pillar of effective chronic illness care 217
7.1.3 Policy Background 218
7.1.4 An alternate perspective of quality improvement in diabetes care 223
7.1.5 Analysis of the formulation of "operational policy" 223
7.1.6 Theories of the policy process 225
7.1.7 Aims & Objectives 232
7.2 Methodology 234
7.2.1 Design 234
7.2.2 Data Sources 234
7.2.3 Participants 235
7.2.4 Recruitment 235
7.2.5 Sample 236
7.2.6 Topic Guide 236

7.2.7 Interview Protocol 236
7.2.8 Analysis 236
7.2.9 Ethical Approval 237
7.3 Results 238
7.3.1 How and why the EAG for Diabetes was established? 238
7.3.2 How did the recommendations evolve? 247
7.3.3 Moving from Formulation through Approval to Implementation 265
7.3.4 Changes in Financial Capacity 277
7.3.5 Changes in the HSE Structure: The Clinical Care Programme. 277
7.3.6 Better Chance of Success 281
7.3.7 Is it Policy? 282
7.3.8 Application of theories to the EAG Process 284
7.4 Discussion 298
7.4.1 Summary of findings 298
7.4.2 Indecision equating to inaction 298
7.4.3 Applying an Alternative Lens Approach 299
7.4.4 Use of Information and Evidence in the EAG 301
7.4.5 Covert Power in Decision-Making 302
7.4.6 Disconnection between policy and practice 302
7.4.7 Strengths and Limitations 302
7.4.8 Conclusion 303
8 CONCLUSION 305
8.1 Summary of Main Findings 306
8.2 Interaction between evidence and context 307
8.2.1 Culture of Quality Improvement 309
8.3 Implications of findings 310
8.4 Conclusion 311
9 REFERENCES 312
10 APPENDICES 329
10.1 Appendix I: PhD Education & Training 329
10.2 Appendix II: Publications 332
10.3 Appendix III: Literature Search Methodology 333
10.4 Appendix IV: GP Survey 335
10.5 Appendix V: Questions contained in shortened GP Follow-Up Questionnaire 352
10.6 Appendix VI: GP Survey open-ended responses 353
10.7 Appendix VII: Ethical Approval for GP Survey 367

10.8 Appendix VIII: Topic Guide for Qualitative Study.....368
10.9 Appendix IX: Prompt (modified checklist) used in interview.....371
10.10 Appendix X: Invitation Letter for Qualitative Study.....372
10.11 Appendix XI: Consent form &Information Sheet for Qualitative study373
10.12 Appendix XII: Use of Memos in Analysis 376
10.13 Appendix XIII: Sample of triangulation between team of analysts.....381
10.14 Appendix XIV: Ethical Approval for Qualitative Research.....384
10.15 Appendix XV: Comparison of Audit Data 385
10.16 Appendix XVI: Policy Study Invitation Letter, Consent & Information Sheet 387
10.17 Appendix XVII: Topic Guide for Policy Study.....395
10.18 Appendix XVIII: Ethical Approval for Policy Study 397

List of Tables

Table 1 Changes to organisation & coordination of care to improve quality 23
Table 2 Overview of systematic reviews of interventions to improve the organisation or coordination of diabetes care 25
Table 3 Overview of individual trials investigating the impact of quality improvement interventions on diabetes care (published 2008-2011). 34
Table 4. Association between the lengths of survey completed & care delivery 58
Table 5 Practice location compared to national profile 58
Table 6 Medical care and non-medical card (private) patient population 60
Table 7: Prevalence of diabetes by type.....61
Table 8 Uses of the practice computer.....63
Table 9: Proportion of GPs with an organised approach to diabetes care 65
Table 10: Type and frequency of clinics held by GPs* 66
Table 11: Processes of care as part of a routine review of patients with diabetes 69
Table 12: Patient characteristics considered when screening 70
Table 13 Association between maintaining a register and features of the practice ...77
Table 14 Association between maintaining a register and computerisation.....77
Table 15: Association between maintaining a register and organisational features of diabetes care delivery.....78
Table 16: Association between maintaining a register and contact with other settings 78
Table 17: Association between having a special interest in diabetes and care delivery 80
Table 18 Emergent themes from suggestions to improve diabetes care 82
Table 19 Combinations of selection criteria 93
Table 20 Proposed Sampling Matrix 93
Table 21 Participant Matrix (N=31).....94
Table 22 Recommended categories for reflection (178).....97
Table 23 Reasons for Referral to the Hospital-based team.....108
Table 24 Reasons for not referring patients to the hospital 109
Table 25 Advantages of adopting a structured approach to diabetes care 111
Table 26 Features & Benefits of Sharing Care 113
Table 27 Advantages and Disadvantages of a Pay-for-Performance Model 120
Table 28 Aspects of personal and vocational incentives 124
Table 29 Advantages of the General Practice Setting.....137
Table 30 Other Barriers & Facilitators referred to by GPs 147
Table 31 Dived opinions on the strengths and weaknesses of a national program for the management of heart disease in primary care and the potential for diabetes care. 168
Table 32 Advantages of a National Diabetes Register.....175
Table 33 Concerns & conditions regarding the establishment of national diabetes register.....178
Table 34 Advantages of engaging in audit in the practice 181
Table 35 Data Collection across the 3 Initiatives.....196
Table 36 Common dataset across 3 primary care-led initiatives 197
Table 37 Process of care recording 200
Table 38 HbA1c Risk Categories.....201
Table 39 Achievement of national targets for blood pressure and lipids among males and females.....202

Table 40 Differences in recording of care processes of care between practices receiving and not receiving financial incentives 205
Table 41 Differences in clinical outcomes between practices receiving and not receiving a financial incentive 206
Table 42 Secondary sources of information 235
Table 43 Participant views on the reasons for the establishment of the EAG compared to purpose put forward by the HSE. 239
Table 44 Why was diabetes assigned an expert advisory group? 240
Table 45 Reasons for joining the EAG 244
Table 46 Remit of the Expert Advisory Group in HSE introduction document compared to participants' accounts 246
Table 47 Rise & Fall of Issues from the EAG Agenda 250
Table 48 Factors underpinning retinopathy as a "quick win" situation 252
Table 49 Barriers to implementing 'integrated care' 259
Table 50 Quotes reflecting overall agreement with "smaller arguments around the fine tuning" 261
Table 51 The Approval Process. 267
Table 52 Differences between the Clinical Care Programme and the EAG according to the participants 281
Table 53 Does the EAG report represent a policy for diabetes 282
Table 54 Training courses undertaken during PhD 329
Table 55 Peer Reviewed Publications 330
Table 56 Other research output 330
Table 57 Conference Presentations over course of PhD 331
Table 58a Comments on providing diabetes care to patients in nursing comes 353
Table 59a Suggestions on providing diabetic services to patients in nursing homes/residential care 353
Table 60a Use of Practice Computer: Storing other reports 355
Table 61a Use of Practice Computer: To make other claims 355
Table 62a Use of Practice Computer: Recording other forms of systematic care 357
Table 63a Receiving electronic reports from other sources 358
Table 64a Receiving electronic reports from consultants 358
Table 65a Replacing paper records for electronic reports 359
Table 66a Comments on recalling patients for review 360
Table 67a Comments on foot examination & how it is conducted 361
Table 68a Other tests/procedures carried out in routine check-up 361
Table 69a Professionals with a special interest in diabetes 362
Table 70a Additional factors considered when screening for diabetes 363
Table 71 Rescreening patients with an increased risk of diabetes 363
Table 72a Open-ended responses on access to services 364
Table 73a Comments on referral to the local hospital specialist 364
Table 74a Characteristics considered when initiating insulin 365
Table 75a Comments regarding contact with the local hospital based team 365
Table 76a Themes on the principal opportunities to develop care 366
Table 77a Comments/suggestions for improvements to diabetes 366

List of Figures

Figure 1 Thesis overview of aims and objectives of each study and the corresponding chapter. 12
Figure 2 The Chronic Care Model with examples of interventions in each area 22
Figure 3 Diabetes Initiatives in Ireland 45
Figure 4 Flowchart of administration of survey 55
Figure 5 Size of practice (no. of GPs) by location of practice 59
Figure 6 Percentage of practices employing a Practice Nurse or Practice Manager 60
Figure 7 Percentage of practices using different computer systems 62
Figure 8 Percentage of GPs receiving electronic reports 64
Figure 9 Percentage of GPs who had replaced paper with electronic records 64
Figure 10 Percentage of GPs with features of diabetes care delivery 65
Figure 11 Type of appointments used by GPs to provide diabetes care 67
Figure 12 Tests used by GPs for screening for diabetes 71
Figure 13 Types of guidelines used by GPs 71
Figure 14 Percentage of practices with access to auxiliary services 74
Figure 15 Percentage of GPs reporting access to providers of ophthalmic examination 75
Figure 16 Percentage of practices receiving educational material from various sources 76
Figure 17 Percentage of practices with/out a register with direct access to services 79
Figure 18 Principle opportunities for developing diabetes care in the practice 81
Figure 19 Remuneration options for providing diabetes care 81
Figure 20 Dimensions of diabetes care delivery (See Appendix 4) 100
Figure 21 Features of a structured approach to diabetes care. 101
Figure 22 Teamwork approach to regular diabetes management 102
Figure 23 Factors influencing the balance of diabetes between settings 105
Figure 24 Barriers & Facilitators to Delivering Quality Diabetes Care 117
Figure 25 Impact of a lack of remuneration at different levels of the health system 121
Figure 26 Enabling change within the practice 163
Figure 27 Maximising existing opportunities and counteracting previous pitfalls. 172
Figure 28 Balance between rewarding and reprimanding audit performance 182
Figure 29.Estimate of population prevalence for Type 2 diabetes in adults in 2010 195
Figure 30 Percentage of patients in each age category by gender 199
Figure 31 BMI according to the WHO classification 203
Figure 32 Prescribing of statins by age and gender 204
Figure 33 Prescribing of aspirin by age and gender 205
Figure 34 Overview of policy & practice developments from 1998-2010 220
Figure 35 Advocacy coalition framework (2007) (272) 231
Figure 36 Strategies to increase the chances of recommendations being adopted 262
Figure 37 Timeline of the approval process 265
Figure 38 Barriers moving from Approval to Implementation Phase 273
Figure 39 Transition from the EAG structure to the Clinical Care Programme 280
Figure 40 Search Results 334

Glossary

Term	Definition
ACF	Advocacy Coalition Framework
CQI	Continuous Quality Improvement
df	Degrees of Freedom
DFI	Diabetes Federation of Ireland
DNS	Diabetes Nurse Specialist
EAG	Expert Advisory Group
GMS	General Medical Scheme
GP	General Practitioner
HSE	Health Service Executive
HSR	Health Services Research
ICGP	Irish College of General Practitioners
IOM	Institute of Medicine
IQR	Interquartile Range
Mdn	Median
NDRP	National Diabetes Register Project
PN	Practice Nurse
QI	Quality Improvement
SD	Standard Deviation
TQM	Total Quality Management
UK	United Kingdom
US	United States

Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other University. The work, upon which this thesis is based, was carried out in collaboration with a team of researchers and supervisors who are duly acknowledged in the text of the thesis. The Library may lend or copy this thesis upon request.

Signed: _____ Date: _____

Dedication

To my parents David and Angela and to my brother Conor and my sister Eimear, for their unwavering support and encouragement.

I would not have been able to start or finish my PhD without you.

Acknowledgements

I want to express sincere thanks to my supervisory team. To Professor Ivan Perry who generously shared his expertise and provided guidance and reassurance when I was uncertain. To Professor Colin Bradley, who encouraged me to undertake qualitative analysis and provided invaluable feedback along the way. You both gave me the freedom to develop and pursue my research interests, safe in the knowledge you would not let me go too far wrong. To Professor Ruairí Brugha who supported my foray into policy analysis and provided advice and detailed feedback on several drafts.

I will always be grateful that I was sent to Cork as part of the Scholars Programme, to join the Department of Epidemiology and Public Health in UCC. I am indebted to Vicky, Tara, Karen, Anne Kelly, Anne Fitzpatrick and Margaret for their administrative support and friendship since I joined the department. I owe huge thanks also to Janas, Bernie and Vera for taking me under their wing. Ivan said on the first day to stick with you and it was sound advice. A special word of thanks to Professor John Browne for organising my placement with the London School of Hygiene and Tropical Medicine, and for his continued encouragement. I also wish to thank Tony Fitzgerald for answering my many stats questions and the wider Graduate Studies Committee for their guidance over the course of my PhD. Finally I want to thank the other PhD students and friends in the Department and Lancaster Hall for distracting me in the best possible way, particularly during my last year, it really kept me going.

To all those involved in the Scholars Programme in RCSI and Trinity College Dublin I would like to express my gratitude. In particular I want to acknowledge the dedication and kindness of Shani Rushin who solved the teething problems of both the scholars and the programme. I would like to thank the Health Research Board for their continuing support of Health Services Research in Ireland. The Scholars Programme provided a unique opportunity to learn in a structured environment while working with the best and the brightest in the field.

I would like to acknowledge all those who collaborated and provided advice on various aspects of my research; Dr Monica O'Mullane, Katie Murphy and the Diabetes in General Practice group, Dr Velma Harkins, Carmel Brennan, Paul Marsden and Celine Croarkin. I would like to thank all those who took part in my research filling out questionnaires, participating in interviews and giving so generously of their time.

I am eternally grateful for the chance to get to know my fellow Scholars: Aisling, Catriona, Brian, Caitriona, Deirdre and Gerry, who took the loneliness out of doing a PhD. I was very lucky to find lifelong friends in UCC and I want to say a special word of thanks to Will and Marion for their friendship. It was reassuring to see you go through the same stages of PhD traumatic stress disorder as me. To my friend Deirdre for the ever-entertaining emails and the use of her couch when I was in Dublin. I was lucky to have friends who didn't mind not seeing me or talking to me for extended periods of time!

Finally I want to express my deepest thanks to my parents, David and Angela, for their constant support. You were always on the end of the phone on slow walks home from the office. I am eternally grateful for all the prayers you said and candles you lit for conferences, yearly evaluations and the final Viva, for quietly transferring money and for never asking when I was going to get a job! I want to thank Eimear, for the long chats when you were on nights and I was on nights and days and Conor for never doubting my ability. In a special way I want to thank Granny Lena for maintaining such a high level of interest over four long years, and for her enthusiasm for the PhD when I had lost mine.

Thesis Abstract

Aim: Diabetes is an important barometer of health system performance. This chronic condition is a source of significant morbidity, premature mortality and a major contributor to health care costs. There is an increasing focus internationally, and more recently nationally, on system, practice and professional-level initiatives to improve the quality of care. The aim of this thesis was to investigate the 'quality chasm' around the organisation and delivery of diabetes care in general practice, to explore attitudes to engaging in quality improvement activities in general practice and to examine efforts to improve the quality of diabetes care in Ireland from practice to policy.

Methods: Quantitative and qualitative methods were used. A postal survey of 600 GPs was conducted to assess the organisation of care. This was followed by an in-depth qualitative study using semi-structured interviews with a purposive sample of 31 GPs. The qualitative methodology was also used to examine GPs' attitudes to engaging in quality improvement. Data were analysed using a Framework approach. A 2nd observational study was used to assess the quality of care in 63 practices with a special interest in diabetes. Data on 3010 adults with Type 2 diabetes from 3 primary care initiatives were analysed and the results were benchmarked against national guidelines and standards of care in the UK. The final study, an instrumental case study of policy formulation, involved semi-structured interviews with 15 members of the Expert Advisory Group (EAG) for Diabetes. Thematic analysis was applied to the data using 3 theories of the policy process as analytical tools.

Results: The survey response rate was 44% (n=262). Results suggested care delivery was largely unstructured; 45% of GPs had a diabetes register (n=157), 53% reported using guidelines (n=140), 30% had formal call recall system (n=78) and 24% employed none of these organisational features (n=62). The lack of coordination between settings was identified as a major barrier to providing optimal care leading to waiting times, *"overburdened"* hospitals and avoidable duplication. The lack of remuneration for chronic disease management had a ripple effect also creating costs for patients and apathy among GPs. There was also a sense of inertia around quality improvement activities particularly at a national level. This attitude was strongly influenced by previous experiences of change in the health system. In contrast GP's spoke positively about change at a local level which was facilitated by a practice *"ethos"*, leadership and special interest in diabetes.

The 2nd quantitative study found that practices with a special interest in diabetes achieved a standard of care comparable to the UK in terms of the recording of clinical processes of care and the achievement of clinical targets; 35% of patients reached the HbA1c target of <6.5% compared to 25% in England. With regard to diabetes policy formulation, the evolving process of action and inaction was best described by the Multiple Streams Theory. The formulation of recommendations by the EAG was facilitated by overarching agreement on the *"obvious"* priorities although the details of proposals were influenced by personal preferences and local capacity. In contrast the national decision-making process was protracted and ambiguous. The lack of impetus from senior management coupled with the lack of power conferred on the EAG impeded progress.

Conclusions: The findings highlight the inconsistency of diabetes care in Ireland. The main barriers to optimal diabetes management centre on the organisation and coordination of care at the systems level with consequences for practice, providers and patients. Quality improvement initiatives need to stimulate a sense of ownership and interest among frontline service providers to address the local sense of inertia to national change. To date quality improvement in diabetes care has been largely dependent the 'special interest' of professionals. The challenge for the Irish health system is to embed this activity as part of routine practice, professional responsibility and the underlying health care culture.

1 INTRODUCTION

1.1 Introduction

This thesis documents a series of studies examining the quality of diabetes care in Ireland from a practice, professional and policy perspective. Focusing on the general practice setting, each study relates to the organisation of care, which has been suggested as a cause of and solution to the 'quality chasm' in health care. The first study examined the level and organisation of diabetes care in general practice including access to support services and links with secondary care. The results informed the follow-up qualitative study which explored experiences of providing diabetes care in general practice in more detail, and identified the barriers and facilitators to delivering high quality care in Ireland. The third study examined GPs' attitudes to engaging in quality improvement activities at local and national level. The final two studies concentrated on bottom-up and top-down efforts to improve the quality of diabetes care in Ireland. A cross-sectional study, combining audit data from three primary care-led diabetes initiatives, demonstrated the quality of care achieved by proactive health care professionals adopting a structured approach to diabetes management. The final study, an example of a top-down effort to improve diabetes care in the policy arena, investigated the formulation of recommendations by the Expert Advisory Group for Diabetes (EAG) as an instrumental case study of policy formulation in the Irish health system.

This chapter briefly outlines why diabetes is a condition of choice for modelling change in health care and the increasing focus on system, practice and professional level interventions to improve the quality of care. The origins of this thesis are summarised, followed by an overview of the context and terminology which provide a backdrop to the research. Finally, the aims and objectives of the research are presented with an outline of the thesis structure.

1.2 Background

Diabetes has become the chronic condition of choice for modelling quality improvement for a number of reasons (2). First and foremost diabetes is a leading cause of death worldwide (3) and a source of significant morbidity and disability for individuals living with the condition. The rising prevalence and cost of diabetes places a substantial burden on health systems (4, 5). Secondly, despite progress in the therapeutic management of diabetes, a gap persists between the ideal standard of care set out in guidelines and the reality in everyday practice (6-9). The traditional orientation

of health systems towards acute episodic care is frequently cited as one of the original causes of the 'quality chasm' in health care (10) and it is now accepted that this model of care will not cope with the future burden of chronic conditions such as diabetes (11, 12). As a result greater attention has been paid to ways of reorganising services, including the reorientation of care towards the primary care setting (13).

Since the term 'quality chasm' was coined by the Institute of Medicine in 2001(10), there has been a growing focus both nationally and internationally on system, practice and professional-level initiatives to improve the quality of chronic disease management. Evidence from quality improvement research has demonstrated the positive impact of organisational and professional interventions on the quality of diabetes care {Renders, 2000 #62;Shojania, 2006 #9;Weingarten, 2002 #451}. The focus on reorganisation can also be seen in policy as the national guidelines for diabetes care in Ireland promote care which is planned, structured and integrated (17). In particular, patient registration, regular recall and review are considered the three key organisational components of effective diabetes management.

However the science of quality improvement is not only about examining the effectiveness of quality improvement interventions. Many experts now contend that understanding the context in which quality improvement flourishes or fails is as important as generating evidence on the statistical significance of different strategies (18, 19). Indeed a review of organisational and professional strategies for diabetes care found that effectiveness was dependent partly on clinical context but also other contextual factors such as the beliefs and attitudes of professionals (8). This thesis looks at the organisational, professional and cultural context of delivering and improving diabetes care in Ireland.

1.3 Building on Earlier Research and Established Networks

Over the past decade both the Department of Epidemiology and Public Health and the Department of General Practice in University College Cork, have become more active in diabetes research in Ireland. Consequently a number of previous projects and new opportunities informed the development of this thesis.

1.3.1 Building on previous doctoral research

This thesis builds on another doctoral thesis conducted in the Department of Epidemiology and Public Health by Dr Margaret Collins. Examining the determinants

of quality of life in patients with diabetes, Dr Collins investigated the impact of three models of care on the quality of care and quality of life. Using a patient report card to measure quality, the findings indicated that less than half the patients were receiving more than seven out of ten processes of care. Structured care in general practice was significantly associated with higher quality of care and quality of life scores compared to traditional and shared care models (20). From this starting point of three models of care, the present thesis explores the understanding and experience of diabetes care arrangements from the GP perspective (Chapter 4). The qualitative study seeks to disentangle the concepts of shared and structured care in Ireland. In the cross-sectional study presented in Chapter 6, the standard of primary care-led structured diabetes management is compared to audit results from a shared model of care in Ireland Quality is assessed using process and outcome measures extracted from GP records, advancing from patient-reported quality of care in the previous doctoral research.

1.3.2 Working with Local Initiatives

In 2003 the Department of Epidemiology and Public Health was commissioned to compile an audit report on the Midland Area Diabetes Structured Care Programme. A resulting publication stated that a quality chasm existed in Ireland between current routine practice and optimal standards in chronic disease management (21). That statement became the focus of this thesis as the PhD student endeavoured to examine the 'quality chasm' in greater depth and explore why it existed. The student went on to establish links with the team in the Midlands and contributed to the most recent audit of care in 2009. As part of a national research placement under the Health Research Board PhD Scholars Programme (Appendix I), the student also worked on an audit of practices participating in the Diabetes Interest Group (DIG) in Cork in 2008. The links with diabetes initiatives led to the opportunity to collate audit data across three schemes to examine the quality of primary care-led diabetes management, the results of which are presented in Chapter 6.

1.3.3 The National Diabetes Register Project (NDRP)

In 2007, the National Diabetes Register Project (NDRP) was established to conduct a programme of research into the feasibility of a national diabetes register. Funded by the Irish Health Research Board, the project was a collaboration between UCC (Department of General Practice, Department of Epidemiology), NUI Galway (Department of Medicine) and the Midland Diabetes Structured Care Programme. Two

of the supervisors of this thesis were lead investigators on the project (CB & IP). Another of the principle investigators, Dr Velma Harkins, was involved in the aforementioned Collaborative Primary Care Diabetes Project (Chapter 6).

There were four areas of research in the NDRP plan; survey of care provision in Ireland including GPs & hospital consultants, qualitative follow-up studies with both groups as well as with people with diabetes, multisite audit of 3 models of care and finally an economic evaluation of three models of care. The PhD student was involved in the general practice components of the project, namely the survey and qualitative follow-up, which were led by the UCC team. The student was responsible for inputting, analysing and interpreting the results of the GP survey and was lead author of the subsequent publication. Together with a postdoctoral researcher Dr Monica O'Mullane, the PhD student conducted the qualitative follow-up study with GPs. When Dr O'Mullane left the team in March 2010, the student became the lead researcher on this arm of the project. She was also involved in the literature review which informed the review included in this thesis and led to two published papers (Appendix I). The National Diabetes Register Project came to a close in the summer of 2010 however the findings continue to inform the design and development of services nationally under the direction of the National Working Group for Diabetes, part of the Clinical Care Programme in the HSE. The design and results from the first phase of research by the NDRP are reflected in the first three studies presented in this thesis and the story of the feasibility of the national diabetes register is weaved through this thesis.

1.4 Context and Terminology

The following section provides a summary of the context which underpinned the research methodology and an introduction to the terminology used in the thesis.

1.4.1 Epistemology

This thesis is a collection of quantitative and qualitative studies. In line with the problem-orientated nature of Health Services Research (HSR), the choice of research design and methodology was guided by the aims and objectives of the thesis (22, 23). The use of both quantitative and qualitative methods is reflective of the pragmatic paradigm underlying this thesis, which refers to the selecting the method or philosophical approach which best suits the issue under scrutiny (24).

Pragmatism rejects the forced choice between quantitative and qualitative methodologies, advocating that decisions about methods should be informed by the research question (24). Any proposal to improve the quality of diabetes care in Ireland will be grafted onto an existing health care structure and integrated into an established professional and organisational context. Hence, a mixed method study with a quantitative and qualitative phase was undertaken to assess and understand the level and organisation of diabetes care in general practice (25). The survey results provided baseline data on the organisation of diabetes care nationally and informed the design of the qualitative study. The qualitative analysis explored GPs' experiences of delivering care in more detail unearthing nuances in the Irish health system which were not captured by the questionnaire, for example the perceived role of luck in accessing auxiliary services. The study also identified the barriers and facilitators to optimal delivery from the GP perspective rather than assuming to know the challenges of providing care in this setting.

Pragmatism acknowledges the influence of values in conducting research, seeking explanations and drawing conclusions. In this vein, the student's values as a Health Services Researcher influenced the topic under scrutiny: the quality of diabetes care. A background in health psychology increased the student's awareness of the influence of beliefs and attitudes on behaviour. This influence is the focus of Chapter 5 which examines attitudes and openness to quality improvement in general practice. Some of the themes which emerge from qualitative research in this thesis, such as the enabling role of local leadership in quality improvement, were rooted in context and present significant challenges in terms of quantitative measurement(26). Interpretation of the results draws on theory from health psychology, sociology and change management to move analysis from face-value description to understanding why attitudes and perspectives emerged (27).

Quality is considered a dimension amenable to measurement through assessment of the structures, processes and outcomes of care (28). The quality of diabetes care is typically measured along these dimensions and benchmarked against national and international best practice. This quantitative approach to evaluating quality was adopted in Chapter 6 to examine the performance of three initiatives which are pioneering quality improvement at the practice level. In contrast qualitative methodology was used to examine efforts to enhance diabetes care in the national policy arena. Policy analysis

typically employs a case study design to investigate how and why questions(29), such as those posed about the process and outcome of the Expert Advisory Group for Diabetes in Chapter 7.

The practical and applied research philosophy of pragmatism should not be interpreted as an 'anything goes' approach to research (30). Seale et al (2004) stress the need to contextualise the principles of qualitative methodology in practice which involves turning to everyday life to understand human nature and social order. This thesis focuses on the everyday experience of organising and coordinating diabetes care in general practice. The researcher does not seek to ascribe value to the opinions, emotions and attitudes contained in results of this thesis but rather focuses on investigating the how they are brought to bear on participants' understandings, actions and interactions surrounding the provision and improvement of diabetes care (30).

1.4.2 General Practice in Ireland

This thesis focuses on the organisation and coordination of diabetes care from the general practice perspective. General Practitioner (GP) services are at the centre of primary care in Ireland. There is no national register of General Practitioners in Ireland, however it is estimated that there are more than 2,500 GPs in the country (31). GPs are independent self-employed health care professionals contracted to provide certain services within the national health system, the Health Service Executive (HSE). Other members of primary care such as Public Health Nurses and Community Diabetes Nurse Specialists are employed directly by the HSE.

Some people have free access to GP services under the General Medical Scheme (GMS) while others are considered 'private patients' and must pay per visit. Individuals and families below a certain income threshold are eligible for a medical card under the GMS and approximately one third of the population qualify (32). The HSE reimburses GPs for care provided to individuals and families with a medical card. The annual capitation fee per patient is based on demographic information (e.g. age) and geographic information (e.g. distance from the GP). People with diabetes who do not have a medical care qualify for the Long Term Illness Scheme which entitles them to medication for the treatment of diabetes free of charge. It does not cover the costs of doctor visits or medicines not related to the treatment of diabetes. Other primary care health care professionals (e.g. community dietician) are part of the HSE therefore private patients (non-GMS) may not have free access to those services and may have to

pay privately (33). GMS patients are registered with a specified doctor but private patients are not registered as universal patient registration is not compulsory in Ireland.

1.4.3 Terminology for Quality Improvement

There are two activities synonymous with achieving quality; quality improvement and quality assurance. The terms are used interchangeable as they form part of the continuous cycle of identifying areas for attention, establishing the criteria for judging quality, assessing quality and implementing change (34). This thesis uses the term 'quality improvement' as an umbrella term to describe these activities. The following definition of quality improvement has been adopted:

> *"the combined and unceasing efforts by all involved (healthcare professionals, patients and their families, researchers, planners and policy makers) to make changes that will lead to better patient outcomes, better system performance and better professional development"* (35).

1.4.4 Terminology for Health Policy Analysis

The study of the policy process involves analysis of how policy decisions are made and how these decisions are shaped into action (36). In this thesis the Expert Advisory Group for Diabetes (EAG) is examined as an example of the policy process, with a focus on how and why decisions to improve diabetes care were made and whether these decisions led to action or inaction. This thesis adopts the definition of health policy a *'web of decisions'* (36) but also *'courses of action and inaction that affect the set of institutions, organisations, services and funding arrangements of the health system'* (p6) (37) . This definition embraces the interaction between state and non-state actors as health policy can be formulated within and outside government, by non-governmental actors and by organisations external to the health system (29). The conceptualisation corresponds to the Expert Advisory Group, a multidisciplinary body of health care professionals, health service management and government representatives.

1.5 Aims and Objectives

There were three broad aims to this research; to investigate the 'quality chasm' around the organisation and delivery of diabetes care in general practice, to explore attitudes to engaging in quality improvement activities in general practice and to investigate efforts to improve the quality of diabetes care in Ireland from practice to policy. Each aim had a number of specific objectives:

1. To investigate the 'quality chasm' around the organisation of diabetes care in general practice in Ireland.
    I. To describe the level and organisation of diabetes care in General Practice in Ireland.
    II. To elaborate on GPs' experiences of delivering care and elucidate the models of care functioning in Ireland.
    III. To explore GPs' perceptions of the barriers and facilitators to providing diabetes care in everyday practice.
2. To explore GPs' attitudes and openness to engaging with quality improvement.
    I. To elicit attitudes to the development of a national diabetes register and the use of audit as mechanisms for quality improvement.
3. To examine efforts to bridge the quality gap around diabetes care in Ireland from practice to policy.
    I. To assess the quality of structured Type 2 diabetes management in practices with a special interest in diabetes, a bottom-up primary care-led approach to improvement.
    II. To analyse the formulation of the recommendations from Expert Advisory Group for Diabetes, a top-down approach to improve the quality of diabetes care.

1.6 Thesis Outline

The thesis comprises of five studies which address the aforementioned aims and objectives. Figure 1 illustrates each aim and objective and the corresponding chapter.

The literature review presented in Chapter 2, outlines the case for diabetes as a model for quality improvement and the gap between evidence-based standards of care and the reality for patients. The chapter charts the emergence of a quality agenda in healthcare and summarises the body of evidence from system, practice and professional level interventions which seek to improve the quality of diabetes care. This is followed by an overview of the models of diabetes care and their defining characteristics. Finally the organisation of diabetes care in Ireland is outlined including established models of care and the policy framework underpinning efforts to improve care

A descriptive study of the organisation and delivery of diabetes care in general practice is presented in Chapter 3. The results of the survey describe the organisation of care within practices and access to services outside practices. It also examines links with secondary care providers. Chapter 4 presents the qualitative follow-up study examining GPs' experiences of providing and organising diabetes care in more depth. This study explores GPs' understanding of models of care and explores the barriers and facilitators to providing care in every-day general practice. Chapter 5 outlines results from a further objective within the qualitative analysis; that is to explore GPs' attitudes and openness to engaging in quality improvement. The results focus specifically on attitudes to a national diabetes register and audit as mechanisms for quality improvement at local and national level.

Chapter 6 examines the quality of care delivered by practices with a special interest in diabetes as part of primary care-led initiatives in 3 regions of Ireland. The study involved practices which had adopted a structured approach to diabetes management including regular audit and feedback. Data on processes and intermediate outcomes for over 3000 patients with Type 2 diabetes were benchmarked against national guidelines, audit results from a shared care initiative and standards of care achieved in the UK. The study highlights some of the challenges facing such initiatives in the absence of a national infrastructure for diabetes care.

The final study presented in Chapter 7 is an analysis of a top-down initiative to improve the quality of diabetes care. This study examines the Expert Advisory Group for

Diabetes and the development of its recommendations as an instrumental case study of policy formulation within the Irish health service. The thesis is summarised with a discussion of the implications for diabetes care and areas for future research.

The final chapter in the thesis summarises and integrates the results from the aforementioned five studies. The discussion in Chapter 8 reflects on the need to consider quality improvement in context and the absence of a quality improvement culture around diabetes care in Ireland.

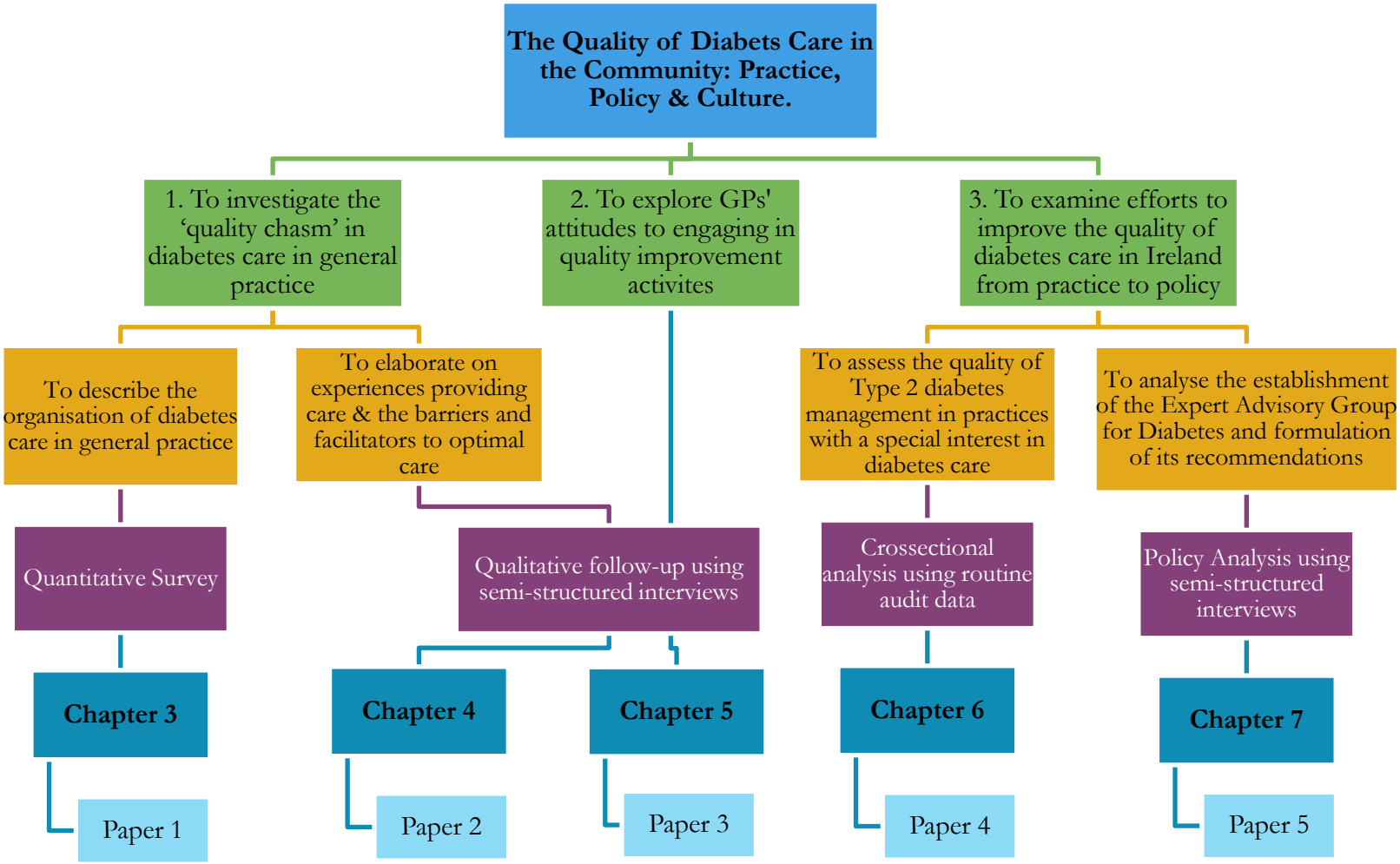


Figure 1 Thesis overview of the aims and objectives of each study and the corresponding chapter.

2 LITERATURE REVIEW

2.1 Introduction

This chapter presents existing knowledge regarding quality improvement in diabetes care, establishing the evidence-base and context which subsequent studies in this thesis will build upon. The first section sets out the rationale behind the choice of diabetes as a model for quality improvement initiatives. Contributory factors include the burden of disease on the health system and the patient, and the demonstrable gap between the ideal standard of care and reality. The second section charts the emergence of the quality agenda in health care and the conceptual frameworks underlining quality improvement including the Chronic Care Model which conceptualises the components of optimal chronic illness care. The third section focuses on one of the proposed solutions to the 'quality chasm'; the reorganisation and reorientation of chronic illness care. A critical synthesis of the evidence documenting the impact of changes in the organisation and coordination of services on the quality of diabetes care is outlined. This body of literature is also used to explore the similarities and differences between various models of diabetes care and the types of improvement strategies they include. The final section of this chapter introduces the organisation and delivery of diabetes care in Ireland as well as summarising efforts of 'local champions' to improve the quality of diabetes care within the health system.

2.1.1 Diabetes as a Model for Quality Improvement

Diabetes has become the chronic condition of choice for modelling health care reform (2). This chronic illness embodies many of challenges facing health systems today including increasing chronic disease prevalence and burgeoning healthcare costs. In addition people with diabetes are cared for by multiple health care professionals across several settings, presenting significant challenges in terms of the organisation and coordination of services within the system. This costly illness highlights the need for health systems to reorganise healthcare from acute reactionary services to systematic planned diabetes management.

2.1.2 Burden of Diabetes on Health and the Health System

The World Health Organisation (WHO) estimated an increase in the worldwide prevalence of diabetes from 2.8% in 2000 to 4.4% by 2030 which equates to an increase from 171 million people to 366 million people in thirty years (4). A study of prevalence estimates from 27 EU countries projected an increase in population prevalence from 7.5% in 2003 to 8.6% of the population by 2008 (38). This European estimation is

slightly higher than prevalence estimates in Ireland. The Institute of Public Health (IPH) estimated that 4.7% of the population had diabetes in 2005 (140,000 adults) with an expected increase to 5.6% of the population by 2015 (190,000 adults) (39). The figures were based on the most realistic forecast whereby obesity increases in a linear fashion. However the figures are likely to underestimate the true prevalence of diabetes as the proportion of undiagnosed cases was not determined due to inadequate primary care data. The Diabetes Federation of Ireland (DFI) suggests that almost half as many people may have undiagnosed diabetes as are currently diagnosed (40).

2.1.1.1. Diabetes-Morbidity and Mortality

Diabetes Mellitus is a group of chronic metabolic disorders characterised by hyperglycaemia as a result of defects in insulin secretion, insulin action or both (41). The main categories of diabetes are Type 1 diabetes and Type 2 diabetes. Type 1 diabetes is attributable to the destruction of insulin secreting cells in the pancreas leading to absolute insulin deficiency. Type 2 diabetes is characterised by defective insulin secretion and contributing insulin resistance. Type 2 diabetes typically has a more gradual onset and people often present with evidence of complications at the time of diagnosis (42). Unlike people with Type 1 diabetes, initially people with Type 2 diabetes do not require insulin therapy to survive but may require insulin into the future. There are 'other specific types' of diabetes including gestational diabetes and diabetes due to genetic defects. Pre-diabetes has also emerged as a potential future health concern. This umbrella term for Impaired Fasting Glucose (IFG) and Impaired Glucose Tolerance (IGT) represents intermediate stages of elevated glucose levels between normal glucose regulation and diabetes. People with pre-diabetes are at increased risk of developing Type 2 diabetes and are vulnerable to developing complications associated with the disease (43).

Diabetes is a significant source of morbidity and mortality due to the severe micro- and macrovascular complications associated with the illness. Microvascular complications include diabetic kidney disease (nephropathy), diabetic eye disease (retinopathy) and diabetic nerve disease (neuropathy). Up to 50% of people with diabetes develop nerve damage leading to foot ulcers and in severe cases, limb amputation (44). Diabetes is one of the leading causes of blindness among adults aged 20-74 years (45). Furthermore diabetes has become the most common cause of end-stage renal disease. The WHO estimate that between 10 and 20% of people with diabetes die of kidney failure (44).

Macrovascular complications include cerebrovascular disease, ischaemic heart disease and peripheral heart disease. Cardiovascular disease is the leading cause of death among people with Type 2 diabetes (46). It is difficult to assess the true burden of diabetes mortality from death certificates as people with diabetes typically die of cardiovascular disease or renal disease rather than causes uniquely related to diabetes (47, 48). Taking into account deaths in which diabetes was a contributory condition, a study in 2000 attributed 5.2% of all cause mortality to diabetes worldwide. This estimate represents an excess global mortality of 2.9 million deaths due to diabetes (3). The risk of mortality is at least double among people with diabetes compared to those without diabetes (44).

2.1.1.2. Cost of Diabetes Care

The management of diabetes and treatment of complications places a significant financial burden on the health system. Global health expenditure on diabetes was projected to cost at least 376 billion US Dollars in 2010 rising to 490 billion USD by 2030 (49). The CODE-2 study (Cost of Diabetes in Europe – Type 2), which assessed the cost of managing Type 2 diabetes in eight European countries, estimated a total direct medical cost of €29 billion a year (1999 values), an average of €2834 per person per year (50). The cost of care was largely attributable to the management of complications as the total cost of managing patients with both microvascular and macrovascular complications increased by up to 250% compared to those without complications (51). A more recent cost analysis conducted in Scotland, examined the in-patient cost of Type 1 and Type 2 diabetes separately. The estimated total annual cost of admissions for people with Type 1 diabetes was £26 million while the cost of admissions for Type 2 diabetes was £275 million. This equated to 12% of the total inpatient expenditure in the country (5). In Ireland the most recent study of the cost of diabetes, based on data from 1999/2000, estimated that €580million was spent on Type 2 diabetes care (52). A substantial proportion of the cost of was attributable to hospitalisations as over half the sample had developed complications. The cost of treating patients with both micro- and macrovascular complications was 3.8 times the cost of treating those without complications (53). This study did not take into account the indirect economic cost of diabetes due to loss of productivity and workdays. In addition, a growing number of people with Type 2 diabetes are being cared for outside the hospital setting however there are no studies to date on the cost of managing diabetes in primary care.

2.1.3 Diabetes Care & the Quality Chasm

Another factor which has contributed to the choice of diabetes as a model for reform is the broad consensus on what constitutes good quality diabetes care (2, 54). A substantial body of research has demonstrated the effectiveness of treatments and therapies in managing diabetes and slowing the progression of complications (42, 55-59) which have informed both national and international guidelines on optimal management (17, 60-62). Despite this progress, a measurable gap has been highlighted between the ideal standard of care set out in guidelines and the reality of everyday care received by patients with diabetes (6, 8, 63, 64).

The quality of diabetes care emerged as an international concern in the late 1980s. In 1989 health departments from across Europe including Ireland signed the St Vincent Declaration, a set of standards and goals to improve diabetes care (65). The onus was placed on individual governments to develop strategies to meet the agreed targets. Over the next two decades a number of countries developed coordinated national programmes for diabetes management. In the UK for example, a National Service Framework for Diabetes was established to improve the care and health of people with diabetes in 1999 (66). Each country in the UK has a separate service framework with established minimum standards of care in each region and an implementation strategy, the progress of which is monitored and ongoing (67).

The gap in the quality of health care is not unique to diabetes. It has been described as *"one of the most consistent findings in health services research" (p57)* (68). Concerns about the quality of health care led the Institute of Medicine (IOM) to coin the term 'quality chasm' to describe system deficiencies in the U.S (10). Among the contributory factors identified by the IOM, was the inability of health systems, which were traditionally orientated towards acute episodic care, to meet the changing needs of patients with chronic illnesses. This orientation towards acute care permeated the whole system including the primary care setting, leaving little scope for planned, proactive care (69). Another related factor was the poor organisation and lack of coordination within health systems to deliver multidisciplinary integrated care necessary to manage complex chronic conditions. Over the past decade, the American concept of a 'quality chasm' has become a worldwide concern and health system redesign has been proposed as a solution. The following section outlines the emergence of a quality agenda in healthcare and the influence of industrial style principles on quality improvement.

2.1.4 The Quality Agenda in Healthcare

In 1996 articles in the New England Journal of Medicine heralded the 'comeback' of quality of care (70). In 2011 the concept has established itself as a key consideration for health care professionals and health system management. According to Blumenthal the emergence of a quality agenda in health care was the result of a number of factors(71). Firstly the increasing complexity of conditions requiring input from multiple disciplines and specialties, demand greater coordination at a health system level. Secondly healthcare became a sector of the economy and therefore is open to the logic and demands of the free-market, competition and customer service. Thirdly quality improvement has become a field of inquiry in itself, driving the quality agenda with advances in knowledge dissemination and research methods. Sciences such as clinical epidemiology and health services research have highlighted how variation in practice can be a learning opportunity and several advances have been made in the measurement of outcomes including patient experience. Finally one of the most common drivers behind quality improvement is the need to contain healthcare costs, a driver that often causes scepticism towards quality improvement among health care professionals (71).

2.1.5 Defining Quality in Health Care

The term 'quality' is scattered throughout research articles and policy documents on organising and delivering healthcare. Its omnipresence often implies that the concept is well defined, however the definition of quality in health care depends on the perspective of the definer (71-74). One of the original writers on this topic, Avedis Donabedian, accepted that *"several formulations are possible and legitimate depending on where we are located in the system of care and on what the nature and extent of our responsibilities are"* (75). A number of definitions centre on delineating the individual components of quality, reflecting its complex and multidimensional nature (73). Donabedian proposed seven pillars of quality emphasising the need for balance between dimensions (76):

- Efficacy - the ability of care to improve health.
- Effectiveness - the degree to which attainable health improvements are realised through care received.
- Efficiency- ability to obtain improvements at the lowest possible cost
- Optimality- most advantageous balance of costs and benefits
- Acceptability- meeting patients preferences in terms of cost, access, effects of care and relationship with health care providers

- Legitimacy- meeting social expectations and norms within society
- Equity – fairness in the distribution of health care and its effects.

The seven dimensions suggest quality is a judgment based on science (efficacy and effectiveness) but also individual preferences and expectations (acceptability) and social values and norms (legitimacy) (76). Campbell et al (2000) propose two all-encompassing dimensions of quality in health care: access and effectiveness (73). All individual dimensions fall under this dichotomy. The authors do however make a distinction between quality of care at an individual level and quality of care at a population level. At an individual level quality is defined according to whether individuals can access the care they need and whether that care is effective when they receive it. At a population level quality is defined according to whether populations can access effective care on an efficient and equitable basis. The distinction highlights the importance of considering the opportunity costs of health care as improving care for the whole population may conflict with care for individuals, particularly in systems with limited resources. Again the definition of improvement depends on balancing dimensions of quality.

There are two activities inherent in efforts to achieving quality; quality improvement and quality assurance. The terms are used interchangeable as they form part of the continuous quality cycle of identifying areas in need of attention, establishing the criteria for quality, assessing quality and implementing change (34). Quality improvement has been defined as *"combined and unceasing efforts by all involved (healthcare professionals, patients and their families, researchers, planners and policy makers) to make changes that will lead to better patient outcomes, better system performance and better professional development"* (35). This definition captures the proactive nature of quality improvement. However efforts to implement improvement originally began as passive diffusion of publications to health care professionals, moving on to the dissemination of guidelines and systematic reviews to inform care (77). It was the influence of industrial style change on healthcare which introduced the more active inclusive approach to quality improvement promoted today.

2.1.6 Quality Frameworks: from industry to healthcare models

Since the 1980s there has been a greater emphasis on continuous monitoring and improvement across the whole health system, reflective of the principles of Total Quality Management (TQM) (78). TQM is a systematic approach to quality improvement in which poor performance is the responsibility of the organisation and not the individual. This approach, also known as Continuous Quality Improvement

(CQI), focuses on improving quality at every level of an organisation thereby creating an organisational culture in which people take responsibility for and commit to improving quality (78).

The principles of TQM originated in the manufacturing and services industry (34) stemming from the work of two 'quality gurus', Deming and Juran (79). Both experts developed their quality control techniques and theories working with manufacturers and corporations in post World War 2 Japan which was struggling to produce high quality goods and services (80). The key message conveyed to senior executives was that improving quality reduced waste and inefficiency, and ultimately saved money. Deming emphasised the need for commitment to quality across the entire organisation, a principle reflected in Total Quality Management. One of his most popular techniques was the systematic approach to problem solving known as the Plan, Do, Study, Action cycle (PDSA) which has transferred to quality improvement innovations in other settings including health care (81). Juran emphasised the need to plan improvement as part of a trilogy of management processes which also included quality control and quality improvement. He recognised the contribution of people to this process, promoting education and training for managers who should assume responsibility for quality (80). There is ongoing debate as to whether frameworks from industry, such as Total Quality Management, are applicable to healthcare delivery (79) and there are few rigorous evaluations of this approach in healthcare (82). However mistakes, inefficiency and poor performance are costly in all organisations including health systems, and a number of the principles from this framework are applicable to quality improvement in health care including leadership and commitment to quality (78).

The phase of quality improvement which followed the industrial style approach was a response to the perceived shortcomings of Total Quality Management. System reengineering proposed more radical change in contrast to the incremental approach promoted by TQM (83). Current thinking emphasises the merits of both approaches: continuous gradual improvement with lateral leadership to produce organisation-wide change (83). This phase is known as system redesign or transformational change. One framework from healthcare which combines transformational change with an emphasis on multi-level involvement is the Chronic Care Model. It is one of the few conceptual frameworks developed specifically to guide change in chronic illness care.

2.1.7 Chronic Care Model: Framework for Improvement in Healthcare

Like TQM, the Chronic Care Model (CCM) focuses on the organisational context of chronic illness care while also adopting a system-wide perspective of quality. This framework proposes profound changes to the organisation and delivery of health care (84). The Chronic Care Model, developed in the United States during the 1990s, is not an abstract theory but rather *"like an evidence-based guideline: a synthesis of system changes to be used to guide quality improvement"* (p76) (81).

The model outlines the components necessary for high quality chronic disease management. Firstly there are three overlapping spheres in which chronic illness care takes place; the practice is embedded in a health system which is embedded within a wider community of resources and policies. There are 6 'pillars' of effective chronic illness care; community resources and policies, health care organisation, self-management support, delivery system design, decision support and clinical information systems (69). Community resources include policies and negotiated relationships or links with other care providers to enhance the continuity of care (81). Health system organisation relates to the structure, values and goals of a system including the promotion and prioritisation of chronic care and payment structures to support service delivery. The remaining four components, self management support, delivery system design, decision support and clinical information systems, exist within the practice setting (69). Figure 2, which illustrates the Chronic Care Model, has been supplemented with examples of interventions in each area. The ultimate goal according to this model is a 'productive interaction' between an informed active patient and a prepared proactive primary care team with the relevant expertise, information and resources to assist patients (69, 81). Each element in the model is interdependent. The prepared proactive care team organise and coordinate patient care facilitated by delivery system design and clinical information systems. Equally these components in the practice could not be sustained without leadership and financing within the health system (69).

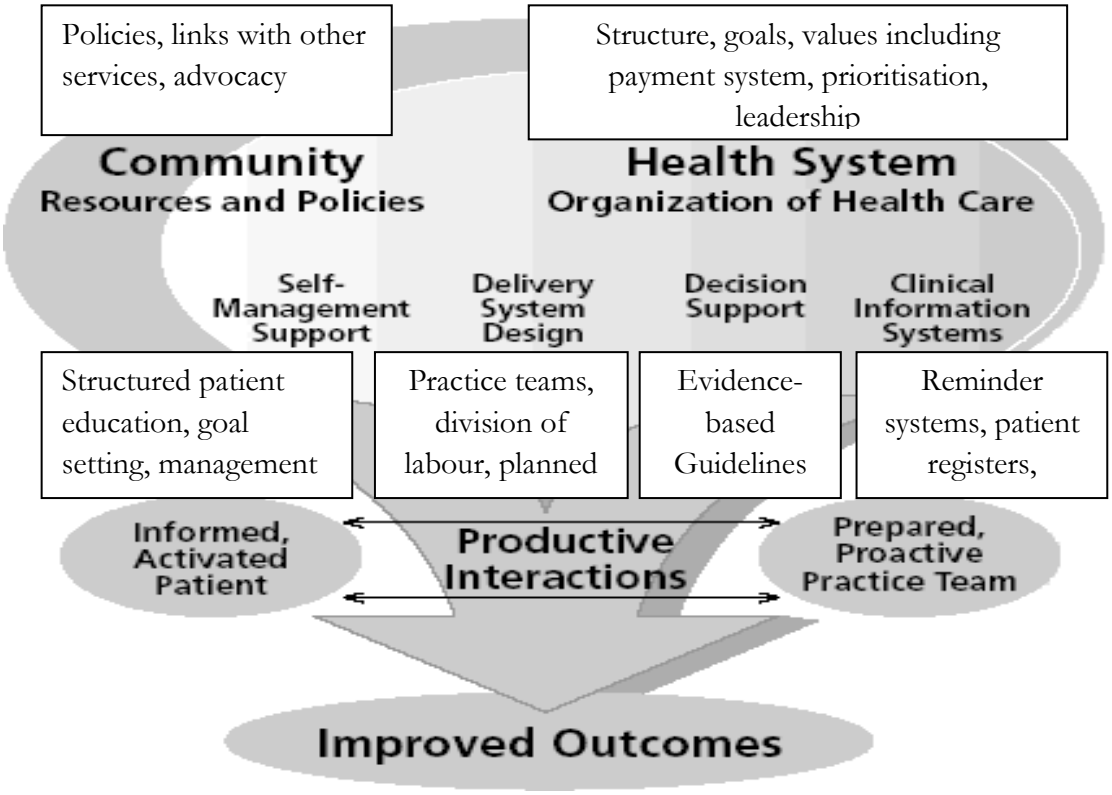


Figure 2 The Chronic Care Model with examples of interventions in each area

The CCM has yet to be implemented in its entirety. Intervention studies tend to concentrate on the 4 elements within the practice, which are more amenable to change by health care professionals than community resources for example (84). Consequently the health care system and community resource components have received less empirical attention and their impact on the quality of care has yet to be tested.

Since the 1990s research on the model has progressed from case studies (84) to a meta-analysis of interventions implementing components of the CCM across numerous chronic illnesses (85), strengthening its claim as an 'evidence based' model. The model is also widely used at a national level in the US by collaborative programmes involving health plans and provider organisations seeking to improve the quality of care (81, 84). At an international level, the Chronic Care Model is recognised as a framework for quality improvement in chronic illness care and as such has informed the health care policies and directives of several countries such as Germany (86) and Canada as well as developing countries (87). The national Framework for Chronic Disease Management in Ireland also refers to the Chronic Care Model as a guide to quality improvement (11). As one of the most widely applied frameworks in the field of quality improvement research, the effectiveness of CCM-based interventions will be addressed within a wider review of quality improvement interventions outlined in the following section.

2.1.8 Improving the Quality of Diabetes Care

Since the term quality chasm emerged in 2001 there has been a steady stream of interventions seeking to reorganise chronic illness care as a means of quality improvement, a number of which have focused on diabetes care. This section presents a critical synthesis of the evidence examining whether changes in the organisation and coordination of care improves the quality of diabetes care. Particular attention was paid to the type of strategies included as part of quality improvement interventions. Given the proliferation of articles on this topic the synthesis of the literature focused on systematic reviews and recent trials examining:

1) Changes *within* the practice setting including organisational and professional interventions.
2) Changes to enhance the coordination of care *between* providers and settings.

Interventions were categorised as changes to the organisation care, the coordination care or a mixture of both approaches (Table 1). This classification was informed by previous taxonomies of organisational change (15, 88), including the classification used by Renders et al in their seminal review of interventions in primary care, community and out-patient settings (14).

Table 1 Changes to organisation & coordination of care to improve quality

TYPE	DEFINITION
Organisational/Professional interventions within the practice	
Knowledge management	Organisation of knowledge within a setting including use of information and communication technology, electronic medical records, electronic patient registers.
Professional interventions	Education, clinician reminders, audit & feedback
Quality management	Continuous efforts to improve, measure and analyse performance including explicit CQI interventions also referred to as TQM.
Coordination between providers & settings	
Team Changes	Changes to structure and organisation of care team including; adding a team member or "shared care" e.g. routine visits by professionals other than physician (e.g. Diabetes Nurse Specialist);Use of multidisciplinary teams; Revision of professional roles (e.g. increasing role of the nurse).
Mixed organisation & coordination	
Integrated care programme	Organisational process of coordination to achieve continuous care for patients with specific diseases including organisational and/or professional interventions. This encompasses chronic disease management programmes and case management which overlap.
*The classification and definition of improvement strategies was based on the taxonomies developed by Wensing et al **(88)**, Shojania et al **(15)** and Renders et al **(14)**, which define organisational, professional and coordination strategies and were originally informed by the list of interventions used by the Cochrane Effective Practice and Organisation of Care (EPOC) group.*	

Search Methodology

The review was restricted to evaluating structural, organisational and professional-level interventions which targeted the setting and/or provider of care rather than the patient. Only articles which focused on diabetes or diabetes as one of a number of chronic conditions were included. Articles were identified by electronic searches of MEDLINE, EMBASE, Cochrane Database of Systematic Reviews and the Clinical Trials Register, CINAHL and ERIC. Review articles were restricted to English-language publications issued between January 2000 and July 2011. A supplementary search was conducted for individual studies published since the most recent systematic review (2008-2011). Combinations of the following search terms were used: "diabetes", "chronic disease", "quality of health care", "quality assurance", "delivery of health care" and "disease management". Reference lists of relevant studies were reviewed to identify further articles (Appendix II for outline of review methods).

Description of Studies

Initially the literature search yielded 1948 potential articles across five databases. Of these 139 were selected based on the title and abstract. A total of 28 articles met the inclusion criteria (see Appendix II). Of the 28 studies 17 were systematic reviews (Table 2) and 11 were individual trials published since 2008 (Table 3). The results of the systematic reviews will be outlined first followed by recent evidence from randomised trials of quality improvement interventions.

Table 2 Overview of systematic reviews of interventions to improve the organisation or coordination of diabetes care

STUDY	FOCUS	AIM
Organisational changes within the practice (organisational/professional)		
Gulburg et al (2009)(89)	Feedback	Assess the effect of feedback to GPs on the quality of care for patients with Type 2 diabetes
Dorr et al (2007) (90)	Information Systems	To examine the function of health care information systems in chronic illness care and improvements in processes and outcomes attributable to such systems.
Coordination changes between providers & settings		
Loveman et al (2003) (91)	Specialist Nurses	To assess the impact of diabetes specialist nurses/nurse case manager in diabetes on metabolic control of patients with Type 1 or Type 2 diabetes.
Smith et al (2007) (92)	Shared Care	To examine the effectiveness of shared care interventions designed to improve the management of chronic diseases
van Bruggen et al (2007) (93)	Shared care	To examine the impact of sharing care and allocating care tasks on the quality in diabetes care and cardiovascular risk among patients with diabetes.
Mixed organisational & coordination strategies		
Ouwens et al (2005)	Integrated care	To investigate the effectiveness, definitions & components of integrated care programmes for chronic illness
Bodenheimer et al (2002) (69)	Chronic Care Model	To examine the extent to which interventions based on the Chronic Care Model improves the management of chronic illness using diabetes as an example.
Norris et al (2002) (94)	Disease Management	To determine the effectiveness & economic efficiency of disease and case management for people with diabetes.
Weingarten et al (2002) (16)	Disease Management	To assess the effectiveness of disease management programmes for peoples with chronic illness (meta-analysis).
Knight et al (2005)(95)	Disease Management	To evaluate the impact of disease management for patients with diabetes on processes and outcomes of care.
Krause (2005) (96)	Disease Management	To examine the economic effectiveness of disease management programmes for patients with chronic illnesses
Tsai et al (2005) (85)	Chronic Care Model	To examine whether interventions incorporating elements of the Chronic Care Model improve care and outcomes for patients with chronic illness and determine which elements are essential for improvement.

STUDY	FOCUS	AIM
Scott (2008) (97)	Chronic Disease Management	To provide an overview of the evidence for chronic disease management including; the effectiveness , the most successful elements and economic efficiency of such programmes.
Glazier et al (2006) (98)	Patient, provider & health system intervention	To review evidence on the effectiveness of patient, provider and health system interventions to improve diabetes care among socially disadvantaged populations
Renders et al (2000) (14)	Organisational & Professional intervention	To assess the impact of interventions targeting health care professionals or the structure of care for patients with diabetes in primary care, outpatient and community settings.
Seitz et al (2011)	Interventions in primary care	To assess the impact of interventions in primary care on cardiovascular risk factors and HbA1c levels in patients with diabetes. Interventions included organisational and professional interventions.
Shojania et al (2006) (15)	Quality Improvement strategies	To assess the impact of 11 improvement strategies for Type 2 diabetes on glycaemic control (meta-analysis)

2.1.9 Reviews of organisational changes within the practice

Two systematic reviews concentrated solely on organisational changes within the practice setting (89, 90). The first review examined the effect of providing feedback to GPs on the quality of diabetes care. There was a positive impact on processes of care including foot exams, eye exams and HbA1c measurement however the impact on patient outcomes was less definitive. There were significant positive changes in HbA1c, blood pressure and cholesterol levels however such indicators were less frequently measured. Only one of ten studies included in the review examined long-term outcomes including complication rates and mortality, however no significant difference was detected (89).

The focus of the second review was less well defined, examining the impact of information systems on the quality of care across a number of chronic diseases including diabetes. Although a wide range of study types were included, the evaluation of effectiveness was based on evidence from experimental studies due to a publication bias detected in non-experimental studies. Overall information systems had a positive impact on guideline adherence and documentation of care but an inconsistent effect on referral rates and visit frequency across all chronic diseases. Clinical outcomes were not broken-down by type of disease and were categorised as laboratory values and standardized instruments. There was no consistent evidence of a positive effect. The review also examined the impact of information systems across a number of different health care settings (out-patients, primary care, hospitals etc) but again did not separate the impact on processes and outcomes in terms of setting (90). Hence it is difficult to draw any definitive conclusions regarding the impact of information systems on diabetes care in primary care from such an all-encompassing evaluation.

2.1.10 Reviews of changes to the coordination of care

Three reviews examined interventions involving team changes (91, 93, 99). Loveman and colleagues investigated the role of the diabetes specialist nurse in improving care (91). Four of the six trials dealt with adult patients however only one of these studies found a significant short-term benefit in terms of HbA1c. The review used a limited number of indicators to evaluate the effectiveness of the diabetes nurse specialist role. Notably absent from the battery of indicators were process of care measures and intermediate outcome measures such as blood pressure and cholesterol levels. However unlike other reviews, this study examined the impact of team changes on long-term

outcomes although there was no evidence of a significant effect. There were inconsistent findings in relation to the occurrence of short-term complications (hypoglycaemic and hyperglycaemic episodes). Few studies in the review evaluated the impact of the nurse specialist role on quality of life, BMI or mortality.

A systematic review of shared care interventions for chronic disease management found little consistent improvement in most outcomes assessed (99). Although 'shared care' falls under the category of team changes according to Shojania et al (15), the interventions included in this study also involved organisational and professional strategies (e.g. clinical protocols, continuing education, audit and feedback) blurring the distinction between types of quality improvement strategies. Three of twenty studies in the review focused on shared care for patients with diabetes and similar to the overall findings there was inconsistent improvements on processes of care, no significant improvements in physical health outcomes and inconsistent findings for psychosocial outcomes. The final article, a review of reviews, which focused specifically on shared care and task delegation for diabetes care, found a positive improvement in terms of processes of care where this indicator was used (93). A number of reviews of delegated care and/or shared care interventions demonstrated a positive impact on HbA1c. There was insufficient evidence of the impact on the cardiovascular of patients with Type 1 or Type 2 diabetes. Given the quality of this review and the level of detail provided, a number of the systematic reviews included in the article are dealt with separately in this synthesis to unpick the findings in more detail (14, 91, 94, 95).

2.1.11 Reviews combining organisation and coordination strategies

Most reviews synthesized evidence on the effectiveness of multifaceted interventions to improve both the organisation and coordination of care. Five articles focused explicitly disease management programmes for chronic illnesses including diabetes (16, 94, 95) one of which examined the cost effectiveness of such programmes (96). Two reviews examined the effectiveness of interventions based on the Chronic Care Model (69, 85).

Multifaceted quality improvement interventions

One of the earliest reviews by Renders et al (2000) looked at the impact of professional and organisational interventions on diabetes care in primary care, outpatient and community settings (14). Of the 41 studies identified, 20 studies combined both professional and organisation change strategies. Patient education was added to

professional and organisational interventions in 15 studies. Professional interventions had a positive impact on process measures as did organisational interventions which facilitated the structured follow-up of patients. A similar trend emerged from interventions *combining* professional and organisational strategies. Computerised reminders and/or audit and feedback had a positive effect on processes of care however the impact on patient outcomes was rarely assessed. Similarly centrally organised systems for tracking patients and arranging follow-up were beneficial in terms of process but not outcomes. Generally those studies which reported a positive impact on patient outcomes tended to have greater involvement from a nurse and/or included patient education.

In an effort to distinguish between the impact of various strategies Shojania et al (2006) assessed the impact of 11 QI strategies on glycaemic control in patients with Type 2 diabetes using meta-analysis techniques (15). Across all 66 trials there was a mean reduction of 0.4% in HbA1c levels (95% CI 0.29-0.54%). However after adjustment for relevant confounders only two strategies were associated with incremental reductions in HbA1c: team changes (0.33%) and case management (0.22%). In particular, interventions in which nurse or pharmacist case managers could adjust medication without awaiting physician approval showed significant reductions in HbA1c levels.

A review conducted by Seitz et al (2011) expanded the research question investigated by Shojania et al to examine the impact of quality improvement on cardiovascular risk factors as well as glycaemic control (100). A similar taxonomy of interventions was used to classify studies: professional, organisational, patient-centred, financial and regulatory (100). Less than half the studies evaluating single professional interventions (e.g. professional education) found significant improvements in HbA1c or any of the cardiovascular risk outcomes. Processes of care such as foot exams improved but there was no significant impact on recording of blood pressure, HbA1c or the assessment of complications. Only two studies examined single organisational interventions, (e.g. shared care, case management) with no significant impact on HbA1c detected. There was no reference to the measurement of cardiovascular risk outcomes in either study. Most studies included in the review were categorised as combined interventions with mixed results. A number of multidimensional studies found improvements in clinical outcomes such as HbA1c levels, cholesterol and blood pressure levels however no improvement emerged consistently from the body of literature.

The effectiveness of multidimensional interventions rather than single strategies was highlighted by Glazier et al in a review of interventions in socially disadvantaged areas (98). Only one intervention targeted the "provider-level" which seemed to involve educational reminders to enhance processes of care. Seven studies focused on system-level changes which ranged from nurse-led case management to treatment algorithms. Interventions involving system-level changes demonstrated a positive impact on HbA1c, lipid concentrations and blood pressure in disadvantaged populations. Changes in processes of care were less well defined in the review beyond highlighting that eye examinations improved in two system-level studies.

Finally a review by Ouwens et al examined the effectiveness of integrated care programmes explicitly, defined as an organisational process of coordination with the aim of achieving continuous care (101). Integrated care interventions consisted of patient (e.g. education), professional (e.g. education), organisational (case management) and coordination strategies (e.g. multidisciplinary teams). There was a positive impact on processes of care for patients with diabetes however there was no significant impact on outcomes. Two of the thirteen reviews included in the article pertained to diabetes, both of which are dealt with separately in this section (14, 94).

Disease Management Programmes

Five reviews examined interventions described as disease management programmes (16, 94-97). A meta-analysis of the effectiveness of chronic disease management suggested that programmes targeting provider behaviour were associated with improvements in terms of provider adherence to guidelines (process measure) and disease control (outcome measure) across a number of chronic conditions. The provider interventions examined were restricted to education, feedback and reminders (16). However, the impact of diabetes-specific programmes on the quality of care was variable (26/102 studies). None of the studies involving provider feedback led to a statistically significant impact on diabetes process (fundoscopy performed, retinal screening, renal screening, foot exam and HbA1c testing) or outcome measures (HbA1c). A number of studies involving provider education and provider reminders conferred a significant benefit in terms of HbA1c and provider adherence.

Another broad review of chronic disease management programmes highlighted the lack of consistent evidence to single out one crucial element of such interventions (97). Focusing on the 7 diabetes-specific reviews included in the study, there was no evidence

of a significant reduction in mortality, hospitalisation or cardiovascular events. There were significant improvements in intermediate outcomes such as disease control (HbA1c), blood pressure control, screening processes and patient self-care. A number of the reviews included in the article are discussed individually given the lack of diabetes-specific information in the article (14-16, 85, 91). Cost savings from chronic disease management were evident in the small number of studies which included this indicator however this finding pertained to only one diabetes-specific study.

A review which focused solely on the economic effectiveness of chronic disease management programmes included 11 articles on diabetes out of a total of 67 (96). Very little detail was given on the type of interventions included beyond classifying strategies as team management, nurse management or patient management interventions. Overall the results demonstrated that chronic disease management programmes were cost effective with statistically significant average effect size of 0.3 (95% CI=0.27-0.35). Disease type did not have a significant influence on effect size however the type of disease management programme (team, nurse, and patient) did have a significant impact on economic effectiveness.

Looking specifically at chronic disease management for diabetes, a systematic review of disease management and case management for people with Type 1 or Type 2 diabetes demonstrated a positive impact on the processes of care (monitoring glycaemic control and retinal screening) and metabolic control (94). Other outcomes were not typically assessed. A similar pattern was evident for case management interventions which also had a positive impact on glycaemic control. When case management was combined with disease management it also had a positive impact on the monitoring of glycaemic control. However there were too few studies to accurately assess the impact of disease or case management on a number of outcomes including lipid concentrations, BMI and psychosocial indicators.

A similar positive impact on glycaemic control was found by another review of chronic disease management programmes for diabetes conducted in 2005 (95). There were consistent improvements in retinopathy screening however inconsistent evidence of improvements in terms of foot examination, HbA1c measurement and referral to podiatry. There was no consistent impact on other outcomes including cholesterol concentration levels, blood pressure levels and the monitoring of glycaemic control.

Reviews of the Chronic Care Model

Two reviews examined the impact of components of the Chronic Care Model (CCM) on the quality of chronic illness care. One article looked broadly at the impact of the CCM elements on the quality of chronic illness care by choosing a disease-specific clinical outcome (HbA1c), quality of life measure (unspecified) and process of care measure (number tested for HbA1c level) to evaluate the studies (85). Of 112 studies identified 31 related to diabetes care. Looking at the pooled estimates for diabetes specifically, 25 studies contributing continuous data on HbA1c found a pooled effect of -0.19 in favour of the intervention (CI 95% = -0.29, -.10). There was no significant impact on quality of life detected. Nine studies examined the number of times HbA1c was measured (1.10; 95% CI= 1.01, 1.19). While no single element of the CCM was sufficient to improve outcomes, a number of components were associated with better outcomes and processes overall. Delivery system design and self-management elements conferred a statistically significant benefit on continuous clinical outcomes and processes. However in both cases there were a greater number of studies included and larger estimated effects. There was no statistically significant impact from interventions involving clinical information studies however only a small number of studies were included.

The other review of elements of the Chronic Care Model focused on diabetes specifically (69). Thirty-nine studies addressed elements of the CCM which incorporated professional and organisational strategies such as reminder systems, performance feedback and planned follow-up as well as coordination strategies such as multidisciplinary care teams. Overall interventions demonstrated improvements in at least one process or outcome measure however the exact indicators to improve were not specified in the review. The majority of studies included in this article were based on those included in the Renders review (14) published the previous year suggesting an independent search strategy was not developed.

2.1.12 Individual studies of Quality Improvement Interventions

Moving on to individual evaluations of quality improvement interventions, eleven trials met the inclusion criteria (Table 3). Five studies examined organisational changes within the practice setting (102-106). Three studies were classified as interventions involving changes to the coordination of care between providers (107-109). Finally three studies involved a combination of strategies to improve the organisation and coordination of diabetes care (110-112).

Effectiveness of Organisational Changes

Most of the studies evaluating organisational changes within the practice utilised IT and electronic communication systems to enhance the delivery of care. One RCT examined the impact of electronic decision support and reminders for providers and patients, based on information from a web-based diabetes tracker monitoring disease risk factors (104). There was a significant difference between the intervention and control group in terms of the composite score of process measures (mean difference= 1.27; 95% CI=0.79-1.75; $p<0.001$) and a significant difference in the composite score of clinical measures (mean difference=0.55; 95% CI=0.04-1.07; $p=0.036$). There was no evidence of an effect on patients' quality of life.

In contrast another study of decision support found no significant improvements in clinical outcomes (HbA1c, BMI, BP, Cholesterol) although processes of care improved (113). The intervention group were more likely to received guideline appropriate care for testing lipids (OR=1.39, $p=0.01$) and creatinine (OR=0.40, $p=0.02$) but not HbA1c testing (OR=1.17, $p=0.43$). The intervention, known as the Vermont Diabetes Information System, also involved other improvement strategies including the implementation of an electronic patient registry and audit and feedback for physicians. The multifaceted nature of the intervention means it is not possible to isolate or directly compare the effect of decision support in this study relative to the previous findings.

Table 3 Overview of individual trials investigating the impact of quality improvement interventions on diabetes care (published 2008-2011).

STUDY	FOCUS	AIM
Organisational changes within the practice (organisational/professional)		
Holbrook et al (2009) (104)	Electronic decision support & reminders	To evaluate whether shared electron decision support (between doctor and patient) with reminders improves the quality of diabetes care in the community.
MacLean et al (2009) (105)	Information System	To evaluate the impact of registry and decision support on the quality of diabetes care
O'Connor et al (2009) (102)	Physician Education	To assess physician learning interventions designed to improve the quality and safety of care
Gulberg et al (2011)(103)	Feedback	To evaluate the effectiveness of providing electronic feedback on treatment status for patients with Type 2 diabetes to general practitioners
Goderis et al (2010) (106)	GP Support Programme	To assess the effectiveness of a support programme for GPs including education and annual benchmarking on Type 2 diabetes outcomes.
Coordination changes between providers & settings		
Peikes et al (2009)(108)	Coordination	To determine the effectiveness of care coordination programmes on hospitalisations, cost and the quality of care for patients with chronic illnesses
Simpson et al (2011) (107)	Team Changes	To evaluate the impact of adding pharmacists to primary care teams on blood pressure control in patients with Type 2 diabetes
Van Bruggen et al (2008) (109)	Guidelines	To evaluate the impact of a facilitator-enhanced intervention to implement local guidelines on shared care for Type 2 diabetes.
Mixed organisational & coordination strategies		
Chan et al (110)	Structured care	To assess the impact of structured care on renal complications in Type 2 diabetes compared to usual care
Peterson (111)	Organisational intervention	To examine the impact of a multidimensional organisational intervention on diabetes processes and outcomes in primary care
Cleveringa et al (2010) (112)	Protocol	To determine the effectiveness of a diabetes care protocol in terms of patient-important outcomes

O'Connor et al examined the impact of simulated physician learning on care processes and clinical outcomes (HbA1c and LDL cholesterol) (102). The intervention involved simulated case management with electronic feedback to primary care physicians on their prescribing behaviour. The intervention was also combined with opinion leader feedback and compared to a control group and intervention-only arm. At 12 months both intervention groups showed significant improvements in risky prescribing behaviour ($p=0.03$) however there was no significant difference between groups in terms of LDL cholesterol testing ($p=0.30$) or LDL cholesterol levels ($p=0.67$). There was also no significant difference detected in the rate of treatment intensification for patients not reaching target ($p=0.41$). Patients whose physicians received simulated learning *only* had significantly better glycaemic control compared to the other 2 groups ($p=0.04$) hence there appeared to be no additional benefit from adding opinion leader feedback to the intervention.

In a similar study, Gulberg et al (2011) examined the impact of real-time electronic patient feedback provided to GPs during their daily clinical work (103). The primary measure of effectiveness was patients' retrieval of prescriptions according to guidelines on diabetes treatment. More people in the intervention group redeemed prescriptions in accordance with guidelines for oral antidiabetic medicine ($p=0.002$), insulin ($p<0.001$), lipid-lowering medication ($p=0.004$) and blood pressure medication ($p=0.03$). There were no significant differences between the groups in terms of secondary clinical outcomes, HbA1c and cholesterol levels, at fifteen months follow-up.

The final clustered RCT evaluating organisational changes in general practice compared a usual quality improvement programme to an 'advanced' quality improvement programme in Belgium (106). There was no control group included in the trial. The usual quality improvement programme involved following an evidence-based protocol for monitoring patients, professional education, case coaching from an endocrinologist in the event of problems, annual benchmarking and feedback, and patient education. The 'advanced' quality improvement intervention represented an intensification of these elements, e.g. intensified education, three monthly benchmarking and feedback, joint meetings with specialists, organised group education for patients and families. Both interventions demonstrated a significant improvement in HbA1c, LDL cholesterol and systolic blood pressure levels. However there were no statistically significant differences between the two interventions in terms of the three primary outcomes. Only physical

exercise and anti-platelet therapy were significantly higher in the advanced improvement group. Also addition elements of the advanced QI interventions were only used by a minority of participants. Hence the findings suggest intensified support for GPs and patients, beyond usual interventions to improve care in Belgium, were not fully utilised and did not have additional benefit in terms of improving patient outcomes.

Interventions to improve the coordination of care

Peikes et al (2009) examined the impact of care coordination plans on hospitalisations, Medicare expenditure and the quality of chronic illness care in the U.S (108). Care coordination plans included enhanced communication and case discussion and changes in medical records systems. Overall there was no significant reduction in hospitalisations and there were no net savings generated as a result of the intervention. One diabetes-specific study found a significant impact on hospitalisations and four studies found significant monthly cost savings for those in the intervention group. Additional quality of care measures measured using a patient survey (e.g. self management skills) improved as a result of the intervention.

Another trial targeting care for patients with Type 2 diabetes looked at the impact of a facilitator-enhanced intervention to implement local shared care guidelines in general practice in the Netherlands (109). The visiting nurse-facilitator had a central role in improving care by providing training for GPs and practice staff in the use of guidelines, encouraging structured care and providing performance feedback. There were significant differences between the groups in terms of measurement of patient outcomes ($p<0.001$). A larger proportion of patients in the intervention group reached HbA1c targets compared to the control group however this was not significant after adjustment for relevant factors such as clustering (70% vs. 58%, $p>0.05$). There were also small but non-significant changes in other clinical outcomes (mean HbA1c, BP, BMI or treatment satisfaction).

Simpson et al looked at the addition of pharmacists to the primary care team and the impact on blood pressure control of patients with Type 2 diabetes. As part of the intervention pharmacists performed medication assessments and limited history and physical exams as well as providing recommendations to optimise medication management based on guidelines. A significantly higher proportion of patients in the intervention group achieved a ≥10% decrease in systolic blood pressure compared to the control group (OR=1.9, 95% CI 1.1-3.3, p=0.02). Concentrating on those with

poorly controlled hypertension at baseline, those in the intervention group were more likely to achieve the target than patients in the control group (OR=2.6, CI 95% 1.3-5.0, p=0.007).

Multifaceted interventions to improve diabetes care

One of the few studies to use long-term outcome measures as its primary outcome was examined the effect of structured care on renal endpoints in patients with Type 2 diabetes (110). Structured care which incorporated guideline driven care and multidisciplinary teams had no significant effect on the composite primary outcomes of end stage renal disease, dialysis and mortality. The composite end point of all three outcomes was equal in both groups (RR=0.96, 95% CI 0.50-1.84). A higher proportion of patients in the structured care group achieved ≥3 clinical targets compared to the control group (61% vs. 28%, p<0.01). Patients who achieved ≥3 clinical targets had a 60% risk reduction in reaching the primary end point compared to those who did not achieve ≥3 targets (RR=0.43, 95% CI 0.21-0.86, p=0.04).

The TRANSLATE Trial was conducted in 24 practices to investigate whether a multidimensional intervention would improve clinical outcomes and processes of care (111). The intervention, which was aimed at patients with Type 2 diabetes, incorporated an electronic diabetes registry, reminders, a coordinator to plan patient visits and monthly review meetings with a local champion. All practices showed significant improvements in process measures however there were significantly greater net improvements for the intervention group in foot examinations (p<0.001), annual eye exams (p<0.001), renal testing (p<0.001), HbA1c testing (p<0.001), blood pressure monitoring (p<0.05) and LDL testing (p<0.001). Only the intervention group showed significant improvements in clinical outcomes. Using a composite score of outcomes the intervention group had significantly greater net improvements in terms of targets for blood pressure, HbA1c and LDL cholesterol compared to the control group (p=0.002).

Finally the Diabetes Care Protocol (DCP) trial focused on the impact of a multidimensional intervention on patient-important outcomes (112). The primary outcome was diabetes-related health status while secondary outcomes included measures of quality of life. The intervention combined task delegation to the practice nurse, computerised decision support system providing feedback and intensification of diabetes treatment. The results of this trial were inconsistent. The intervention was

deemed to be non-inferior to usual care in terms of diabetes related health status however comparison between the groups on secondary outcomes were inconclusive. Within group analysis showed a worsening of scores on some health profile and health status subscales for both the intervention and control group.

2.1.13 Summary of the Evidence

The preceding section synthesised evidence of the effectiveness of interventions to improve the organisation and coordination of diabetes care from systematic reviews and individual trials. As suggested by the Agency for Healthcare Research and Quality (AHRQ) everything seems to work for diabetes in some instances for some outcomes (8). Similar types of interventions can produce inconsistent results depending on the indicators chosen to evaluate improvement and the lines drawn between different types of strategies. For example a Cochrane review of shared care for chronic illness found no consistent benefit in terms of process or clinical outcomes (99). In contrast a diabetes-specific review of shared care and task delegation found improvements in process measures and a number of studies demonstrated a positive impact on HbA1c (93). Interestingly there were different studies of shared care included in both reviews despite an overlap in their search timeline. It is important to note that while the Cochrane review only included three diabetes studies, the quality and rigour of literature search was higher.

There are a number of ways of categorising quality improvement. As Norris and colleagues point out, case management can be implemented as part of a broader disease management programme, as a single intervention or in combination with other interventions (94). This is true of most strategies. The various lenses for viewing strategies are reflected in the substantial overlap between the studies included in different reviews. For example the review of professional and organisational interventions by Renders *et al* (14) was included in four other reviews (69, 93, 97, 101). Categorisation is even more challenging given the lack of detail provided in many articles (16, 69, 85, 96). Lack of descriptive detail can lead to problems identifying or recreating the necessary conditions for effectiveness (114). Guidelines have been proposed to enhance the writing, reviewing and interpretation of quality improvement research in the hope of bringing more structure and rigour to the field (115).

Indicators of Quality Improvement

The results of this synthesis highlight the attention given to process measures over clinical and patient-reported outcomes beyond glycaemic control. Some researchers favour the use of process measures suggesting they are more sensitive as an error in care delivery does not always lead to a poor outcome (116). Processes are common, under the control of the health professional and can be changed more readily (73). Davies & Crombie suggest the while clinical outcomes have intuitive appeal they are influenced by several factors beyond the health care professionals control (117).

While a number of articles found significant improvements in glycaemic control as a result of the intervention (16, 94, 95, 97) there was inconsistent evidence of an effect on cardiovascular risk factors such as blood pressure, cholesterol and BMI (94, 95, 100). Outcomes beyond glycaemic control are often neglected in evaluations of quality improvement interventions. Mortality among people with diabetes tends to be as a result of cardiovascular disease or renal disease rather than causes uniquely related to diabetes (47), and yet we continue to measure HbA1c while ignoring cardiovascular and other risk factors.

The follow-up periods of the trials included here rarely extended beyond twelve months. The overemphasis on intermediate outcomes measured in the short-term may underestimate the true effect of QI interventions which has yet to be realised (118). Quality improvement interventions should include long-term outcomes in their battery of indicators such as cardiovascular events, visual impairment and mortality. Chan et al was one of the few researchers to assess change in long-term outcomes (110). The selection of quality indicators should be guided by theory, the objectives of the program or previous research (114). Most studies do not outline the mechanisms by which interventions are expected to change the quality of care hence there is often a nonexistent link between the components of an intervention and the indicators used to evaluate improvement (119, 120).

Patient reported outcomes were also neglected in the studies within systematic reviews (14, 94, 98) and indeed by the reviews themselves, making it difficult to draw conclusions regarding effectiveness. For example Knight et al (2005) alluded to the assessment of patient-reported outcomes in their review of disease management programmes however they grouped health status, physical functioning and patient

satisfaction under the term quality of life (95). Multifaceted interventions generally incorporate a patient-focused component; therefore patient-important outcomes should be assessed. In their review of over 100 chronic disease management programmes Weingarten et al found that patient education was the most common interventions used in over 70% of programmes (16).

Isolating the success factor

One of the main challenges when evaluating complex multidimensional interventions is disentangling the impact of the various components to identify which are most effective. Ovretveit & Gustafson (2002) suggest the activities of quality improvement interventions *"may be mutually reinforcing and have a synergistic effect"* (114). This point is particularly relevant in the case of diabetes registries. The authors of the TRANSLATE trial stress the central role of the disease registry in supporting other improvement strategies such as enhancing the work flow through patient-specific provider alerts, decision support and facilitating monthly progress reviews (111).

The confusion is multiplied when no significant improvements are detected by a study; are all similar interventions ineffective or did the problem lie with the design and methodology of the trial (121). In 2000 the Medical Research Council developed a framework to guide the design and implementation of complex interventions (122) and this has since been updated. The revised version recognises that the phases of development and implementation may not always be linear and while randomised controlled trials are the favoured design these are not always possible (123).

Translating Research in Practice

Questions have been raised about the external validity of RCTs in evaluating multidimensional quality improvement initiatives which require significant time and resources to run effectively in a research setting. Such interventions are less likely to translate to a real health care setting (124). One study of an advanced quality improvement programme found that additional more intensive elements of the intervention were only used by a minority of participants (106). Norris et al (2002) highlight that health care professionals who are selected by researchers or volunteer themselves to such interventions may be more committed to change and more adept at the processes involved (94). These are just some of the issues affecting the translation of quality improvement research into real world change. Understanding the context in

interventions succeed and fail is as important as determining the effectiveness of various QI strategies (18).

2.1.14 Untangling Models of Diabetes Care

The body of literature outlined above illuminates some of the distinctions and similarities between 'models' of diabetes care. A model of care relates to the way diabetes management is arranged across settings and organised within a setting. Models of care exist in under several terms which are often ill-defined: 'integrated care', shared care (Europe), 'managed care' and chronic disease management programme (USA) and 'structured care' (7). The literature on models of care is embedded within the wider field of quality improvement research as different multidimensional models target the practice, provider and setting to improve the quality of care. For this reason a number of the aforementioned studies will be reiterated here in an attempt to untangle the terminology around models of care.

2.1.14.1 *Shared Care*

Shared care was one of the first demonstrations of efforts to improve diabetes care delivery. The concept was a consequence of the shift from an acute response to chronic disease management to increased responsibility in primary care for the management of diabetes (125). The Netherlands has been a pioneer of the shared care approach with health care providers working together in regional networks under the term 'transmural care' (126, 127). When introduced in the Maastrict region, shared care comprised of a change to the care setting and the health care provider. Care for patients with Type 2 diabetes shifted from the outpatient clinic delivered by the endocrinologist to the general practice setting where care was provided by a nurse specialist. The endocrinologist continued to review patients annually while the GP was ultimately responsible for patient care and took on a greater role with patients and other care providers. The nurse specialist had an interfacing role, co-coordinating care between the two settings, which had a positive impact on HbA1c levels and was as good as the traditional model on other clinical outcomes (128). The establishment of shared care in Maastricht led the way for a more formal disease management model in the region. This disease management model was proposed as an integration of shared and traditional care models that had been operating in the hope of providing structured and integrated care for all patients (129). Thus concepts of sharing and structuring care were combined in an effort to provide more comprehensive disease management. The blend of

structured and shared care concepts is also reflected in a recent systematic review of shared care interventions which included organisational and professional components such as *"pre-specified clinical protocols, referral guidelines, continuing education of participating clinicians, specifically designed information systems and ongoing audit and evaluation of services delivered"* (p2)(99).

2.1.14.2 *Chronic Disease Management*

The experience in the Netherlands suggests the concept of shared care was regarded as a precursor for fully developed chronic disease management programmes (7). Chronic disease management programmes are designed to deliver structured, proactive, integrated care and are often based on the Chronic Care Model (CCM) (130). The systematic review by Norris et al defined disease management according to 4 key elements; 1) identification of the population with diabetes, 2) implementing guidelines or standards of care, 3) regular management of identified people 4) use of information systems for tracking and monitoring patients. Additional interventions can be patient-orientated (e.g. education), provider-orientated (e.g. education also, reminders) or system-orientated (e.g. practice redesign) (94). In the US there is a distinction among chronic disease management programmes between those based on primary care and integrated within the health system and commercial plans developed by companies to which employers and health care plans contract out disease management (130). The latter format of disease management is a for-profit service marketed to customers as a cost containment strategy. The focus is often on patient education and self management employing e-health technology and telemedicine without having to engage the physician in behaviour change or reorganisation (131).

2.1.14.3 *Structured Care: an organised approach to delivery*

Chronic disease management programmes, particularly those based on the Chronic Care Model, deliver structured care to patients in an effort to improve the quality of care. However the term structured care is often used by itself in interventions and in Ireland it has particular connotations with primary care management, therefore it warrants clarification.

In the literature, structured care is largely defined by the strategies it incorporates to improve care delivery. Hence structured care can be thought of as an approach to care delivery applicable in many care settings. For example, a systematic review by Griffin and Kinmonth (1998) differentiated between structured and unstructured care by the

presence or absence of an organised system for recall and prompting for patients and doctors (132). In the more recent TRANSLATE Trial a structured care intervention involved the use of guidelines and prompts for GPs, continuing education, regular patient follow-up, individualised patient goal setting and feedback for both patients and GPs. Hence the model of structured care was characterised by a series of *"multifaceted disease management strategies"* (p8) (133). Finally, a study examining the impact of a nurse facilitator-enhanced intervention on Type 2 diabetes included training for GPs and practice staff in the use of guidelines, encouraging structured care and providing performance feedback (109). This intervention was conducted in the Netherlands using locally adapted *shared care* guidelines. This interchangeable use of terminology muddies the waters in terms of a distinction between shared and structured care and definitions proposed by the studies outlined above suggest a substantial overlap between terms.

2.1.15 Diabetes Care in Ireland

The traditional approach to diabetes care in Ireland was to refer patients to specialist hospital-based care upon a diagnosis of diabetes where patients were managed indefinitely (134). However for more than a decade there has been a shift towards greater primary care involvement. A survey of diabetes care in general practice in Ireland, conducted prior to the establishment of the Health Service Executive (HSE), found that up to 60% of Type 2 diabetes care was being provided by the GP as well as up to 24% of Type 1 diabetes care (135). However the balance of care between general practice and the hospital setting is not always straight-forward and there are a variety of diabetes care arrangements in Ireland including traditional hospital-based management, shared care between GPs and hospitals and primary care-led management.

2.1.15.1 *Quality of Diabetes Care in Ireland*

In line with international evidence, the provision of structured diabetes care in the general practice has also produced favourable results in Ireland in terms of processes and outcomes of care (20, 136-138). However this model of care is not common-place and there is a dearth of information on the quality of routine diabetes management at a national level. In the 1990s it was observed that quality improvement initiatives were *"sporadic and individually driven"* (79) and this has remained the case in diabetes care. There are currently 10 local diabetes initiatives across the country, illustrated in Figure 3, ranging from shared care schemes to structured care initiatives set up by GPs, to more recent initiatives which are mainly characterised by the appointment of a Diabetes

Nurse Specialist. A number of schemes were initiated and pioneered by groups of interested health care professionals, 'local champions' of diabetes care. Some initiatives independently monitor and assure the quality of care through routine audit and feedback (136, 137, 139, 140). However the quality assurance of diabetes care in Ireland is largely limited to these initiatives and the 2003 survey of diabetes care in general practice found that only 14% of GPs participated in a formal diabetes care scheme (135). Outside such groups, participation in quality improvement is largely unknown.

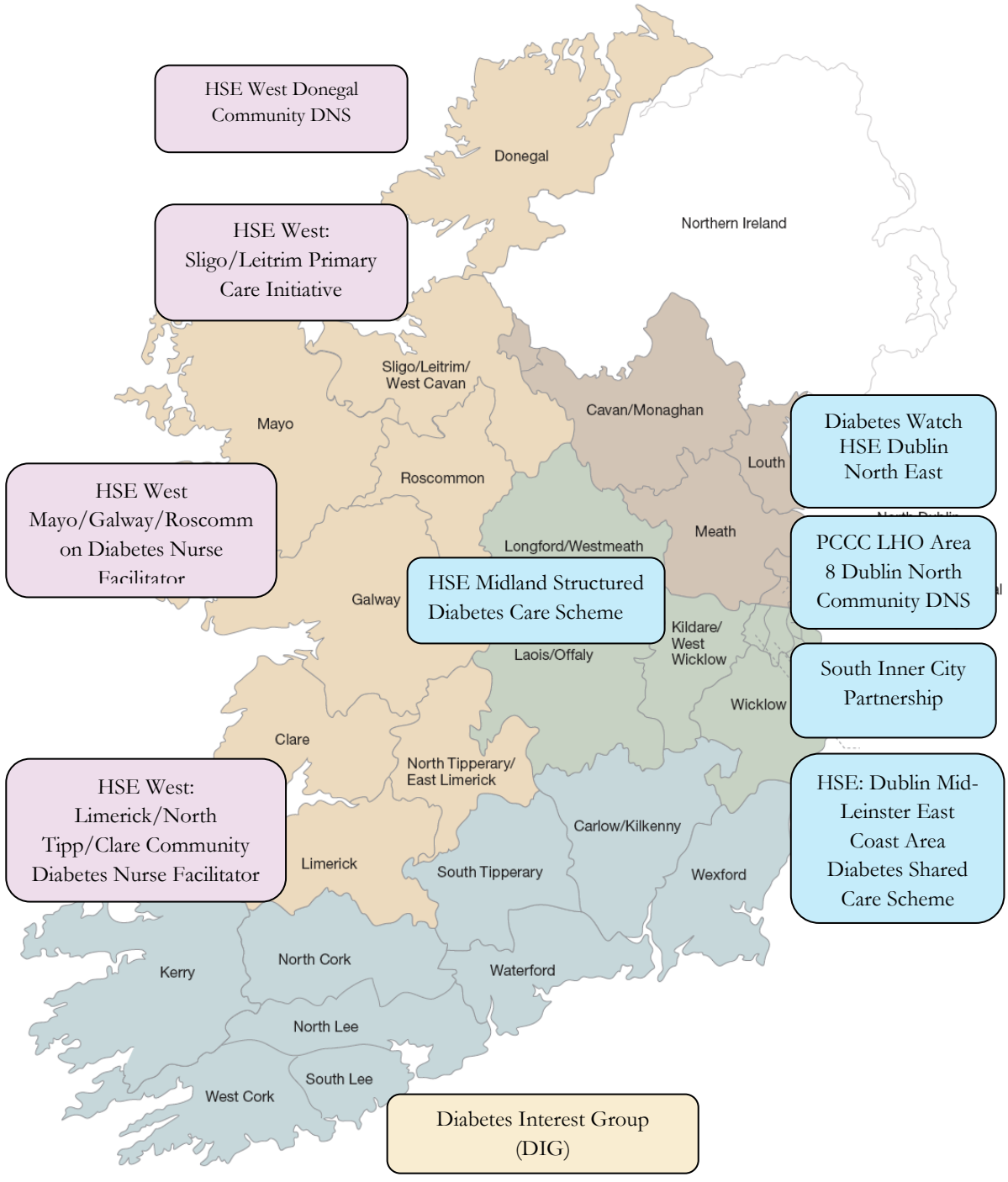


Figure 3 Diabetes Initiatives in Ireland

-Map reproduced with permission from the Health Service Executive

2.1.15.2 *Models of Care in Ireland*

The terminology used to describe models of care in Ireland is context-specific and based on participation in local quality improvement initiatives. Shared care is defined as the *"joint participation between hospital consultants and general practitioners in the planned delivery of care for patients with a chronic condition, informed by an enhanced information exchange over and above routine discharge and referral notices"* (141). This model is currently formally provided by the East Coast Area Diabetes Shared Care Programme (ECAD), which was established jointly by a GP and an endocrinologist. There are number of primary care initiatives in Ireland providing a structured approach to diabetes care in the general practice setting (137, 140). Providing structured care in this context encompasses a systematic approach to management including maintaining patient registers, regular audit, continuing professional education, and the routine review and management of patients in general practice. Notably in an Irish context use of the term 'structured care' has connotations with primary care-led management, traditionally used to distinguish this model from shared care schemes, however this is not to imply that shared care or hospital-led care is unstructured in its delivery.

Recent developments in policy have led to the promotion of an integrated model of diabetes care in Ireland. This model of care, endorsed in the national guidelines for diabetes management, refers to the joint responsibility of primary and secondary care for the care of patients with diabetes (17). The working definition of integrated care proposes that the majority of patient visits take place in general practice with review in diabetes centres. Depending on patient need, this interval could be agreed locally by integrated partners between primary and secondary levels, depending on circumstances and resources (142). This model was also endorsed in the recommendations from the Expert Advisory Group for Diabetes (1). It is the first time a model of care has been agreed at a national level, the implementation of which is part of the Clinical Care Programme for Diabetes under the auspices of the Quality and Clinical Care Directorate in the HSE.

2.1.15.3 *Improving Diabetes Care at a National Level*

The report by the Expert Advisory Group for Diabetes represents the most recent attempt to develop a cohesive strategy for the provision and improvement of diabetes care in Ireland. The recommendations follow on from a series of reports on the deficiencies of diabetes care and the need for change. In 2000 the government was urged to form a policy planning group dedicated to the development of a national

diabetes care programme, in response to the internationally agree St Vincent Declaration (143). This call has since been reiterated by a number of multidisciplinary groups including the Diabetes Services Development Group (144), a working group established by the Department of Health (145) and most recently the Expert Advisory Group set up by the Health Service Executive (146).

Each report has prioritised similar areas included the development of national retinopathy screening, information technology and communication (ITC) requirements, improving paediatric services and the integration of providers and settings. However at the time of writing the provision and coordination of diabetes care was not the subject of a dedicated national strategy document akin to those for cardiovascular disease (147) and cancer care (148) in Ireland, an absence which has been highlighted at European level. A report from the International Diabetes Federation European Region and the Federation of European Nurses in Diabetes in 2005 documented the absence of a national diabetes plan in Ireland although one was expected that year according to the DOHC. At the time eleven out of twenty-five countries in Europe (44%) had national framework or plan for diabetes. By 2008, thirteen out of twenty-seven member states (48%) had a national plan in place for the management of diabetes including newly developed plans in countries such as Romania, Poland and Lithuania. Ireland, along with Germany and Luxembourg, was one of the countries reiterating the promise of a national diabetes framework. Responsibility for the development of a national diabetes programme has since been assumed by the newly established Clinical Care Programme for Diabetes (CCP) set up by the HSE in 2009 under the Quality and Clinical Care Directorate to improve access to and quality of services in a number of areas. The outcome of this latest national-level effort to improve the organisation and coordination of diabetes care is awaited.

2.1.16 Summary

This chapter outlined the case for diabetes as a model for quality improvement (2) due to its rising prevalence, mounting financial and human costs and the gap between the evidence-based standards of care and reality. Diabetes represents many of the challenges facing health systems seeking to reorganise services and orientate care away from the traditional acute model of episodic disease management.

This chapter summarises the emergence of a quality agenda in healthcare which was influenced by the principles of industrial quality frameworks. The Chronic Care Model, a framework for optimal chronic disease management, reflects the profound change proposed by system redesign while emphasising the inclusive proactive approach to change endorsed by Total Quality Management. The 'quality chasm' has become an international concern with increasing attention paid to structural, organisational and professional interventions to improve the quality of care. The synthesis of evidence from systematic reviews and recent randomised trials suggests multidimensional quality improvement interventions improve the processes of care although their impact on clinical outcomes is less consistent. A review of quality improvement strategies targeting organisation and provider behaviour in diabetes found that effectiveness was dependent partly on clinical context but also other contextual factors such as the beliefs and attitudes of professionals (8). In the field of quality improvement research understanding the context in which quality improvement flourishes or fails is as important as generating evidence of the effectiveness of different strategies (18, 19). This thesis will examine the organisational, professional and cultural context of diabetes care in Ireland.

2.1.17 Overview of Research

Chapter 3: Diabetes Care in Ireland: a Survey of General Practitioners.

This chapter reports on the survey of the organisation and delivery of diabetes care in general practice. The results describe access to services outside the practice and links with secondary care providers. The relationship between maintaining a diabetes register and the level of organisation in the practice is examined.

Chapter 4: Providing Diabetes Care in Ireland; Everyday Experiences and the Barriers and Facilitators to Optimal Delivery.

This qualitative study, informed by results of the GP survey, is outlined in Chapter 4. It examines experiences of providing diabetes care in more depth and explores GPs' understanding of the various models of diabetes care. This chapter also explores the barriers and facilitators to providing diabetes care in general practice.

Chapter 5: Attitudes to engaging in Quality Improvement in General Practice.

This chapter presents results from the second objective within the qualitative study; to explore GPs' attitudes and openness to engaging in quality improvement activities. The results focus in particular on attitudes to a national diabetes register and audit as mechanisms for quality improvement at local and national level.

Chapter 6: The Quality of Primary Care-Led Diabetes Management: a Bottom-Up Approach to Improvement

This study examines the quality of care delivered by 3 primary care initiatives which have adopted a structured approach to diabetes management. Data on processes and intermediate outcomes for over 3000 patients with Type 2 diabetes are compared to national and international standards.

Chapter 7: Improving Diabetes Care through Policy Formulation; a Case Study of the Expert Advisory Group for Diabetes.

The final study examines the Expert Advisory Group for Diabetes and its recommendations as an instrumental case study of policy formulation within the Irish health service.

3 Diabetes Care in Ireland: a Survey of General Practitioners

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Abstract

Background: In Ireland an increasing proportion of diabetes care is being provided in general practice. The aim of this study was to examine the organisation and delivery of care to patients with diabetes in this care setting.

Methods: A postal questionnaire was administered through the Irish College of General Practitioners to a random sample of 600 GPs. The survey addressed four key topics; characteristics of the practice, diabetes care delivery, the use of services and opportunities for developing diabetes care. The questionnaire was developed was based on an instrument previously used in the UK to assess diabetes service provision.

Results: The response rate was 44% (N=262). There were an additional 86 responses to a follow-up shortened version of the survey resulting in a 58% response rate for 9 key questions. Most respondents were from an urban (43%, n=112) or a mixed area (39%, n=101) and 19% of practices were single-handed (n=66). Forty-six percent of GPs maintained a diabetes register (n=157) and 55% reported using guidelines (n=140).While 30% had a formal call/recall system for review (n=78), a further 20% indicated that an informal yet regular approach was in place (n=54). Almost one quarter of GPs did not employ *any* of these components in the practice (24%, n=62). There was a significant association between maintaining a diabetes register and other aspects of care delivery such as engaging in formal recall ($p<0.001$), using guidelines ($p<0.001$) and a declared special interest in diabetes ($p=0.001$). Just over 60% of respondents had direct access to a dietician (63%, n=165) and 57% direct access to chiropody services (n=149). Most GPs were in favour of a mixture of capitation and fee for patient as remuneration for providing diabetes care (54%, n=136). Training for GPs and nurses was cited as the main opportunity for developing diabetes care (76%, n=196).

Conclusions: The results of this survey suggest a substantial proportion of diabetes care in general practice is unstructured with limited adoption of diabetes registers, routine recall and guidelines. Maintaining a register is likely to be a marker of enthusiasm and investment in quality improvement in the practice. Despite the policy emphasis on the transfer of chronic illness care to the community, considerable organisational gaps and resource deficiencies remain in general practice.

This paper has been published in Primary Care Diabetes (2009) (Appendix II)

3.1. Introduction

Diabetes Mellitus is emerging as one of the most significant problems facing health systems around the world with an estimated increase in the worldwide prevalence of diabetes from 2.8% in 2000 to 4.4% in 2030 (4). In Ireland the prevalence is expected to increase from 4.7% of the population in 2005 to 5.6% by 2015 (39). The rising prevalence and the ever increasing cost of chronic diseases such as diabetes have led to health services examining ways to reconfigure services with growing emphasis on the development of primary care services (13).

Consequently General Practitioners (GP) are assuming greater responsibility in the delivery of diabetes care (149). Care in the community has been found to be as effective as hospital-based care when it is structured and supported by specialist input (132). It has also been shown that care provided in the primary care setting can enhance diabetes quality of life without compromising quality of care (20). The first national survey of diabetes care in Ireland in 2003 found that while a significant amount of diabetes care was delivered in general practice, particularly for Type 2 patients, this care was largely unstructured. Less than half of the GPs surveyed reported using a register while just over half engaged in routine recall (135). Other countries such as the US which have examine the use of 'diabetes care management processes' such as the use of registers and guidelines have also found limited adoption (150).

The level of organisation in general practice is associated with processes and clinical outcomes of care(151). Hence there is increasing interest in professional and organisational interventions which enhance the structure of diabetes care delivery as an avenue for improving outcomes. In particular centrally organised systems for tracking patients and arranging follow-up improved the process of diabetes care in primary care, out-patient and community settings. Computerised reminders and/or audit and feedback were found to have a similarly positive effect on the process of care (14). Quality improvement strategies have also been shown to improve patient outcomes in general practice. The TRANSLATE Trial, which incorporated an electronic diabetes registry, reminders, a coordinator to plan patient visits and monthly review meetings with a local champion, led to significant improvements in clinical outcomes (111). As reflected in the aforementioned trial, patient registration is one of a variety of quality improvement strategies typically incorporated as part of a multidimensional intervention, making it difficult to demonstrate its independent contribution to quality.

A review of the literature conducted by this PhD student and colleagues found that registers are assumed to be a central and underlying feature of diabetes management (152).

The organisation and delivery of diabetes services is complex and differs between countries involving secondary care, primary care or shared care systems integrating services from both settings (138). This study examines the organisation and delivery of diabetes care in the Irish general practice setting including the use of diabetes registers in the practice. Before quality improvement strategies such as a patient register can be developed on a national scale, the current level of diabetes care needs to be assessed.

3.1.1 Aims and Objectives

As part of the overall aim of this thesis to investigate the 'quality chasm' around diabetes care in Ireland, a sequential mixed methods design was used to examine the organisation of diabetes care in general practice, beginning with a quantitative GP survey which is the focus of this chapter. The objectives of this study were:

1. To describe the organisation of diabetes care in general practice in Ireland.
2. To look at the relationship between maintaining a diabetes register and other organisational features of the practice.

3.2 Methodology

3.2.1 Design

A cross-sectional postal survey of a random sample of GPs practicing in the Republic of Ireland was conducted in collaboration with the Irish College of General Practitioners (ICGP). This study represents the first phase of a sequential mixed methods design (153). As such the results of this survey were used to inform the design of a qualitative follow-up study.

3.2.2 Instrument

A questionnaire was developed from a survey instrument used to assess diabetes care in general practices in the Galway region (154). The instrument had previously been adapted for an Irish context from a survey used in the UK to assess diabetes service provision (155). To ensure content validity for the purpose of this national study, the questionnaire was piloted among a convenience sample of thirteen GPs. Seven of the thirteen GPs responded to the pilot phase and minor adjustments were made to the layout and wording of the questionnaire. The survey addressed four key topics: the characteristics of the practice, the organisation of diabetes care delivery, the use of services and opportunities for developing diabetes care (Appendix IV). In addition the questionnaire was used to establish GPs willingness to be involved in a qualitative follow-up study, the second phase of the mixed methods research design.

3.2.3 Sample

The sample was recruited through the Irish College of General Practitioners database. Approximately 2500 GPs are registered with ICGP representing 90% of practicing GPs in Ireland (31). A random sample of 600 GPs was selected from the ICGP database by an ICGP researcher to maintain members' anonymity. The sample size was calculated to provide a representative sample of GPs based on previous research carried out by the ICGP.

3.2.4 Procedure

The questionnaire was circulated in June 2008 with a cover letter outlining the purpose of the study and a stamped addressed envelope to return the survey. On the back page of the questionnaire GPs were given an 'opt-in' option to participate in a qualitative follow-up study by providing their name and contact details. In addition participants

were provided with a postcard to return separately from the questionnaire to discriminate between the proportion of responders and non-responders.

Follow-up

Due to ICGP regulations precluding telephone contact with members it was not possible to conduct follow-up phone calls to further increase the response rate or characterise non-responders to the survey. However, a second round of questionnaires was sent out two weeks after the first mailing to all those who had not returned a responder postcard in an attempt to increase the response rate. This questionnaire was a shorter version of the original survey, containing nine key questions (See Appendix V). Figure 4 illustrates the survey administration process.

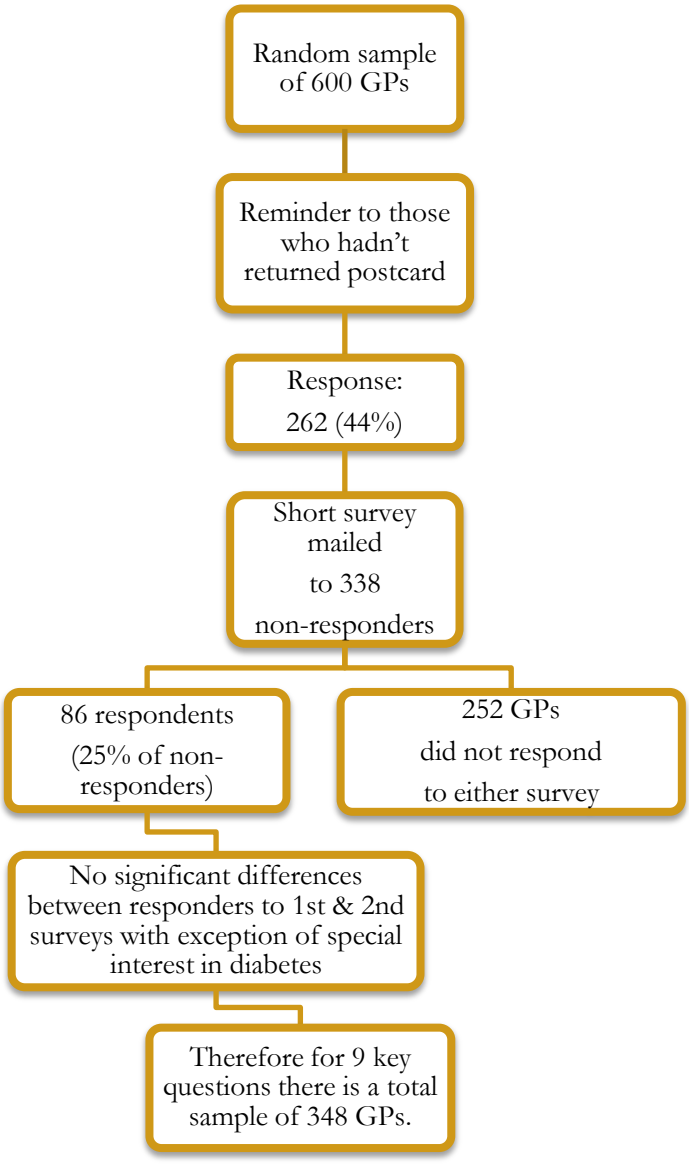


Figure 4 Flowchart of administration of survey

3.2.5 Data Management

The questionnaire was produced in a scannable format for automatic data capture and entry using *TeleForm* scanning software (156). Firstly the *Teleform* Designer was used to create the questionnaire and generate a unique ID number for each form. Once completed the questionnaires were scanned and recognised by the *TeleForm* Reader. Unknown fields and participant hand-writing were highlighted by the Reader which were checked and verified in the *Teleform* Verifier. The data were transferred directly to an Excel file and imported into SPSS (Version 15) for analysis. A number of questionnaires were randomly checked to ensure complete and accurate data transfer.

3.2.6 Analysis

3.2.6.1 *Quantitative*

Standard descriptive statistics are used throughout the results section. Categorical data are presented as number and percentage. The percentage is based on the number who answered the question unless otherwise stated. Continuous data are described using median and interquartile range (IQR) as data were highly skewed. Data were compared using non-parametric analysis, the Mann-Whitney test and Kruskal-Wallis test for differences between groups. Chi-squared tests were used to examine the statistical significance of associations between categorical data. The difference between proportions and 95% confidence intervals (95% CI) are reported when appropriate as tests of statistical significance have been argued to be of limited value (157). Bonferonni adjustment was applied to the alpha value 0.05 where multiple comparisons were conducted.

3.2.6.2 *Qualitative*

There were opportunities throughout the survey for respondents to expand on their answers using open-ended fields. Responses were coded in NVIVO 8 software. Thematic analysis was applied to responses. Inter-coder reliability was carried out on the most common 25% of themes on the main open-ended responses (158). For example where 20 themes emerged, the top 5 themes were subject to inter-coder reliability. For the purpose of this chapter only the main themes are highlighted (see Appendix VI for emergent themes).

3.2.7 Ethical Approval

Ethical approval for this study was granted by the Irish College for General Practitioners (ICGP) (Appendix VII).

3.3 Results

This section begins with an outline of the final response rate and the practice profile of the sample including the level of computerisation. The organisation and delivery of diabetes care in general practice is then presented including the use of a diabetes register and call/recall system as well as links with hospital-based specialist teams and access to services (e.g. dietician). The relationship between maintaining a register and other organisational features are explored followed by analysis of the relationship between having a special interest and the organisation of care in the practice.

3.3.1 Response Rate

The final overall response rate was 44% (N=262). A follow-up mailing of a shorter version of the survey to increase the response rate resulted in an additional 86 respondents for 9 key questions (N=348, 58%). Respondents to the initial questionnaire were compared to those who responded to the shorter questionnaire on nine common questions to identify any differences between the two groups.

3.3.1.1 Comparing responders & initial non-responders

A Mann-Whitney test indicated no significant difference between the groups in terms of number of doctors employed (U=10058; p=0.3); total patient population (U=8323; p=0.5) or total diabetes patient population (U=5663; p=0.6). There was no significant difference between length of survey completed and key features of practice organisation as illustrated in Table 4. The length of the survey was significantly associated with whether practices reported having a special interest in diabetes (χ^2= 6.372; p=0.009) however following Bonferonni adjustment this association was no longer significant. As there was no difference between GPs who responded to the initial survey and those who responded to the follow-up survey, the latter group were included in the analysis of 9 key variables to produce a response rate of 58% for those questions (n=348).

Table 4. Association between the lengths of survey completed & care delivery

Characteristic	Long Qn. N (%)	Short Qn. N (%)	% Difference	95% CI	p
Practice Characteristics					
Practice Nurse	220 (84)	66 (77)	7%	-2 to 18%	p=0.13
Computer System	244 (94)	77 (90)	4%	-3 to 12%	p=0.5
Diabetes Module	117 (66)	30 (53)	13%	-2 to 27%	p=0.13
Diabetes Care Delivery					
Diabetes Register	121 (46)	36 (43)	3%	-9 to 15%	p=0.7
Specific Clinics	58 (22)	20 (23)	1%	-12 to 9%	p=0.96
Special Interest	84 (81)	54 (63)	18%	5 to 31%	p=0.009*

*Not significant after adjustment

3.3.2 Practice Profile

This section outlines the profile of participating GP practices in terms of location, staff levels and practice population including the prevalence and incidence of diabetes.

3.3.2.1 Practice Location

The majority of practices were in urban (43%, n=112) or mixed locations (39%, n=101). Less than 20% of practices were in a rural location (18%, n=47) (Table 5).

Table 5 Practice location compared to national profile

	Urban N (%)	Rural N (%)	Mixed N (%)	Total N
Current survey (2008)	112 (43)	47 (18)	101 (39)	260
National Profile (2006)[159]	205 (43)	100 (21)	171 (36)	476

3.3.2.2 Staff

Doctors

The median number of doctors per practice was 3 (IQR=2-4). Using a Kruskal Wallis test, a significant difference was detected between the 3 locations in terms of number of doctors working in the practice (H= 14.76, df =2; p=0.001). Examination of the median values indicated that practices in urban and mixed locations employed 3 doctors while rural practices employed 2 doctors. As Figure 5 shows rural areas had the highest proportion of single-handed practices (36%, n=16).

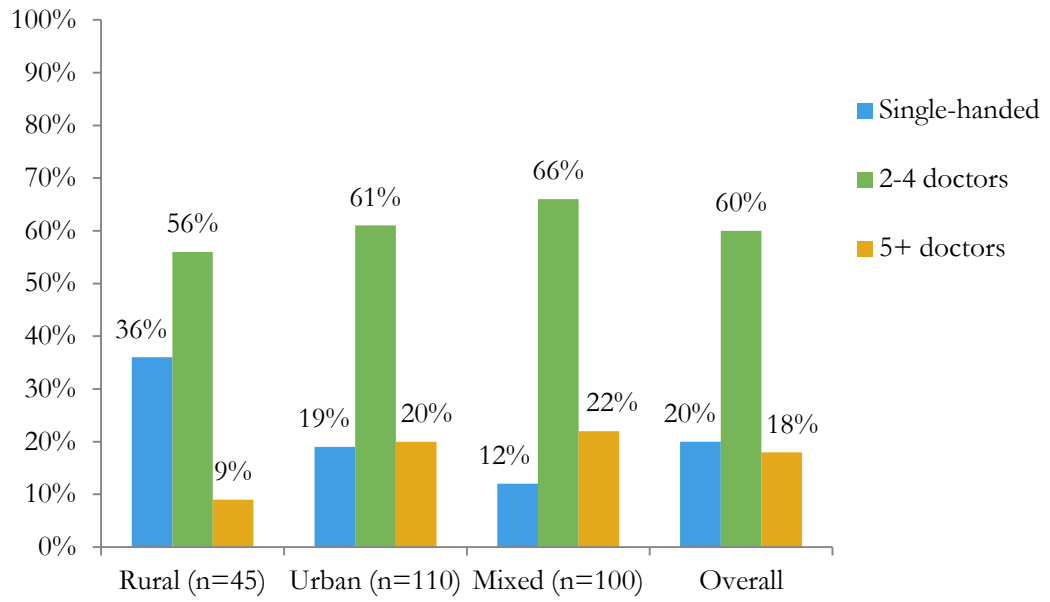


Figure 5 Size of practice (no. of GPs) by location of practice

Practice Nurses

The majority of practices employed a Practice Nurse (83%, n=286). There was a significant difference between practices with and without a practice nurse in terms of the number of doctors (U=4354; p=0.000) with a higher median number of doctors in practices with a Practice Nurse (Mdn= 3 IQR=2-4 vs. Mdn=2, IQR=1-3). While chi-square analysis revealed a significant association between the location of the practice and whether or not a practice nurse was employed (χ^2= 7.73, p=0.02), similarly high proportions of practices in each location employed practice nurses. Ninety-two percent of mixed practices employed a practice nurse (n=93) compared to 78% or urban practices (n=87) and 85% of rural practices (n=39) (Figure 6).

Practice Managers

Just over half of respondents had a practice manager (52%, n=134). Fifty percent of practices had both a practice manager and a practice nurse (n=128). There was no significant association between the location of the practice and employing a manager (χ^2= 1.299, p=0.052) (Figure 6). However there was a significant difference between practices with and without a practice manager in terms of the number of doctors in a practice (U= 4162; p=0.000) with practices with a practice manager having a higher number of doctors (Mdn=3 IQR2-5 vs. Mdn=2 IQR=1-3).

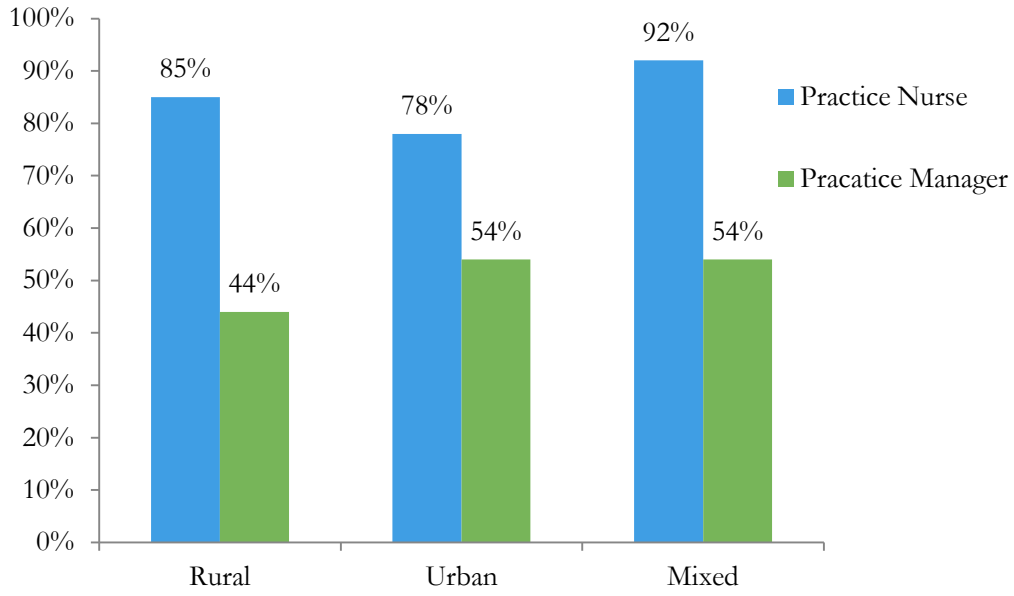


Figure 6 Percentage of practices employing a Practice Nurse or Practice Manager

3.3.3 Practice population

Data on the practice population were positively skewed therefore medians and interquartile range are reported and non-parametric analysis was conducted. The median patient population for practices was 4000 patients (IQR=2200-6750) (Table 6). However it is important to note 62% of GPs indicated that patient figures were a best estimate (n=150) while 38% (n=92) said the numbers were based on information from the practice IT system.

Table 6 Medical care and non-medical card (private) patient population

	Medical Card Patients	Non-Medical Card Patients	Total Population*
Median	1200	2755	4000
IQR	703-2000	1200-4728	2200-6750
Mean (sd)	1568 (1508.5)	3874 (4973)	5314 (4544)
Range	0-10000	100-6000	100-25000

*Some respondents did not provide total figures which were the sum of GMS and private patients.

Size of Practice & Location

A Kruskal-Wallis test detected a significant difference between the three types of practice location in terms of the number of patients ($H= 6.979$; $df= 2$; $p<0.05$). Rural practices appeared to have the lowest patient population (Mdn= 3000) followed by urban practices (Mdn= 4500) and mixed practices (Mdn=4750). Practices with a practice manager had significantly more patients (Mdn= 5645) compared to those

practices without a manager (Mdn=3000) (U = 3277; P<0.001). Similarly those employing a Practice Nurse had significantly more patients (Median=4400) compared to those who did not employ a Practice Nurse (Median=3000), (U=4290; p<0.001).

Diabetes prevalence and incidence

The overall prevalence of diabetes in the practice population was 3.6% (data available for 69% of practices, n=239) ranging from 0.2% to 23%. The prevalence of Type 1 diabetes was 0.7% (range 0-5%) while the prevalence of Type 2 diabetes was 2.8% (range 0.06-16%) (Table 7). The cumulative incidence was calculated as 0.7 per thousand for Type 1 diabetics and 3.5 per thousand for Type 2 diabetics. Only 28% (n=66) said figures were based on data from the practice IT system.

Table 7: Prevalence of diabetes by type

	Type 1 N=215	Type 2 N=219	Overall N=239
Mean (sd)	0.7 (0.85)	2.8 (2.27)	3.6 (3)
Median (IQR)	0.5 (0.3-0.8)	2.1 (1.3-3.4)	2.9
Range	0-5	0.06-16	0.21-23.3

Diabetic patients in nursing homes/residential care

The median number of patients in nursing homes was 1 (IQR= 0-5) (range=0-150 patients). Seventy-two percent indicated these numbers were based on a best estimate (n=135). Of those GPs who had patients with diabetes in nursing homes/residential care, the majority reported that patients received care from the GP *and* hospital specialist services (51%, n=53). Forty-one percent of respondents indicated that care was delivered by the GP only (n=43) and 7% reported that care was delivered by the specialist service only (n=7).

Suggestions for providing care to patients in nursing homes/residential care

Respondents recommended the use of protocols and increased training to improve care delivery in nursing homes and residential care. Other suggestions included a community diabetes nurse providing care to patients in residential care homes and visiting specialists (Appendix VI).

> "*there should be a mobile 'on the road' nurse to look after diabetes patients that are in nursing homes/residential care; should have a diabetic nurse to visit weekly/monthly.*"

3.3.4 Organisation in the Practice

3.3.4.1 *Computer Systems*

Most practices had a computer system (93%, n=321). The most common software system in use was Health One (38%, n=121) (Figure 7). Forty-six percent had a diabetes module on their computer system (n=147) while 28% did not know (n=89). Of those with a diabetes module 61% reported using it (n=89, 26% of total sample).

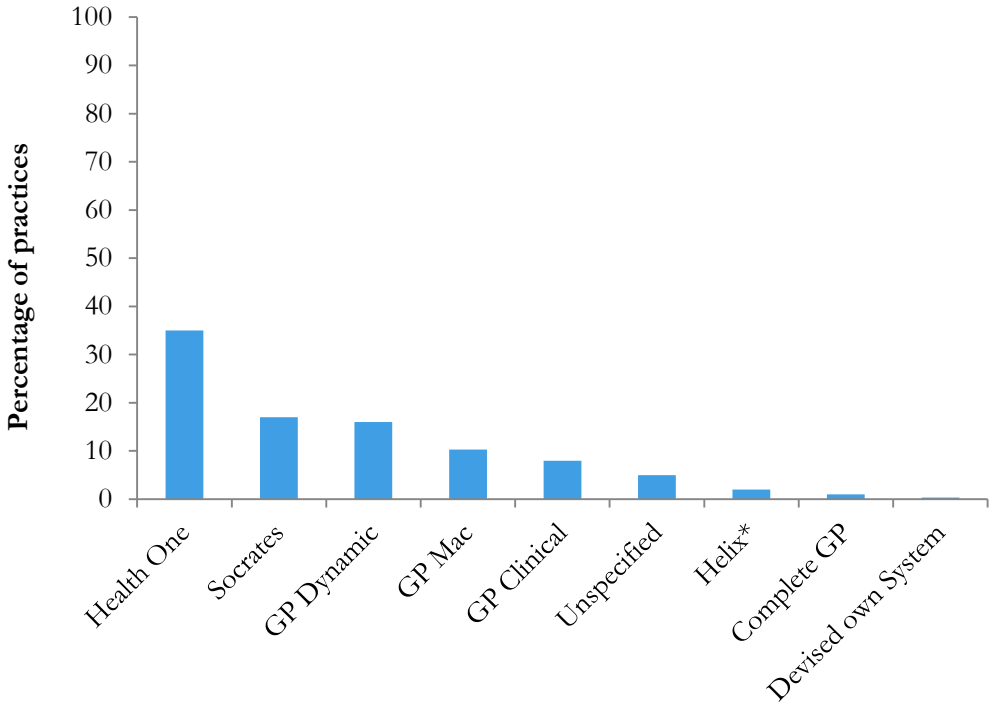


Figure 7 Percentage of practices using different computer systems

**Helix software was the parent company of GP Dynamic and GP Clinical therefore respondents may have been using either of those two computer systems.*

3.3.4.2 *Uses of Practice Computer System*

The use of computer systems is organised according to the following functions:

i) Use of computer to gain payment and issue prescriptions
ii) Linking with other services to receive information electronically, increasing efficiency
iii) Becoming a 'paper light' practice.

i) Gaining payment and issuing prescriptions

In most practices the computer system was used for issuing repeat prescriptions (98%, n=229) and maintaining a register of all patients (97%, n=227). Table 8 lists the various uses of the practice computer system in order of frequency as well as details provided by respondents in open-ended sections (Appendix VI for themes).

Table 8 Uses of the practice computer

Practice Computer Use	N (%)*
To issue repeat prescriptions (n=223)	229 (98)
To maintain a register/list of all patients (n=234)	227 (97)
To issue acute prescriptions other than in consultations (n=231)	215 (93)
To issue acute prescriptions in consultations (n=233)	215 (92)
To maintain continuation records of consultations (n=231)	211 (91)
To store reports from hospital laboratories (n=232)	211 (91)
To store reports from X-ray departments (n=232)	202 (91)
To record antenatal visits (n=235)	202 (86)
To store reports from specialists (n=232)	194 (84)
To make GMS claims (n=231)	158 (68)
Store other reports (n=161) [E.g. Medico-legal reports]	119 (74)
To make claims for ante-natal care (n=231)	113 (49)
To record Heart-watch visits (n=229)	98 (43)
To record other forms of systematic care of patient groups (n=172) [E.g. Diabetes/endocrine care, maternity care]	95 (55)
To make other claims (n=175) [E.g. Vaccination claims, childhood immunisation claims]	59 (34)

ii) Receiving Electronic Reports- Linking with other services

Eighty percent of GPs reported receiving electronic reports from hospital laboratories (n=194) and 33% received reports from X-ray departments (n=78) (Figure 8). Only 7% of GPs (n=13) received reports from other hospital departments such as out-patients departments, admissions and discharge, and specialists. Other sources of electronic reports included on-call and out-of hours' doctors' services (See Appendix VI).

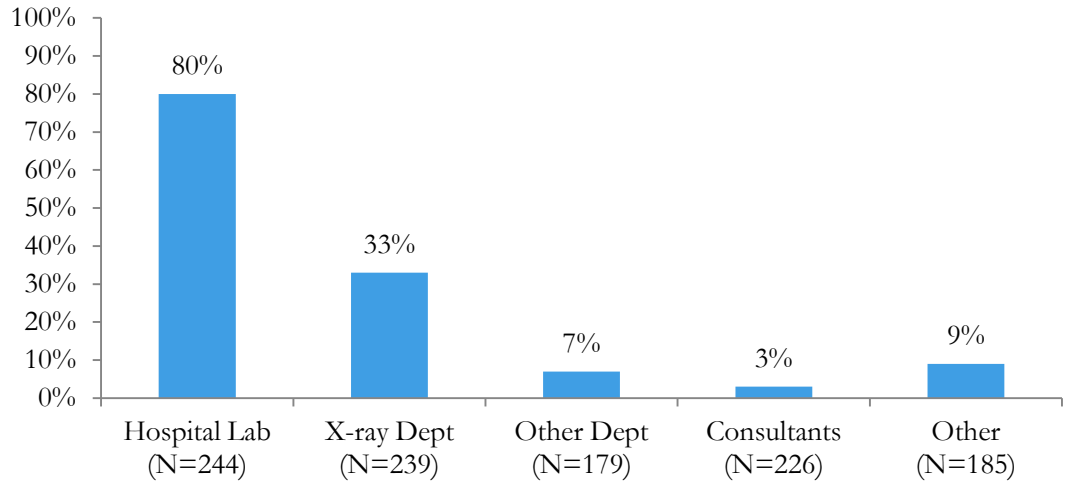


Figure 8 Percentage of GPs receiving electronic reports

Electronic reports were usually filed automatically in patients' electronic records (42%, n=87). A number of other methods were also used; automatically and scanning (20%, n=41), automatically and manual filing (3%, n=7), and manual filing and scanning (3%, n=6). Eleven percent who used manual filing alone (11%, n=22).

iii) Becoming a 'paper light' or paperless practice: Use of Electronic Records

Just over half of respondents viewed themselves as paperless practices (51%, n=124) and 80% routinely use electronic records during consultations (n=209). Figure 9 shows the percentage of GPs who replaced paper records in favour of electronic records for various aspects of patient management. Other electronic records included medico-legal reports and practice correspondence (see Appendix VI for full analysis).

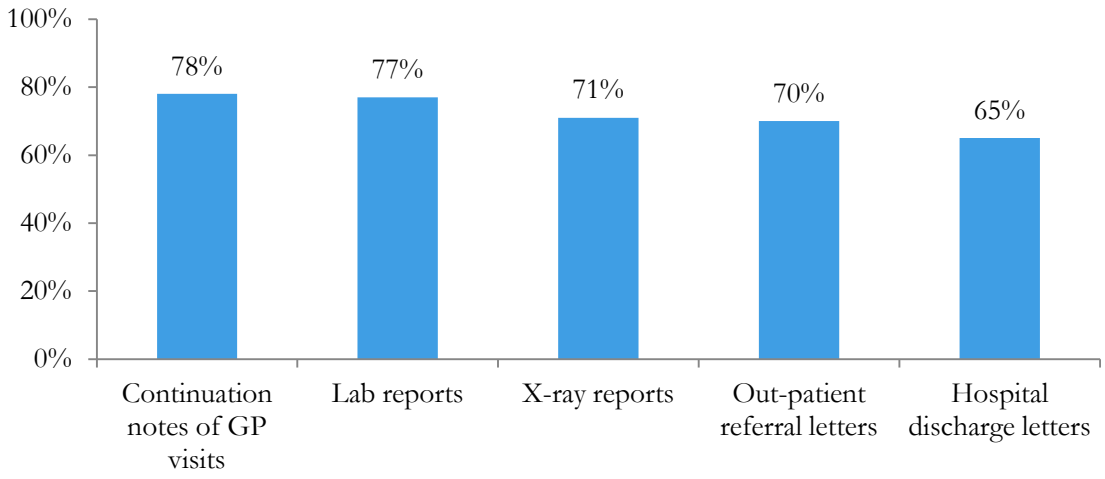


Figure 9 Percentage of GPs who had replaced paper with electronic records

3.3.5 Organisation and Delivery of Diabetes Care

This survey examined a number of features of diabetes care delivery displayed in Figure 10. Overall 46% of practices maintained a diabetes register (n=157). While 30% (n=78) of practices had a formal call and recall system for reviewing diabetes patients a further 20% (n=54) indicated a routine systematic approach to recall was in place by reporting the frequency with which patients were recalled (informal recall). Just over half of the practices surveyed reported using guidelines (55%, n=140). Almost one quarter of practices employed all three features (23%, n=60) [register, routine recall, guidelines] however a similar proportion did not utilise *any* of these features (24%, n=62). Each of the features in Table 9 will be examined in more detail.

Table 9: Proportion of GPs with an organised approach to diabetes care

	Total N	n (%)	SE	95% CI
Specific Clinics for Diabetes	347	78 (22)	0.022	18-26%
Formal Recall System	261	78 (30)	0.028	25-36%
Informal Recall	262	54 (20)	0.025	15-25%
Diabetes Screening	262	243 (93)	0.016	90-96%
Guidelines	253	140 (55)	0.031	47-59%
Diabetes Register	343	157 (46)	0.027	40-50%

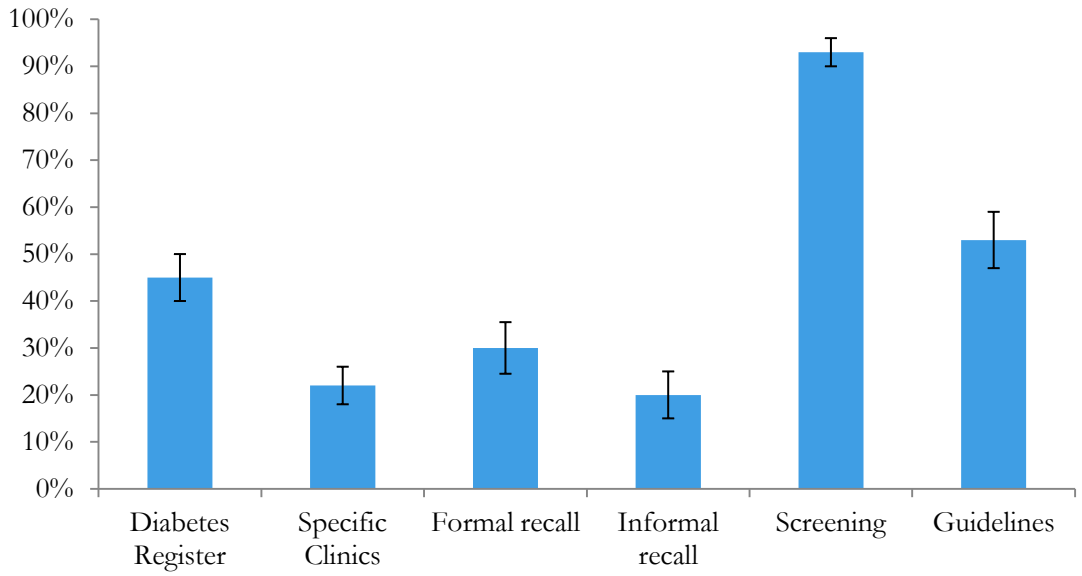


Figure 10 Percentage of GPs with features of diabetes care delivery

3.3.5.1 *Specific Clinics*

Only 22% percent of respondents (n=78) held specific diabetes clinics thus the follow-on questions were not applicable (NA) for the majority of respondents. Clinics were commonly led by the Practice Nurse (15%, n=37) followed by a combination of the Practice Nurse and the GP (10%, n=26). Most clinics occurred every three months or less frequently (Table 10).

Table 10: Type and frequency of clinics held by GPs*

Type of clinic	Total N	N (%)	NA (%)	Frequency of Clinic✦	
				0-3 months N (%)	4-12 months N (%)
GP-led	250	22 (9)	203 (81)	16 (76)	5 (23)
Practice nurse-led	252	37 (15)	202 (80)	26 (70)	11 (30)
Combined practice nurse & GP	249	26 (10)	203 (82)	17 (69)	8 (32)
Pharmaceutical nurse-led	245	9 (4)	203 (82)	7 (78)	2 (22)
Other: E.g. dietician, insulin initiation, chiropody	203	11 (5)	203 (86)	9 (82)	2 (18)

*Responses were not mutually exclusive ✦% as a proportion of those who reported clinics

What constitutes a clinic?

Responses to the open-ended section suggested the definition of a 'clinic' encompassed a planned routine recall visit at any time during the working day as well as a specific time set aside for diabetes related visits only: *"the patient is invited in as part of the normal day"*, similarly a clinic was part of "*structured care- repeat appointment of 3 months- not a specific day for clinic"*. (See Appendix VI for thematic analysis).

3.3.5.2 Call/Recall

Appointments for Diabetes Care

Other than at specific diabetes clinics, diabetes management was attended to during appointments. The majority of practices (45%, n=117) used a combination of patient-initiated appointments specifically for diabetes, doctor/nurse initiated appointments specifically for diabetes and opportunistic appointments. Fifteen percent of GPs (n=40) reported using opportunistic appointments only, that is the patient receiving diabetes care during a consultation for something other than diabetes (Figure 11).

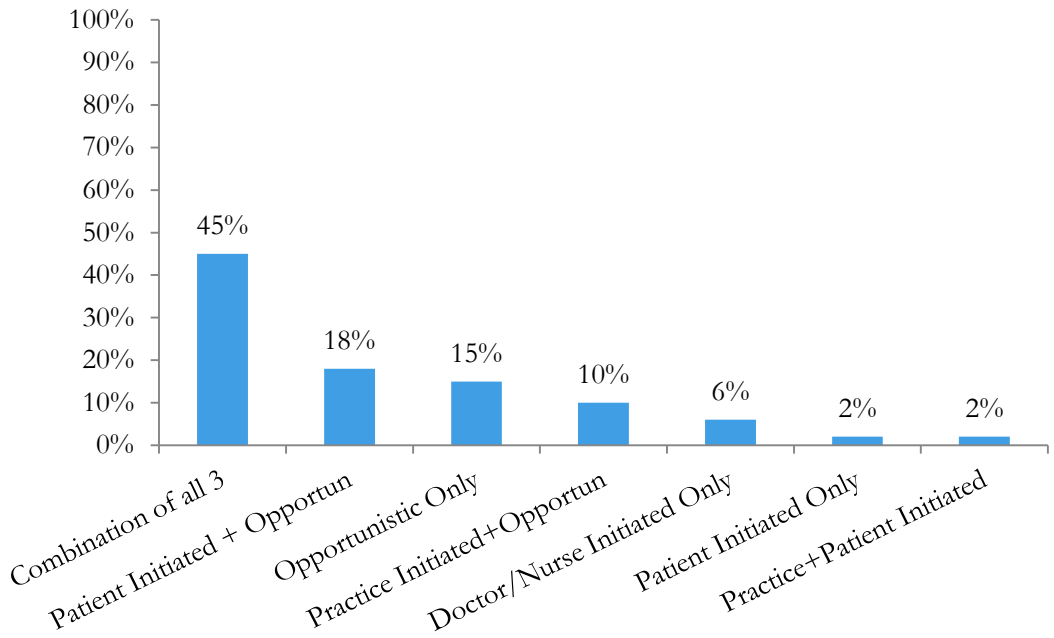


Figure 11 Type of appointments used by GPs to provide diabetes care

Call and recall for review

Thirty percent of practices had a *formal* call and recall system for reviewing patients with stable Type 2 diabetes (n=78). A further 54 practices answered 'no' to this question but went on to indicate the frequency with which patients with Type 2 diabetes were recalled for review. This suggested that while these practices did not have a *formal* call/recall system in place, they did recall patients on a regular basis. Therefore overall, 50% (n=132) of practices were classified as routinely recalling patients with stable Type 2 diabetes for review. Of those GPs who recalled patients (n=132), most did so every 1 to 6 months (91%, n=120). Only 7% of practices (n=9) recalled patients every 12 months for review. In open-ended responses a number of GPs (n=30) highlighted the flexibility of review and its frequency. GPs referred to recalling patients were recalled "as required" depending on their medical condition or HbA1c level:

> *"Twice yearly if stable, up to 3 times per annum if unstable."*

A number of GPs referred to barriers to developing systems and recalling patients including the "lack of incentive". A lack of standard practice in recall for diabetes patients was raised by another respondent (see Appendix VI for full thematic analysis).

3.3.5.3 *Review*

Attendance

According to the GPs surveyed, on average 76% of patients with Type 2 diabetes attended for their diabetic review. This proportion ranged from 30-100% among practices. However in most cases this figure was based on a best estimate (82%, n=89) rather than on actual numbers from the practice IT system. A substantial proportion of GPs did not respond to the question (59%, n=154). There was a significant difference between GPs who provided actual numbers and those who gave a best estimate in terms the proportion of Type 2 patients who attended for review ($U=470$, $p<0.05$). The median of those providing actual numbers was 90% while the median of those providing an estimate was 80%.

Processes of Care as part of Routine Review

As part of a routine review GPs reported complete measurement of blood pressure (100%, n=258) and almost complete measurement of HbA1c (99%, n=257) and lipids (99%, n=257). Table 9 outlines the various processes of care undertaken by GPs as part of a routine check-up of patients with diabetes. Fifty-two percent of GPs (n=123) reported that patients had their blood taken prior to the diabetic review while 48% of GPs (n=116) took bloods at the time of review.

Foot & Eye Care

Less than 30% of GPs carried out an eye exam in the practice (28%, n=65), patients were more commonly referred to a community ophthalmic physician (53%, n=109) or an ophthalmic surgeon/medical ophthalmologist (83%, n=183). Almost two-thirds of GPs reported carrying out a foot exam as part of a routine check-up (61%, n=143). Open-ended responses detailed the contents of the examination including: *"Skin and nail condition and peripheral pulses; Circulation (+/- Dopler); Sensation (Micro-filaments); footwear vibration, sense"*. While it was part of the annual review in some practice, in others foot care was occasional and opportunistic.

> *"A bit hit and miss…We often expect this to occur in the clinic. Microalbuminuria and ACR are covered at the hospital annual review".*

Table 11: Processes of care as part of a routine review of patients with diabetes

	Process	Total N	N (%)
Lifestyle	Height	230	111 (48)
	Weight	248	230 (93)
	BMI	231	165 (71)
	Waist Circumference	222	83 (37)
	Dietary Review	249	215 (86)
	Smoking status	252	245 (97)
Management Review	Medication review	259	259 (100)
	Blood glucose monitoring diary review	257	244 (95)
	Aspirin Therapy Status	250	226 (90)
	Statin Therapy Status	254	246 (97)
Tests	Blood Pressure	258	258 (100)
	Fasting glucose	246	219 (89)
	Random Glucose	219	109 (50)
	HbA1c	258	257(99)
	Serum Creatinine	252	244 (97)
	Lipids	258	257 (99)
Urinalysis	Dipstick	240	215 (90)
	Microalbuminuria	237	150 (63)
	Albumin:Creatinine Ratio	229	102 (45)
Eye exam	Eye examination by GP	233	65 (28)
	Eye examination by Community Ophthalmic Physician	206	109 (53)
	Referral to Ophthalmic surgeon/medical ophthalmologist	221	183 (83)
	Referral to optician/optometrist	183	76 (42)
	Examination as part of a screening programme	165	50 (30)
Foot exam.	Foot examination	234	143 (61)

Other tests/procedures

Other routine clinical and medical examinations performed in the practice included "overseeing yearly ECG", vaccinations and testing "thyroid function". As part of routine procedure, GPs indicated that they would refer patients to specialist services if they deemed it medically appropriate to do so.

3.3.5.4 *Screening*

Almost all respondents reported screening for diabetes in the practice (94%, n=243). Obesity and having a family history of diabetes were considered the most important factors when screening for diabetes (Table 12). 'Other' factors considered important included renal failure/kidney problems, patient requests and thyroid dysfunction.

Most GPs reported re-screening patients every 6 to 12 months (72%, n=174) with 7% of GPs re-screening more frequently (<6months) (n=17). Screening was usually opportunistic with few or no protocols in place in the practice. In some cases the frequency of rescreening was dependent on patient risk factors (see Appendix VI for full analysis of open-ended question).

Table 12: Patient characteristics considered when screening

	Characteristic	Total N	N (%)
1	Obesity	246	246 (100)
2	Family history of diabetes	247	247 (100)
3	Patients with recurrent infections	246	241 (98)
4	Patients with ischemic heart disease	241	236 (98)
5	Patients with peripheral vascular disease	242	235 (97)
6	Patients with hypertension	243	234 (96)
7	Women with history of gestational diabetes	245	234 (96)
8	Patients with cerebrovascular disease	239	228 (95)
9	Age	242	218 (90)
10	Patients who have had a baby >4kg	237	181 (76)
11	All pregnant women	240	145 (60)
12	Ethnic origin	221	95 (43)
13	Other	83	37 (45)

Tests for screening patients

Most GPs reported using more than one test to screen patients for diabetes. The most commonly used test was fasting venous glucose (97%, n=229) while only 19% of practices refer patients to the hospital for screening tests (n=38) (Figure 12).

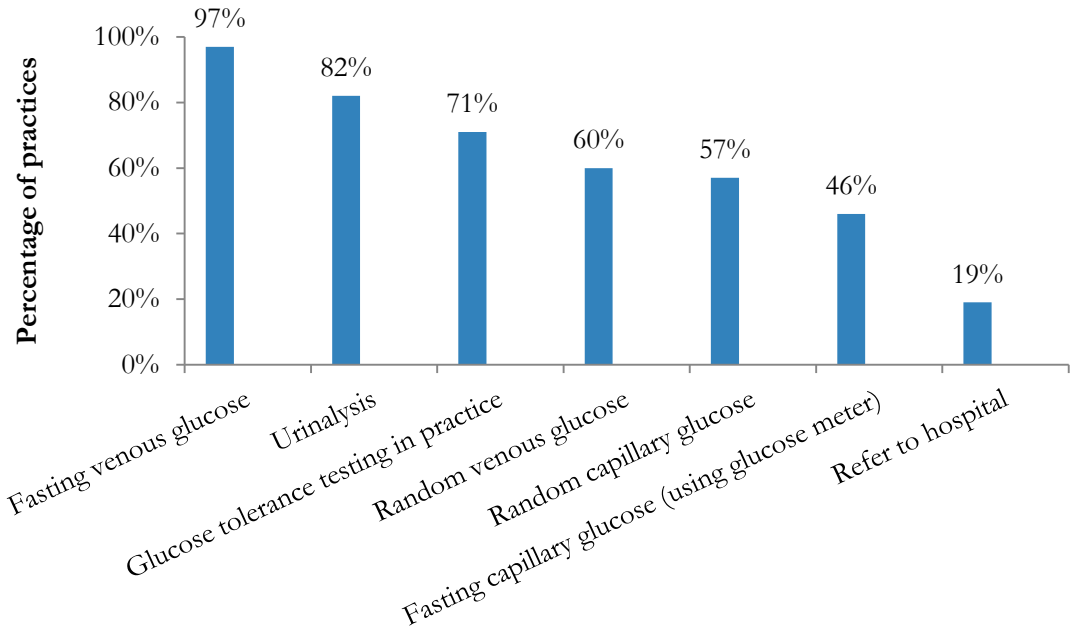


Figure 12 Tests used by GPs for screening for diabetes

3.3.6 Guidelines

Just over half of GPs surveyed reported using guidelines for the care of patients with diabetes (55%, n=140). The most commonly cited guidelines were those developed by the ICGP (23%, n=59). Nine percent used local guidelines developed in the practice or in conjunction with the local hospital or consultant (n=24) (Figure 13).

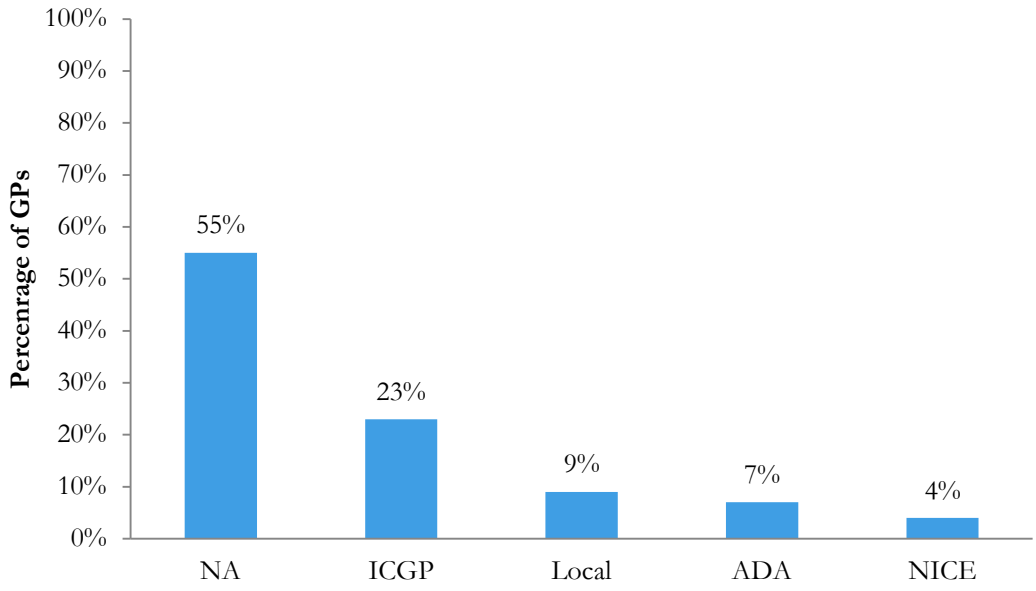


Figure 13 Types of guidelines used by GPs

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3.3.7 Care Pathways

This section presents results on the management of particular patient groups (newly diagnosed/requiring insulin). The level of integration and interaction between health care settings and providers is also outlined.

3.3.7.1 *Working with Secondary Care Providers*

Referrals to the local hospital-based specialist team

Approximately half of GPs routinely provided patients with the contact details of the hospital-based diabetes team (53%, n=133). The majority of respondents (99%, n=255) *always* referred a child with a suspected diagnosis of diabetes to the local hospital-based specialist teams. Eighty-two percent of GPs (n=211) *always* referred women with gestational diabetes to the local hospital-based specialist team. Referral of patients with gestational diabetes appeared to work in two directions; "*Patients with gestational DM tend to be referred by an obstetrician to a diabetes team"* or *"women get referred to a maternity hospital diabetes specialist"*. Other patients commonly referred to the hospital-based team included patients with Type 1 diabetes, patients with complications and those with inadequate metabolic control (see Appendix VI for full analysis of open-ended responses).

Newly diagnosed patients

When asked to indicate how they would manage patient a newly diagnosed with Type 2 diabetes, GPs indicated a combination of strategies. Seventy-one percent reported managing a newly diagnosed patient in the practice until the need arouse for additional care (n=158). In some cases GPs would work up the patient and then refer right away (53%, n=122) while 17% would refer patients immediately on occasions (n=35).

Initiating insulin

With regard to patients with Type 2 diabetes starting insulin, the majority of GPs *always* referred these patients to the local hospital-based specialist team (83%, n=213). Most GPs indicated they would rarely or never undertake insulin initiation in the practice (75%, n=178). Only 5% of GPs (n=11) indicated they would initiate therapy in his/her practice. Forty-five percent of GPs reported that patients were taught to adjust their insulin treatment in the practice (n=116).

Twenty-seven percent of GPs (n=54) reported *sometimes* or *always* initiating insulin therapy depending on patient characteristics. The main characteristics identified by GPs for consideration were: patients understanding of his/her illness, metabolic control,

compliance, motivation, ability to administer insulin and age (see Appendix VI. for themes).

Liaising with the local hospital-based team

Most GPs did not have a formal shared protocol with his/her local hospital based specialist diabetes team (90%, n=232). Only 10% of GPs reported having ever had a joint meeting with the hospital based team (n= 25) while only 3% had regular meetings with the hospital based team (n=7). Of those who had regular meetings, the meetings were usually held every 4 to 6 months (n=5).Some GPs commented on local arrangements with the hospital setting in the open-ended section. These links varied from information sharing to informal communication, to little or no contact with the hospital (see appendix 7.1.13 for thematic analysis of all responses).

"No formal meeting but can phone Dr X & DNS in the hospital at any time".

3.3.8 Access to auxiliary services

As Figure 14 illustrates access to and waiting times for auxiliary support services which varied depending on the service under consideration. Most open-ended responses in relation to auxiliary services referred to disparate waiting times for appointments and the difference between public and private access to services (see Appendix VI for full thematic analysis).

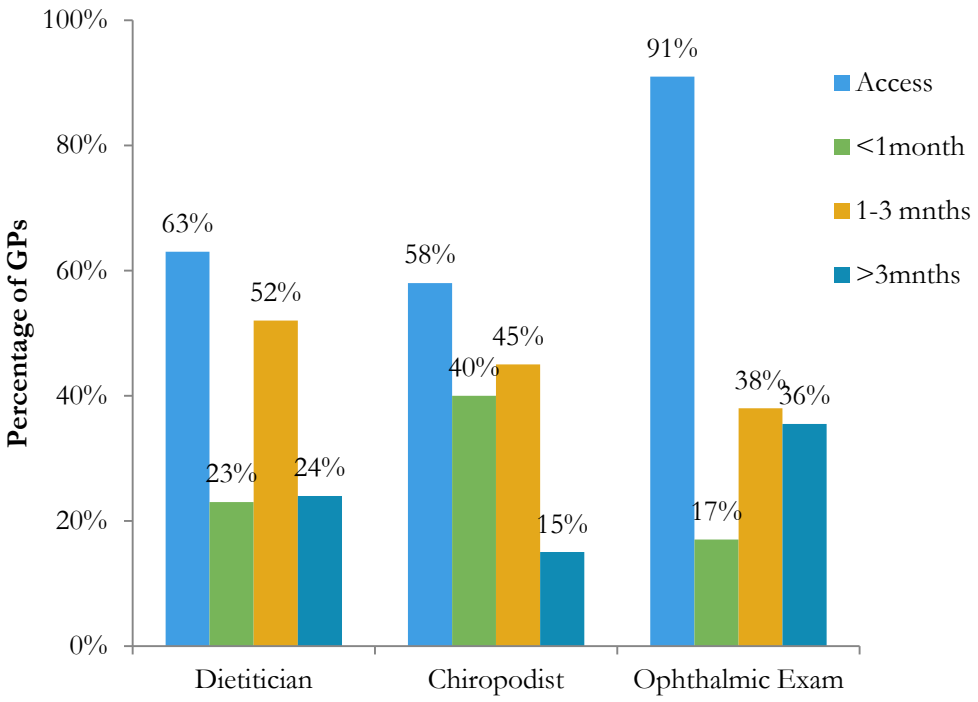


Figure 14 Percentage of practices with access to auxiliary services

Dietician

Sixty-three percent of GPs had direct access to a dietician (n=164), most of whom referred patients with diabetes to this service (81%, n=134). Approximately half of GPs reported a wait of 1 to 3 months for an appointment (52%, n=77) while 24% of GPs' patients had to wait longer than 3 months for an appointment (n=35).

Chiropodist

Fewer GPs had direct access to chiropody services (58%, n=149). Again most GPs referred patients to this service (71%, n=111). Forty percent of GPs estimated a waiting time of less than 1 month for an appointment (n=51). Forty-five percent of GPs reported a wait between 1 and 3 months for an appointment (n=57) and 10% reported waiting times of longer than 3 months (n=13).

Ophthalmic Examination

Most GPs had access to ophthalmic examination for patients (91%, n=234). Ophthalmic examinations were carried out by a variety of professionals as outlined in Figure 15. Of the GPs reporting access to ophthalmic examination most had access to more than one such professional (54%, n=127). Seventeen percent of GPs (n=31)

indicated a wait of less than 1 month and 38% reported a wait of between 1 and 3 months (n=70). Over one third of GPs had access to a systematic population-based retinal screening programme (36%, n=91).

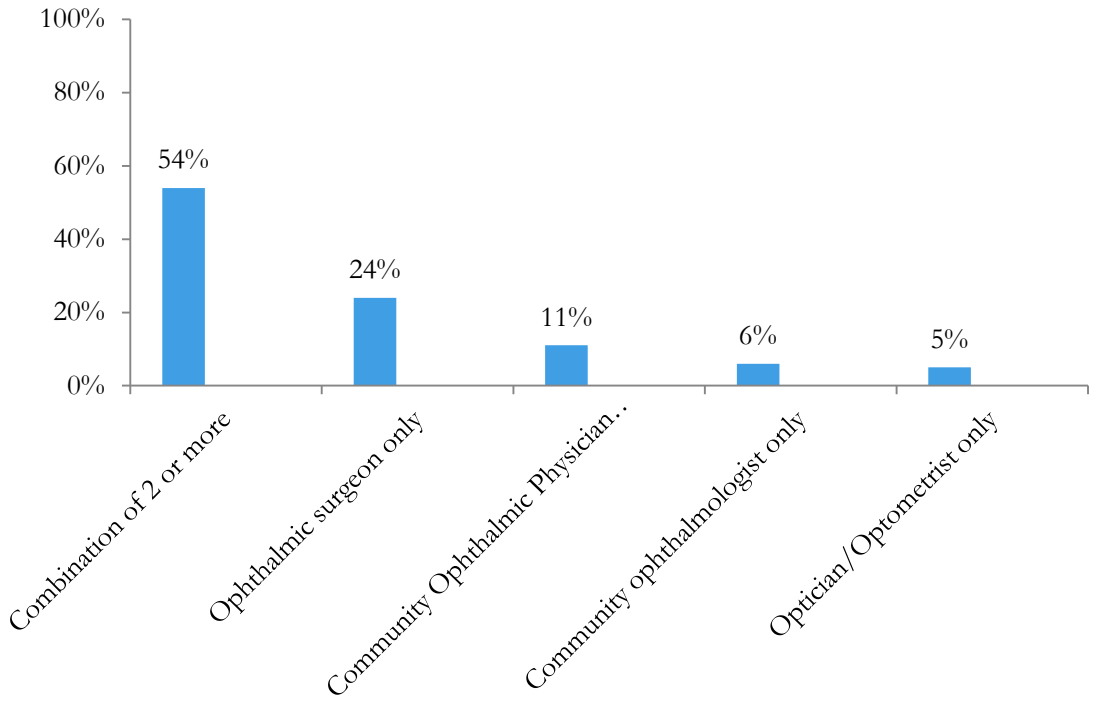


Figure 15 Percentage of GPs reporting access to providers of ophthalmic examination

Access to Educational Information

The majority of practices had space to display educational/health promotional materials (83%, n=214). The main source of educational posters was the Diabetes Federation of Ireland (DFI) (49%, n=105) (Figure 16). Commercial companies were the most popular provider of booklets (63%, n=134). Only 10% of practices said they provided membership forms for the DFI (n=25).

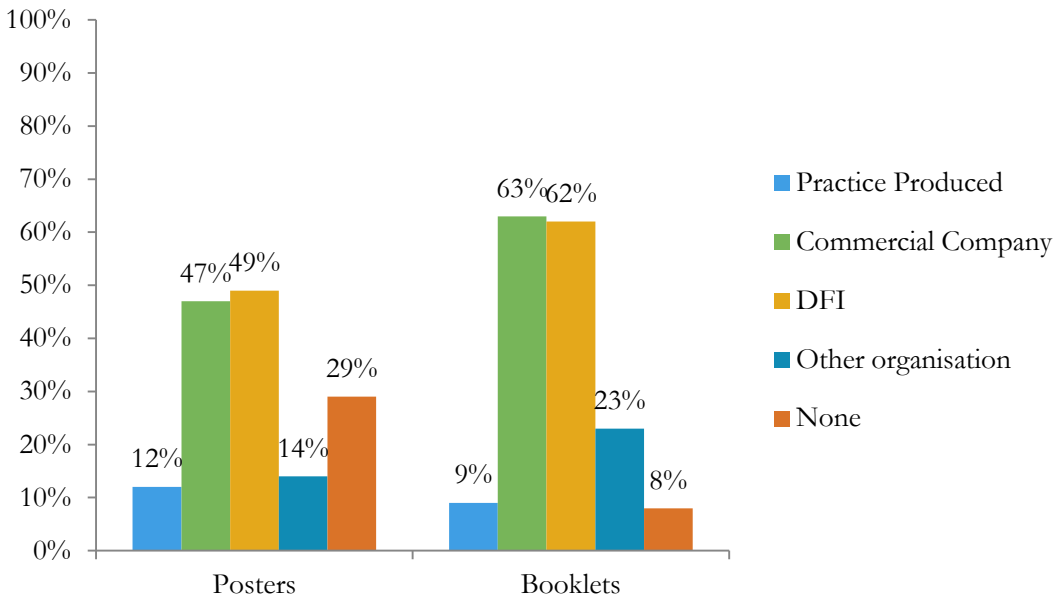


Figure 16 Percentage of practices receiving educational material from various sources

3.3.9 Relationship between having a diabetes register & practice organisation

Maintaining a diabetes register was not significantly associated with practice characteristics. Mann Whitney U analysis showed no significant difference between practices with or without registers in terms of number of doctors in the practice (U=12667; p>0.05); number of patients overall (U=10559; p>0.05) or number of diabetes patients (U=7940; p>0.05). Having a diabetes register was not significantly associated with the level of staff employed by the practice (Table 13). The location of the practice was not significantly associated with maintaining a diabetes register (χ^2=5.4; df =2; p>0.05). Sixty percent of rural practices maintained a register (n=28) compared to 48% of mixed practices (n=44) and 40% of urban practices (n=48).

Table 13 Association between maintaining a register and features of the practice

Characteristic	Register N (%)	No Register N (%)	% Difference	95% CI	p
Practice Nurse	137 (88)	147 (79)	8%	0.6 to 16%	P=0.06
Practice Manager	64 (54)	69 (50)	4%	-8 to 17%	P=0.5

Relationship with practice organisation

Maintaining a diabetes register was significantly associated with the level of computerisation in the practice (Table 14). There was a significant association between having a register and whether or not there was a diabetes module on the computer system (χ^2=12.714; df= 1; p<0.001) and whether or not a practice was paperless (χ^2=5.676; df=1; p<0.05) although this was not significant after Bonferroni adjustment.

Table 14 Association between maintaining a register and computerisation

Characteristic	Register N (%)	No Register N (%)	% Difference	95% CI	p
IT Infrastructure					
Computer System	148 (96)	169 (91)	5%	-0.7 to 10%	P=0.15
Diabetes Module	96 (64)	49 (41)	23%	11 to 36%	P=0.000†
Paperless	69 (59)	54 (43)	16%	4 to 29%	P=0.02*

† Significant after Bonferroni adjustment. *Not significant after adjustment

3.3.9.1 *Relationship with other features of diabetes care delivery*

As Table 15 illustrates, maintaining a register was significantly associated with features of diabetes care delivery; holding specific clinics (χ^2=54.406; df= 1; p<0.001); having a formal recall system (χ^2=61.753; df= 1; p<0.001) and the use of guidelines in the practice (χ^2=43.249; p<0.001). Maintaining a register was also significantly associated with whether practices had a special interest in diabetes (χ^2=10.732; p=0.001). Of those reporting a special interest in diabetes 84% (n=72) maintained registers compared to 61% (n=62) who did not maintain a register.

Table 15: Association between maintaining a register and organisational features of diabetes care delivery

Feature of care delivery	Register N (%)	No Register N (%)	% Difference	95% CI	p
Specific Clinics for diabetes	64 (41)	13 (7)	34%	25 to 43%	P=0.000†
Formal Recall	65 (54)	12 (9)	45%	35 to 56%	P=0.000†
Guidelines	91 (78)	49 (36)	42%	31 to 53%	P=0.000†
Special Interest	72 (84)	62 (61)	23%	11 to 36%	P=0.001†
Diabetes Screening	113 (95)	128 (93)	2%	-4 to 7%	P=0.08

†Significant after Bonferroni adjustment.

3.3.9.2 *Relationship between maintaining a register & care pathways*

The relationships between maintaining a register and links with other service providers are detailed in Table 16. There was a significant association between having a register and having a formal shared protocol with the local hospital team (χ^2=5.044; df=1; p<0.05) however this was not significant after adjustment for multiple testing and the percentage of GPs with a formal shared protocol was low in the sample (10%, n=26).

Table 16: Association between maintaining a register and contact with other settings

Characteristic	Register N (%)	No Register N (%)	% Difference	95% CI	p
Care Pathway					
Formal shared protocol	18 (15)	8 (6)	9%	2-20%	P=0.03*
Regular joint meetings	6 (5%)	1 (0.7)	4%	0.1-8%	P=0.86
Access to Dietician	95 (79)	67 (49)	30%	19-41%	P=0.000†
Access to Chiropodist	81 (67)	68 (50)	17%	5-29%	P=0.009*
Access to pop. based retinal screening	56 (48)	35(26)	22%	10-33%	P=0.001†

† Significant after Bonferroni adjustment *Not significant after adjustment

After adjustment maintaining a register was significantly associated with access to auxiliary diabetes services; dietician (χ^2=23.859; df =1; p<0.001), and population-based retinal screening programme (χ^2=11.855; df=1 p<0.01). Figure 17 demonstrates the difference between those with and without a register in terms of access. In each case access was greater among those maintain a register.

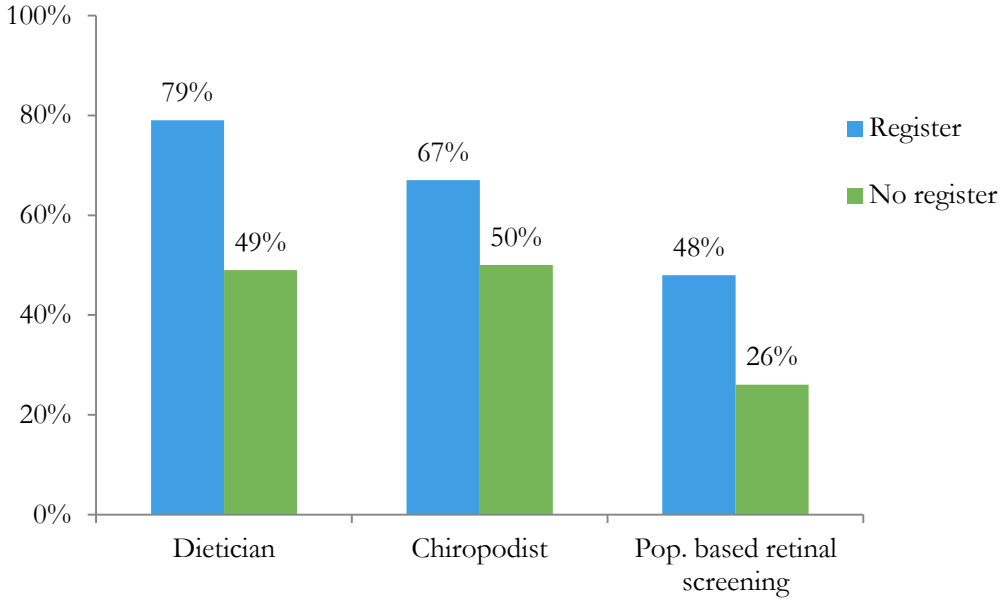


Figure 17 Percentage of practices with/out a register with direct access to services

3.3.10 Special Interest in Diabetes

While 73% of GPs reported a special interest (SI) in diabetes within the practice (n=138), only 55% of the total sample responded to this question (n=190). It was typically a GP or nurse who had a special interest in diabetes; 51% (n=81) and 45% (n=71) respectively. Other professionals in the practice with a special interest included the visiting dietician and the Diabetes Nurse Specialist (DNS) (see Appendix VI).

3.3.10.1 *Relationship between having a special interest & care delivery*

Practices reporting a special interest in diabetes were compared with those without a special interest in terms of practice characteristics and organisation (Table 17). There were no significant differences in terms of size and level of staffing. There was no significant association between practice location and having a special interest in diabetes (χ^2=4.177; df= 2; p=0.124). Of those with a special interest 20% were rural practices (n=17), 38% were urban (n=32) and 42% were mixed practices (n=35). There were no significant differences in terms of the size of the patient population (U= 2559, p>0.05) or diabetes population (U= 1565, p>0.05). However there were a number of significant associations between having a special interest in diabetes and the organisation of diabetes care: having a register (p<0.001), holding clinics (p<0.001) (Table 17).

Table 17: Association between having a special interest in diabetes and care delivery

Characteristic	Special Interest N (%)	No SI N (%)	% Difference	95% CI	P
Practice Nurse	121 (88)	36 (69)	19%	7-34%	p=0.004*
Practice Manager	38 (46)	11 (55)	9%	-31-15%	P=0.66
Computer System	128 (93)	47 (90)	3%	-5-15%	P=0.69
Diabetes Module	70 (68)	6 (24)	44%	23-60%	P=0.000†
Paperless	42 (54)	8 (42)	12%	-13-34%	P=0.5
Diabetes Care Delivery					
Diabetes Register	72 (54)	13 (25)	29%	13-42%	P=0.001†
Specific clinics for DM	45 (33)	3 (6)	27%	15-36%	P=0.000†
Formal Recall	29 (35)	2 (10)	25%	3-38%	P=0.06
Guidelines	55 (67)	6 (30)	37%	13-56%	P=0.005*
Diabetes Screening	77 (92)	18 (90)	2%	-9-22%	P=0.8
Access to/contact with other providers					
Formal shared protocol	8 (10)	1 (5)	5%	-15-14%	P=0.52
Regular joint meetings	-	-	-	-	-
Access to Dietician	60 (72)	11 (55)	17%	-5-40%	P=0.23
Access to Chiropodist	53 (64)	10 (50)	14%	-9-37%	P=0.38
Access to retinal screening	32 (40)	6 (35)	5%	-21-26%	P=0.93

† Significant after Bonferroni adjustment *Not significant after Bonferroni adjustment.

3.3.11 Opportunities in Developing Diabetes Care

Most respondents selected GP/Practice nurse training as the principal opportunity for developing diabetes care in their practice (76%, n=196) followed by easier access to specialist advice (65%, n=166) (Figure 18). Other suggestions put forward by respondents included access to dieticians and ophthalmology services in particular, shared care arrangements and protocols. (See Appendix VI for a summary of all themes emerging from analysis of responses.)

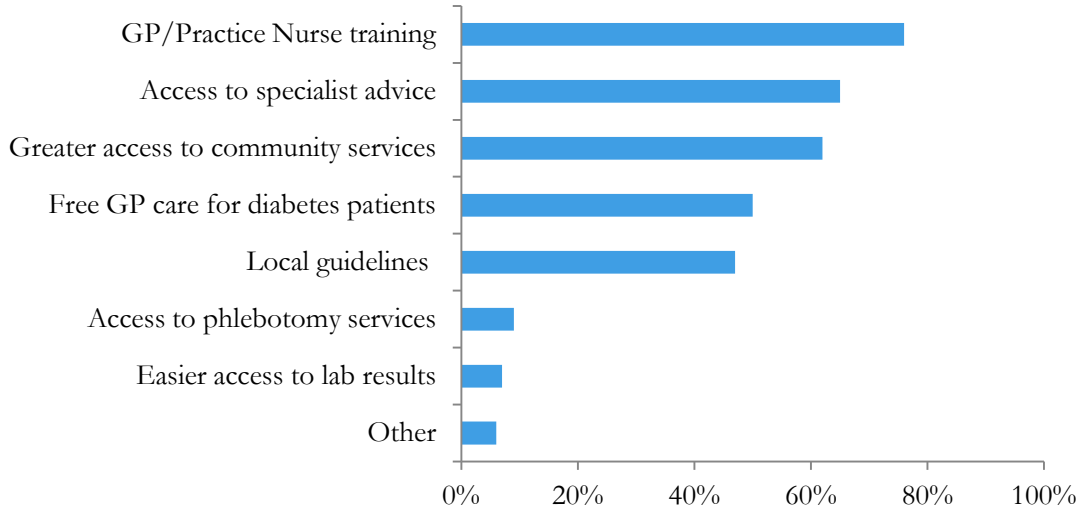


Figure 18 Principal opportunities for developing diabetes care in the practice

3.3.11.1 *Remuneration for Diabetes Care*

Over half of the GPs surveyed thought that a mixture of capitation and fee per patient should be used as remuneration for diabetes (54%, n=136) while less than one quarter were in favour of target-based payment for diabetes care (19%, n= 49) (Figure 19).

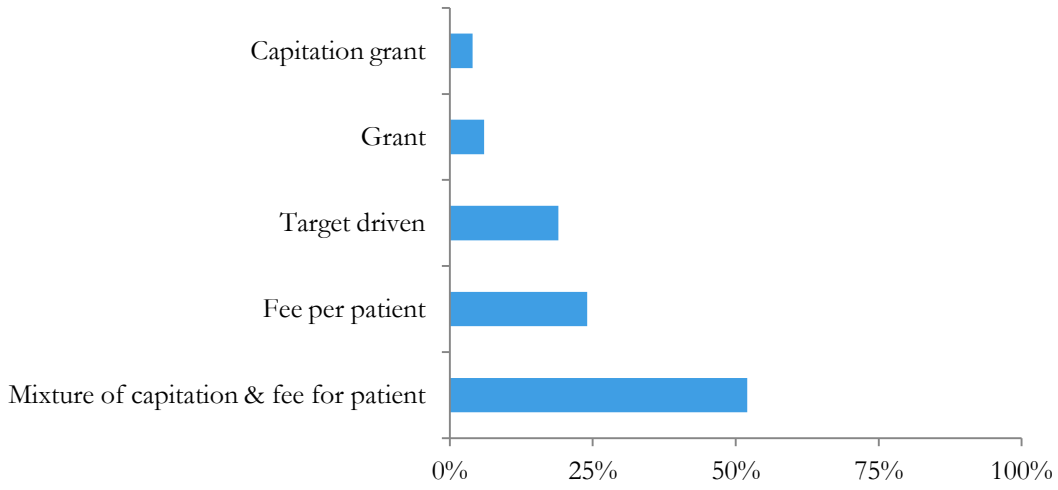


Figure 19 Remuneration options for providing diabetes care

3.3.11.2 *Suggestions for improvements to diabetes care in Ireland*

The last section of the survey provided respondents with an opportunity to provide comments and suggestions on improving diabetes care. Most respondents elaborated on the opportunities for development presented in Figure 18. The most common themes are outlined in Table 18 (See Appendix VI for full thematic analysis). As illustrated by respondents' quotes, some issues such as time constraints and workload were proposed as barriers while remuneration and shared care were seen as potentially beneficial.

Table 18 Emergent themes from suggestions to improve diabetes care

Factor	Sample of responses
Incentives/ Remuneration	"I won't get involved in the huge complicated task of looking after the diabetic needs of my patients unless there's a transfer of funds to pay for it"
Working with secondary care providers	"Better lines of communication with specialists [are] essential. Currently OPD is seeing patients who should be in primary care & we cannot get support for those who need it. Consultant care for all diabetics is unrealistic so a system where consultants provide quality support to primary care in managing diabetes is essential" "We'd like the opportunity to have joint meetings with the hospital team & collaborate with them. At present they have different protocols & philosophies to us which are frustrating our care."
Access to Community Services	"Running diabetic clinic in GP practice pointless without dietician & access to community services such as ophthalmologist & chiropody - have to attend hospital for these, thus losing the patient to hospital, not GP run".
Lack of resources	"I would not attempt to look after diabetes needs of patients unless it was a 1st class service I could provide, and with present resources it's not possible."
Time	"Diabetes care takes a lot of patient contact time. Initially on diagnosis of T2 diabetes there are numerous visits & education/bloods etc until the hospital appointment comes up. It would want to be well paid to make it worth GPs time as DM care to be done properly is very time consuming"
Workload	"It is demoralising to contemplate burgeoning workload involved in tandem with dwindling hospital resources". "Due to workload we have had to reduce commitment to our diabetes patients, suspending dedicated clinics... & now referring all new diabetics to hospital (in spite of having acquired extra qualification in diabetes care!)"

3.4 Discussion

The present study assessed the level of diabetes care delivered in general practice in Ireland and identified areas for further development. A substantial proportion of diabetes care delivery was unstructured with limited adoption of strategies to enhance delivery such as maintaining a register and engaging in routine recall. The survey showed that less than half of GPs maintained a diabetes register while only half of GPs operated some form of call/recall system for reviewing patients, whether formal or informal. The findings are consistent with the first national survey of diabetes care in general practice in 2003 (135), suggesting little progress has been made in organising the delivery of diabetes care.

3.4.1 Integration between settings

There was deficient access to dietetics and foot care services among the GPs surveyed. While most GPs reported access to ophthalmic examinations this service was provided by a variety of service providers. Respondents referred to a patient's public/private status as a key determinant of waiting times across all ancillary services. The survey also showed that the majority of GPs did not have a formal shared protocol with the local hospital based specialist diabetes team and had little formal contact with this setting. Shared care and protocol-driven management in general practice have previously been found to relate significantly to metabolic control in an Irish sample of patients with diabetes (160). The lack of integration reported by GPs was echoed in the more recent survey of outpatient diabetes care in 35 public hospitals in Ireland. Over half the hospitals surveyed reported rarely or never discharging patients back to GP care (n=20) (161). The results from GPs in Ireland contrasts with findings from the UK survey of care provision where 39% reported a formal protocol and 14% had regular joint meetings with the hospital-based specialist diabetes team (155). The GPs in this survey did express interest and enthusiasm for integrated care arrangements with shared care emerging as one of the suggested opportunities for developing diabetes care into the future. There are a number of structural, resource and practice implications arising from these findings such as the development of communication pathways and patient tracking systems to facilitate integration between settings.

3.4.2 Use of strategies to enhance organisation and delivery

The survey found that approximately half the sample used guidelines for care. Less than one quarter of GPs referred to the national guidelines for diabetes care in the

community which emphasise patient registration, recall and regular review as the key components of comprehensive diabetes management (17). A patient registration system could facilitate the latter two components of integrated diabetes management as it allows patients to be recalled for review or referral at appropriate intervals based on evidence-based guideline, as well as facilitating the auditing of care and outcomes for quality improvement (162). This dual relationship is supported by the significant associations between maintaining a diabetes register and other aspects of diabetes care delivery demonstrated in this study. Among others, there was a significant association between maintaining a register and having a diabetes module on the practice IT system as well as engaging in formal recall. A survey of diabetes care in primary care health centres in Sweden found a positive association between having a call-recall system and the use of guidelines, echoing the synergy between quality improvement strategies indentified in this study.

It seems likely that maintaining a diabetes register is a marker of a greater interest among practices in quality improvement activities overall (15). There was a significant association between having a special interest in diabetes and maintaining a register however the substantial proportion of missing data on the former variable should be taken into account. This study highlights the need for further exploration of the attitudes of GPs towards quality improvement. Health professionals are key players in the success or failure of quality improvement programmes depending on their willingness to learn, accept and adapt to changes in practice (163). A follow-up qualitative study with GPs, presented in Chapters 4 and 5, explores issues such as the possibly iterative relationship between having a special interest in diabetes and adopting strategies to organise care as well as the other factors driving engagement in improvement.

The main barriers to developing care, lack of resources, time constraints and workload, concur with other studies and reflect published primary care concerns around providing diabetes care in general practice (135, 164). Our study extends prior results on barriers to care by also highlighting the principal opportunities for diabetes care improvement. Training for GPs or practice nurses was the most important opportunity according to GPs again suggesting willingness among GPs to deliver diabetes care with adequate support. Further investigation is warranted as to how special interest translates into practice.

Improving links with community services and secondary care were perceived as facilitators of care delivery. A number of GPs referred to arrangements with secondary care providers or expressed interest in developing such links. These responses reflect the variability of care characteristic of Ireland. The last 10 years has seen the introduction of specific structured or shared care programmes for diabetes in Ireland (137, 138). However some of these initiatives have not been sustained due to lack of funding and resources. This study reiterates the call for further research to identify the factors critical to the success of shared or structured care arrangements (132).

Among this sample of GPs remuneration was cited as an important factor for the development and integration of diabetes care. A mixture of capitation and fee per patient was proposed as the most suitable method of payment. There may be credence in linking remuneration to the three pillars of effective integrated diabetes care; registration, recall and review. A comparable strategy has been proposed by the Obama administration in the U.S where bonus payments will be given to physicians who adopt and use electronic health records effectively (165). The NHS in the UK also has a well-established incentive structure, the Quality Outcomes Framework, which links remuneration with quality assurance.

3.4.3 Strengths and Limitations

This study has some limitations because of the relatively low response rate however the profile of the sample in terms of urban/rural breakdown is broadly comparable with the national profile (159).While the response rate is lower than that achieved by an earlier GP survey of diabetes care in 2003 (135), it is similar to the 46% response rate received by the National Audit of Stroke Care Survey of GPs in 2006 which used the Irish Medical Directory rather than the ICGP approach to sampling and recruiting (166) and the survey of diabetes care conducted in the UK(155). A recent systematic review of the response rate in over 350 GP postal surveys found a mean response rate of 61%. One quarter of the studies had a response rate of less than 50% (n=91 studies). A number of strategies were incorporated to increase the response rate including endorsement by a professional association (ICGP) (167) and providing freepost return envelopes (168). The extent and intensiveness of follow-up was restricted under the regulations of the Irish College of General Practitioners which prohibited telephone follow-up of non-responders to maintain anonymity.

Given the self selecting nature of survey research and thus the inevitable bias towards GP with an interest in diabetes one would expect to have found a bias towards optimal care delivery in this sample. Therefore given the significant deficits in the level and organisation of diabetes care documented in this study it is arguable that the problems highlighted here have been understated. With regard to strengths of this study, the survey instrument has also been used to assess service provision in the UK (155) and adapted and used previously in an Irish setting (154).

3.4.4 Conclusion

This study provides an important benchmark of the organisation of diabetes care in general practice in Ireland. The findings suggest limited progress towards more organised care delivery since 2003. Maintaining a diabetes register was associated with other quality improvement efforts and it is likely that a register is a marker of enthusiasm and investment in quality improvement for patients with diabetes in the practice. Despite the focus on improving diabetes care in recent years, considerable gaps in care remain suggesting that the problems and solutions stem beyond clinician engagement to systems level interventions addressing service design, care delivery and remuneration.

4 Providing Diabetes Care in Irish General Practice; Everyday Experiences and the Barriers and Facilitators to Optimal Delivery

Sheena Mc Hugh

Dr. Monica O'Mullane

Prof. Ivan J. Perry

Prof. Colin Bradley

Abstract

Aims: The aim of this qualitative study was to explore GPs' experiences of delivering diabetes care in more detail and to elucidate the models of care in Ireland. The second aim was to identify the barriers and facilitators to providing optimal care in everyday general practice.

Methods: A purposive sample of 29 GPs and 2 Practice Nurses (nominated to represent the practice) participated in semi-structured interviews. Participants' practices varied by (a) location (rural/urban), (b) size (single-handed/group practice) c) extent of computerisation in the practice. The topic guide focused on 5 subjects, 3 of which are dealt with in this chapter: management and organisation of diabetes care in the practice; barriers and facilitators to delivering care; and finally a wish-list for the development of diabetes care in Ireland. A prompt on the factors promoting or hindering care, based on the findings of the preceding survey was used during the interviews. Analysis was conducted using the Framework approach.

Results: Four dimensions of diabetes care delivery were identifiable in the data; 1) a continuum of organisation *within* the practice from *"ad-hoc"* to structured care, 2) the balance of care between general practice and the hospital setting, 3) the extent of sharing between settings 4) involvement in formal or informal initiatives to improve diabetes care. A proposed *"ideal"* arrangement was *"sharing"* responsibility rather than either/or care, combining the strengths of general practice and hospital services, however there were varying opinions about the need for joint involvement. The barriers and facilitators to optimal diabetes care delivery were intertwined as obstacles occurring at the systems level had a ripple effect at an organisational, social, professional and patient level. The "*non-existent"* remuneration for diabetes care created a sense of apathy in general practice and was perceived to be indicative of the lack of value placed on chronic disease management in the health system. There was a subset of GPs delivering structured care who were motivated by *"vocational"* incentives such as job satisfaction and personal experience. The lack of coordination within the system had a number of consequences including waiting times, overburdened hospital services, a bureaucratic *"palaver"* and *"in the meantime"* care for patients. The general practice setting was identified as a facilitator in the delivery of diabetes care however its potential was limited by the lack of resources.

Conclusions: The study explored the myriad of care arrangements in Ireland and the interrelated barriers and facilitators to optimal diabetes care which have an effect on practice organisation, professional attitudes and relationships as well as patient care. At present intrinsic motivation is a determinant of the provision of structured systematic diabetes care in general practice. However this will not be sufficient to drive widespread implementation of the proposed national model of integrated care. While a national programme needs to be flexible to account for local capacity and interest, there is still a need for coordination at a systems-level and accountability at a professional-level.

The paper will be submitted for publication to Social Science & Medicine

4.1. Introduction

According to an article on optimal diabetes management published in 1982, the *"care of diabetics requires enthusiasm and organisation"* (169). The authors recommended that the management of uncomplicated diabetes take place in general practice by trained staff working closely with specialists in the hospital setting. Features of effective diabetes care identified in 1982 included regular review, the use of special records for diabetes care and nurse involvement. Since then, there have been significant advances in the management and treatment of diabetes (42, 55, 59) however gaps have opened up between the ideal standard of care and the reality for clinicians and patients.

4.1.1 Importance of organisation in providing effective diabetes care

Enthusiasm and organisation, in various guises, have emerged from the body of quality improvement research, as the building blocks to bridge the gap (6-8, 63, 81). The Chronic Care Model (CCM) emphasises the role of a proactive practice team in delivering planned structured care for patients with chronic illness. The model also proposes major reorganisation within the practice to meet the needs of patients (81). There is evidence to suggest the reorganisation of care improves the quality of diabetes care processes and patient outcomes (14, 111). However a survey of diabetes care in general practice in Ireland (Chapter 3) highlighted the lack of structured delivery in this setting, reflected in the absence of patient registers and the lack of routine recall (170). The survey also found deficient access to services necessary to support the management of diabetes in general practice. Over 30% of GPs did not have access to dietetics services while more than 40% did not have direct access to chiropody services. A similar survey of diabetes care conducted among public hospitals in Ireland also found insufficient support services in the secondary care setting (unpublished) (161).

4.1.2 Importance of integration between settings

The availability of community resources, including relationships and links with other health care professionals, is a key component of effective integrated chronic illness care(81, 84). Diabetes is particularly challenging to coordinate as there is the myriad of health care providers and settings involved in providing care, within which the patient can become lost. The organisation and delivery of diabetes services differs within and between countries involving secondary care and primary care providers to varying degrees (138). Over time the terminology surrounding models of care have developed multiple meanings, definitions and connotations. Terms scattered throughout the

quality improvement literature include 'integrated care', shared care (Europe), transmural care (Netherlands), managed care (USA), structured care and more broadly chronic disease management (171) (see Chapter 2 for summary of models of care).

Ireland reflects the intricacies of the literature as each model of care has context-specific connotations. There are currently ten formal diabetes initiatives across Ireland ranging from shared care arrangements between GPs and hospital teams (139) to structured care initiatives set up by GPs (137, 172). The national guidelines for diabetes management endorse an integrated model of care in which patients with stable diabetes would receive the majority of care in primary care while patients with more complex needs would have access to a greater level of specialist support (17). However the aforementioned surveys of diabetes care in general practice and the hospital setting have highlighted the lack of formal integration between settings. Over half of hospitals reported rarely/never discharging patients back into GP care. Only 3% of GPs had regular meetings with the local hospital diabetes team and most did not have a formal shared protocol with the hospital-based team.

Given the array of care arrangements in Ireland it is difficult to quantitatively assess the extent to which diabetes care is coordinated between settings or provided independently by practices to meet the immediate needs of the local community, although certainly the aforementioned surveys highlight some of the barriers to coordination. This qualitative study will seek to untangle the myriad of models and levels of integration between settings in order to bring some clarity to the picture of diabetes care in Ireland. Qualitative research is no longer seen as an add-on in health services research (173). Particularly in the area of quality improvement, one of the key questions for health services research is the barriers for clinicians in meeting the needs of patients with chronic illnesses (174).

4.1.3 Aims & Objectives

As part of the wider aim of this thesis to investigate the 'quality chasm' in diabetes care organisation in general practice, the two objectives of this study were;

1. To elaborate on experiences of delivering diabetes care in general practice and elucidate the models of care functioning in Ireland.
2. To explore perceptions of the barriers and facilitators to providing diabetes care in everyday general practice.

4.2 Methodology

4.2.1 Design

A qualitative study was carried out involving face-to-face semi-structured interviews with a sample of GPs and Practice Nurses. The study was conducted by 2 researchers (SMH and MOM). Each researcher followed the same procedure when independently interviewing participants. Results were analysed separately before comparing the convergence and divergence of findings.

The qualitative design and methodology underpins two chapters in this thesis (Chapter 4 and 5). This chapter constitutes the second phase of a mixed method sequential design, which was preceded by a quantitative GP survey (Chapter 3)(153). The findings of the survey were used to inform the topic guide for this study while the results of this qualitative investigation will be used to understand in more depth the patterns and differences which emerged in the cross-sectional study.

The themes presented in Chapter 5 emerged from the same qualitative methodology and phase of data collection, but dealt with the issue of quality improvement and participants' attitudes towards change.

4.2.2 Participants

4.2.2.1 *Recruitment*

Participation in the qualitative study was by means of 'opting-in' during the preceding GP survey. GPs, who indicated willingness to be contacted by providing their contact details on the last page of the survey, were eligible to participate (Appendix IV).

4.2.2.2 *Sampling Frame*

In total 213/262 survey respondents provided follow-up details (81%) representing 25 of the 26 counties in the Republic of Ireland. A purposive sample was selected from this pool, based on three sets of criteria previously used to distinguish between practices in Ireland(160).

4.2.2.3 *Selection criteria*

1. Urban/Rural practices
2. Single handed/ Group practice: group practices were defined as those with >1 GP employed.
3. Fully computerised using the system for clinical consultation / Computer system used for administration only or no computer.

There were 8 categories from which to recruit participants (Table 19). All potential participants were screened by telephone to establish their profile. During screening a number of GPs could not be contacted and so could not be included in the sample.

Table 19 Combinations of selection criteria

Rural/ Single / Computer	Urban / Single/ Computer
Rural/ Single/ Non-computer	Urban /Single /Non-computer
Rural/ Group/ Computer	Urban/ Group/ Computer
Rural/ Group/ Non-computer	Urban/ Group/ Non-computer

4.2.3 Sampling Matrix

The 3 sets of inclusion criteria formed the sampling matrix, containing a number of cells in which a quota of GPs was specified (Table 20)(158). The quota indicates that some coverage was required in each cell. The ranges given in each category of computerisation are slightly different (4-5 or 3-4) so that they add up to achieve the correct numbers overall. The specification would achieve a sample of 28-32 GPs.

Table 20 Proposed Sampling Matrix

	Urban (14-16)	Rural (14-16)
Single	7-8	7-8
Computerised Non-computerised	4-5 3-4	4-5 3-4
Group	7-8	7-8
Computerised Non-computerised	4-5 3-4	4-5 3-4

Overall 31 participants were interviewed. The group was composed of 29 GPs and 2 Practice Nurses who were nominated by the GP in their practice to participate. All criteria were represented in the group although the non-computerised practices were more difficult to recruit as illustrated in Table 21.

Table 21 Participant Matrix (N=31)

	Urban (16)	Rural (15)
Single (15)	6	9
Computerised Non-computerised	4 2	8 1
Group (16)	10	6
Computerised Non-computerised	10 0	6 0

4.2.4 Topic Guide

The semi-structured topic guide was informed by both the objectives of the study and the results of the GP survey outlined in Chapter 3. It included five broad subjects for discussion (Appendix VIII);

- Current provision of diabetes care
- Factors influencing the optimal delivery of diabetes care
- Wish list for diabetes care in Ireland
- How have things changed locally and nationally
- Attitudes to the development of a national diabetes register and engaging in audit in the practice.

Themes which emerged from the latter two topics are presented in Chapter 5 which focuses on change in the health system and attitudes to quality improvement.

A written prompt of the factors influencing the provision of care was also included in the interview schedule to stimulate discussion (Appendix IX). The prompt was developed from the responses to the following two open-ended questions in the preceding GP survey:

Q What do you see as the principal opportunities for developing diabetes care in your practice?

Q We welcome your insight into diabetic care and thus any comments/suggestions for improvements are appreciated whether positive or negative.

Originally the prompt was devised as a checklist in which the interviewee would indicate whether a factor was a barrier or facilitator to care delivery (Appendix IX). However feedback from GPs and experience during the interviews suggested that this format was restrictive and superficial as a number of GPs conceptualised certain factors as both barriers and facilitators depending on their presence or absence in the practice e.g. resources. It was decided by the research team to modify the checklist, resulting in a written prompt around which GPs could discuss their views and experiences.

4.2.4.1 *Pilot*

The first two interviews were used to pilot the topic guide highlighting which questions worked well and where changes were needed. It also allowed the researcher to assess the timing and pace of the interview. As the content and focus of the topic guide did not change substantial the two interviews were included in the overall analysis.

4.2.5 Procedure

A total of 31 interviews were conducted by 2 researchers (MOM and SMH) between July and January 2010. A letter of invitation was sent to the sample of GPs (Appendix X). This letter indicated that a researcher would contact the GP in the coming week to register his/her interest in the study and arrange a suitable time for the interview if applicable. GPs who indicated interest in taking part during the follow-up phone calls were then sent an outline of the topic guide and a letter of reminder regarding the time and date of the interview. Interviews took place in the GP surgery or the participant's home at a time selected by the participant. The interviewee was given an information sheet and consent form to sign (Appendix XI). The interviews lasted between 25 minutes and 1.5 hours and were digitally recorded with permission. A summary of the interview was sent to each participant upon completion of the analysis. This was a stipulation for the ethical approval but also provided an opportunity for respondent validation. Participants were given 4 weeks to respond with comments however none of the participants replied.

4.2.6 Analysis

Analysis was an ongoing and iterative process. All interviews were digitally recorded and transcribed verbatim by the individual interviewer. A pragmatic approach was adopted for analysis using Framework Analysis (158) which is increasingly popular in Health Services Research (175). To begin, the researchers familiarised themselves with the data (reading and re-reading), moving on to open-coding of the transcripts to identify initial

themes and concepts. A thematic index or conceptual framework was developed from these codes based around the core topics of the interview topic guide but also including newly emerging themes. In this study, it was decided not to apply the index to the data as data were already quite orderly given the semi-structured nature of the interview schedule. Data were then sorted and synthesized by theme bringing similar concepts together (thematic charting). Throughout this stage the language and expressions of the GPs were maintained as far as possible to avoid losing the meaning and context. In the quotes presented in this chapter words in parenthesis and ellipses (…) were added by the researcher; to clarify meaning in the first instance or to indicate the removal of unrelated text in the second instance. An identification number was assigned to each participant reflecting the order of the interviews as well as the researcher who conducted the interview (GP 1=MOM, GP101=SMH). Alphabetic codes were also applied to quotes to reflect location (U=urban, R=rural), practice size (S=single, G= group) and level of computerisation (C=computerised, NC=non-computerised).

Memos

Memo writing was also used as an analytic tool in conjunction with coding. Charmaz (2006) compares memo writing to having a conversation with yourself, allowing space to clarify thoughts and questions, identify avenues to pursue, make connections or comparisons between data and uncover assumptions of both the participant and the researcher (176). The last function reflects the role of memo writing in researcher reflexivity; writing and acknowledging your own thoughts, actions and decisions (177). Memo writing was guided by a typology proposed by Saldana as 'recommended categories for reflection' (Table 22) (178). Appendix XII includes a sample of the memos written during the analysis based on but not restricted to this typology.

Table 22 Recommended categories for reflection (178)

Reflect on and write about...
How you personally relate to the participant of the experience
Your research question
Your choice of codes and how you define them
Emergent patterns, categories, themes
Possible relationships, networks, connections between themes
Emergent or related existing theory
Any problems with the study
Personal or ethical dilemmas with the study
Future directions for the study
Final report of the study

4.2.6.1 *Inter-coder reliability*

Following the initial wave of analysis a number of interviews (3 from each researcher) were subject to inter-coder reliability by an independent party familiar with the aims of the study (CB). Following independent analysis, the two researchers examined the convergence and divergence in their findings outlined in the next section.

4.2.6.2 *Triangulation*

The qualitative study was conducted by a team of researchers from inception to completion. Two researchers were involved in the collection and analysis of the data. Each researcher analysed their set of interviews separately[1] generating a set of themes and concepts pertaining to their data. The two researchers examined the convergence and divergence in their findings. Discrepancies arouse from two conditions; 1) different labels or codes applied to the same concept or 2) unique concepts emerging from one researcher's analysis not identified by the other researcher. More often than not, a similar *"constellation of themes"* were identified, the difference lay in the labels applied to the themes i.e. *"packaging"* as described by Armstrong et al (1997) in a study employing multiple analysts (179). Through discussion it became clear that the codes related to the same concept. Occasionally, unique codes emerged from one analysis which was then discussed with the wider group (other researcher and independent rater) (Appendix XIII). These unique insights are maintained and highlighted in the results section.

4.2.7 Ethical Approval

[1] Fifteen interviews were conducted by Sheena Mc Hugh and sixteen interviews were carried out by Monica O'Mullane.

Ethical approval was sought and granted by the Irish College of General Practitioners in June 2009 (Appendix XIV).

4.3 Results

This section presents the emergent themes from GPs' experiences of providing care to patients with diabetes. It is organised in two parts. Section 1 examines the experiences of delivering care in general practice illustrating the four dimensions of diabetes management which emerged from GPs' accounts. GP descriptions included practice procedures, links with secondary care and the use of support services which were used to elucidate the models of diabetes care in practice (Section 1A). Section 2 outlines the barriers and facilitators to providing diabetes care in everyday general practice.

Section 1: Dimensions of Diabetes Care Delivery

Emergence of themes

Four dimensions of diabetes care were delineated from GPs experiences in everyday practice (Figure 20*). The 1st dimension pertained to whether care was *"ad hoc"* or structured within the practice. This was a practice level issue and does not seek to infer about the nature of care delivered in the hospital which was not the focus of the interview. The 2nd dimension was the varying balance of care between settings which emerged from GPs accounts of how care is delivered between settings and the extent to which patients are managed in general practice. Some participants referred to the ideal scenario of greater sharing between settings, implying that it was not the current reality. The theme also reflects how GPs felt about anchoring diabetes care in general practice.

The 3rd dimension reflected the extent to which care was shared between settings. It was identified as a separate dimension as there were a subset of GPs providing the majority of care for patients with Type 2 diabetes (i.e. balance of care in general practice) and were not sharing management with the hospital team according to their accounts. The 4th and final dimension distinguished between formal initiatives to improve care delivery and care arrangements established independently by the GP (informal) without the support of a formal initiative (See Appendix XIII for development of dimensions)

Note Figure 20-GPs on the right-hand side of the diagram were those providing structured care to patients. GPs placed in the top portion of the diagram were providing the majority of routine diabetes management (GP-led care). On the right-hand side moving from top to bottom practices were involved in greater sharing of care with the hospital team. For example, GP105 referred patients to hospital for routine management (hospital-led) and attended to patients' diabetes as they presented as the practice for other issues (ad-hoc).

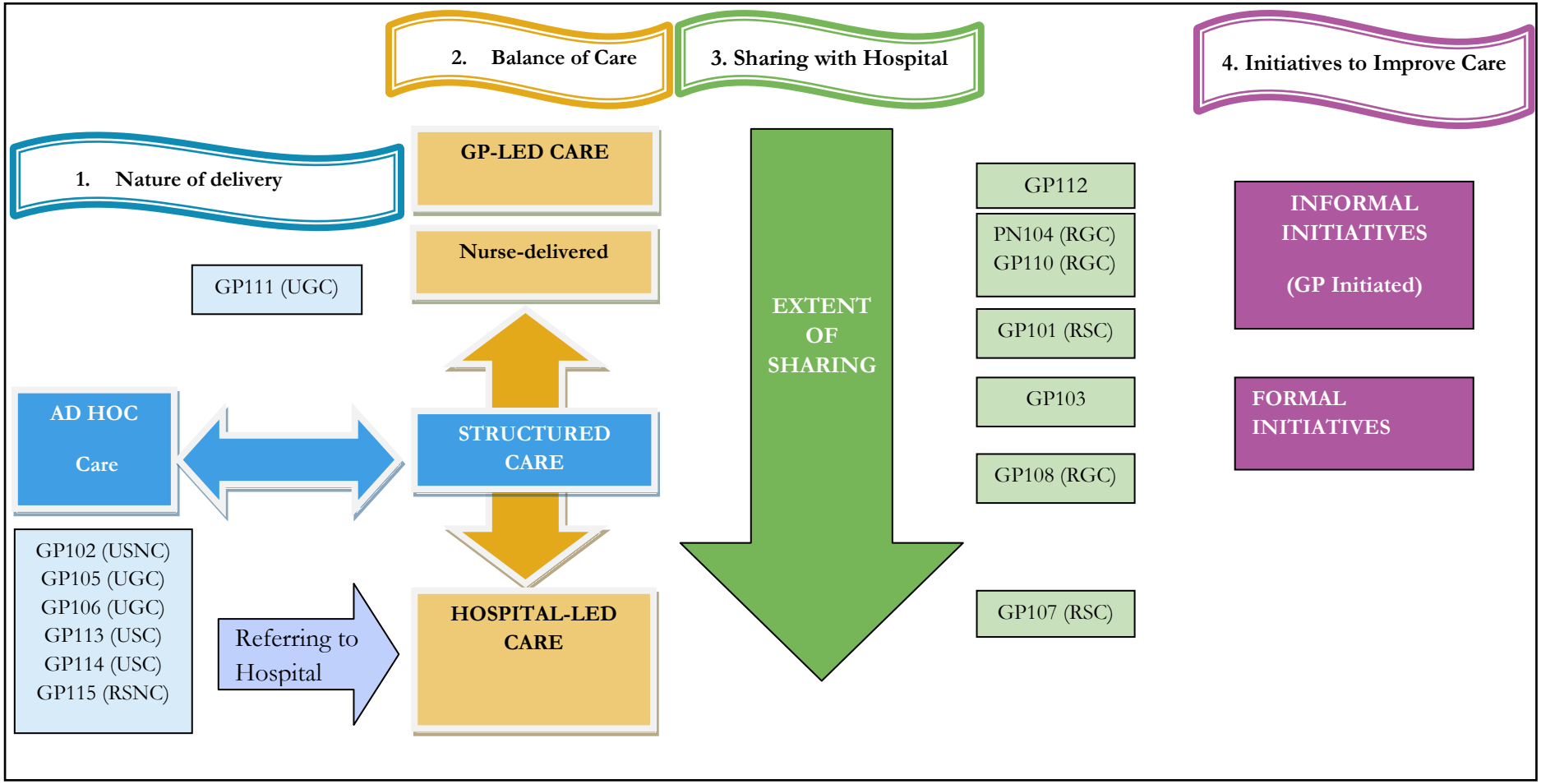


Figure 20 Dimensions of diabetes care delivery (See Appendix XIII)

4.3.1 Nature of care delivery: continuum from ad hoc to structured care

The first distinction which emerged from the data was between practices providing care in a structured way and those providing care on a more "*ad-hoc*" basis. The distinction was made by the GPs themselves and was also reflected in their descriptions of how care was delivered. There was a *continuum of structured to ad-hoc (non-structured) care* rather than an all or nothing situation, as there were elements of opportunism in structured care namely; GPs providing care as part of a daily surgery, manual recall and the role on patient responsibility. Equally there were some indications of structure in practices providing care in an ad-hoc way e.g. having targets for regular review although it was patient-initiated.

4.3.1.1 *Features of a Structured Approach to Care*

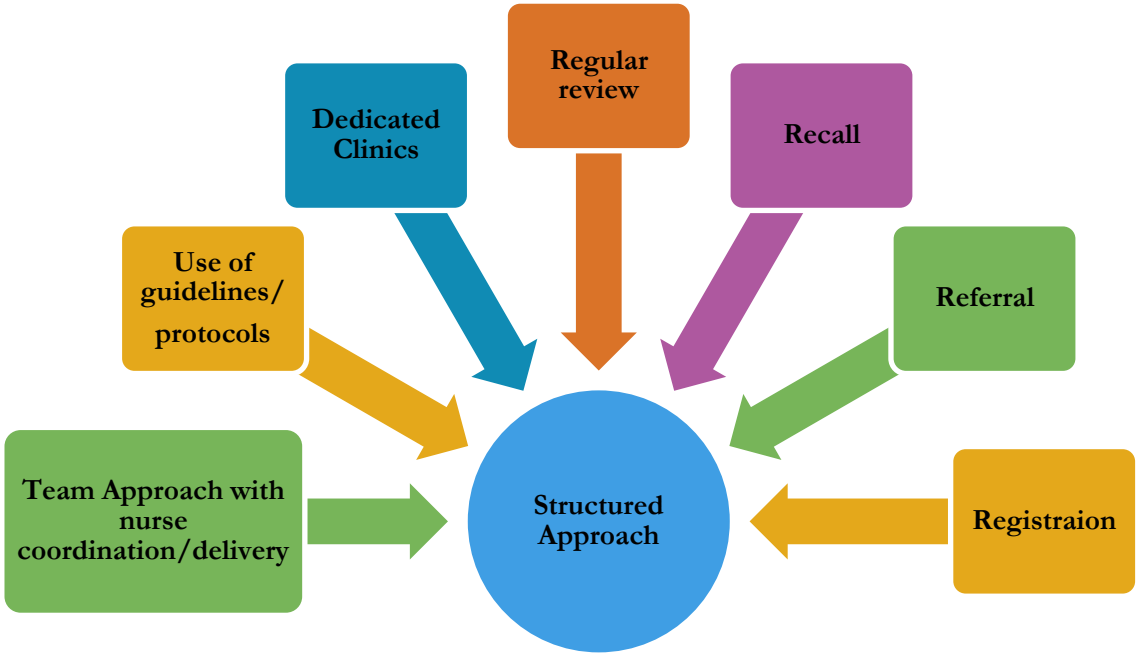


Figure 21 Features of a structured approach to diabetes care.

Structured care was characterized by certain features that made delivery more organised (Figure 21) but was also reflected in the sequential stages of delivery which GPs referred to. For example, when asked to describe care GP112 identified 3 key features from the outset: registration, referral and recall. Upon diagnosis patients were registered and referred to the nurse and the dietician and entered into the recall system of the practice. The common features of structured practices were registration, recall and regular review, using a protocol and "keying into that" on the computer or following guidelines. A number of practices held special clinics often led and coordinated by nurses. 'Clinics' referred to both special dedicated clinics within the practice for patients with diabetes

(e.g. Thursday morning) or protected time for diabetes care used and organised at the discretion of the nurse (e.g. fitting a number of diabetes appointments into the diary over the course of a week).

Delegation within Practices & the Facilitating Role of the Nurse

Another feature of practices providing structured care was the delegation of tasks between the GP and the Practice Nurse. Participants' descriptions reflected a clear understanding of who was delivering different components of diabetes care, as part of a team approach to regular management (Figure 22). This approach was best described by one GP as *"a combination of themselves and ourselves"* (GP112, RGC). It illustrates the integral role of the nurse in facilitating the delivery of planned structured care.

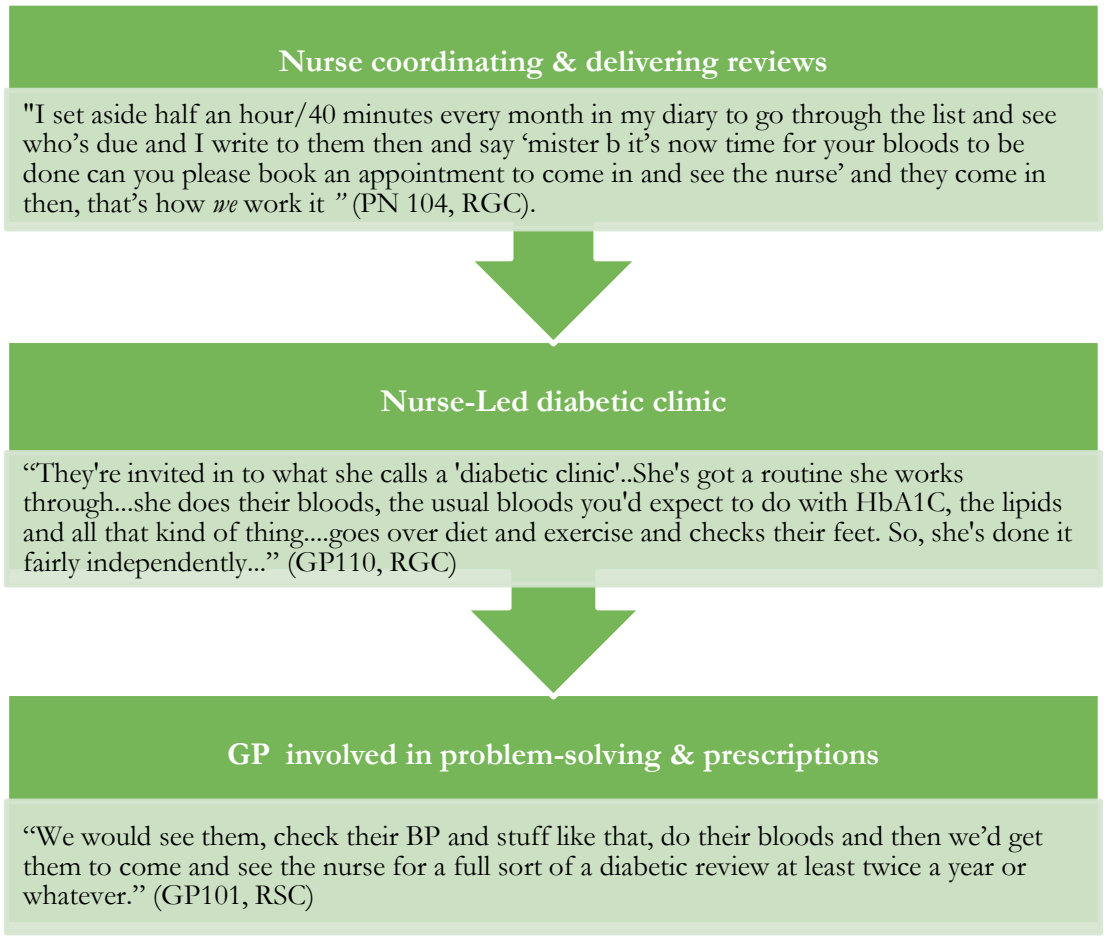


Figure 22 Teamwork approach to regular diabetes management

Opportunistic aspects of care within a structured approach

Despite the features of structured care, there was an inevitable level of opportunism to diabetes management due to a number of factors.

- ***Diabetes as part of GP's daily surgery***

Firstly management was *opportunistic for GPs* themselves as they would see patients for particular problems and also attend to their diabetes management as part of everyday surgery. For example GP110 felt care was provided *"partly"* on an ad-hoc basis by the GP during a routine surgery while the nurse had a systematic approach of fitting diabetes sessions into her day.

- ***Lack of electronic recall system***

Even structured care practices were reliant on *manual recall of patients*, via a paper-based system usually coordinated by the nurse. For example Practice Nurse 104 talked about setting aside time each month to go through the list to see who was due and writing to notify the patient. GP 108 also talked about the Practice Nurse working through the list and keeping a diary to co-ordinate appointments for shared care clinics.

- ***Patient Responsibility: an "adult approach" to recall***

Finally the recall process was ultimately *reliant on the patient* returning. A number of GPs spoke about having regular but patient-initiated follow-up. In describing her opportunistic approach to recall and review, GP115 highlighted the enabling role of the nurse in coordinating care;

> *"The patients come back themselves, I say to them during the consultation to come back for a check-up. I don't send letters or anything like that….I try to avoid reminders, it's their responsibility...I mean maybe if you had a nurse you could do those things...."* *(GP115, RSNC)*

As this quote reflects, the seemingly ad-hoc approach to recall was purposeful among some GPs. Furthermore, this approach was not only adopted by single-handed GPs who did not have the support of nurses. GP108 (RGC), whose practice provided structured care, adopted a new *"adult approach"* to follow up whereby patients are contacted with an appointment and advised to come to the surgery for their bloods prior to the appointment. For those who don't attend, *"it's their problem"*. This approach

was compared to a previous system of nurses *"pursing"* patients which led to patients becoming *"dependent and incapable"*.

An important distinction between the two approaches to follow-up, noted by GP108, is that it was *possible* to pursue patients when they had more nurses. GP101 (RSC) also referred to periods in the practice history when a practice nurse was not available and as a result *"care went back to an ad hoc thing"*. This theme reiterates the central role of the nurse in providing regular follow-up (Appendix XII).

4.3.1.2 *Features of ad-hoc care*

Ad-hoc management was described by one participant as *"picking up a diabetic at random, giving medications and checking BP"* (GP105). The two prominent features of ad-hoc care which emerged from GPs' descriptions of care were opportunistic follow-up and problem-led rather than routine management. Both elements of ad-hoc management were intertwined as opportunistic follow-up occurred when a patient presented with a problem or for a prescription. For instance, one GP spoke about following-up through medicines; *"they do require meds, that's how we treat them"* so they *"probably"* come back in for them (GP109 RSC). Another GP in an urban group practice described care as "ad hoc" because he did not run structured clinics and attended to patients when they presented with their problems (GP106, UGC). It was suggested by one GP that unstructured opportunistic management of Type 2 diabetes in general practice was the rule rather than the exception. The lack of a patient register was given as a reason for the opportunistic follow-up of patients, reflecting the synergy between elements of structured care.

4.3.1.3 *Continuum of Structured to Ad-hoc Care*

Just as there were elements of opportunism in structured care practices, there were also shoots of structure appearing in practices with an ad-hoc approach. For example GP111 was placed along the continuum in Figure 20 as she referred to becoming more organised for newly diagnosed patients. While initially suggesting care was *"not particularly organised"*, the GP also spoke about having her *"own agenda"* to check things when the patient visits and not just responding to problems.

4.3.2 Balance of Care

The 2nd dimension of diabetes care related to the balance of care between general practice and the hospital setting. A number of GPs felt they were providing the majority of care, particularly structured care practices (GP2, GP3, GP112 RGC, PN104 RGC, GP110 RGC, GP101 RSC, GP103 UCG).

> *"When we have to initiate insulin we do it here, under the guidance of the nurse who's been trained in that and ourselves…to be honest, I would say, 85% of our diabetics are managed exclusively here."* (GP112, RGC)

Practices providing care in an 'ad-hoc' way usually referred patients to the hospital for management and dealt with problems as they arouse on a daily basis (See Figure 22) (GP105 UGC, 106 UGC, 113 USC, 114 USC, 115 RSNC). GPs were classified as being involved in a model of hospital-led care if they stated it explicitly; did not appear to provide systematic care in the practice; or more often than not provided little detail on how care was delivered (Appendix XIII). A lack of detail was reflective of a lack of engagement or familiarity with the care pathway for patients.

> *"Basically we have a very good diabetic clinic in [the hospital]. So [the consultant] does a lot of the management for us so we would really be screening and referring on there" (GP107, RSC).*

Figure 23 illustrates the factors which determined whether the balance of care fell towards hospital-led management or general practice-led diabetes management.

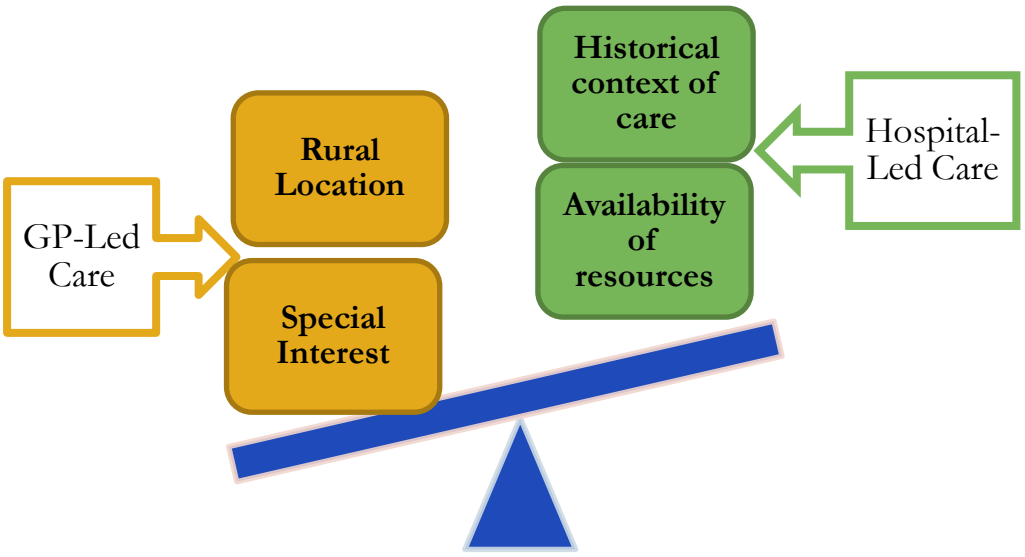


Figure 23 Factors influencing the balance of diabetes between settings

4.3.2.1 *Factors determining the balance of care*

- **Availability of resources**

For some participants the balance of care was determined by the resources available in the hospital and/or unavailable in general practice. For example, GP5 (UCG) perceived his role to be to *"diagnose, prescribe and refer"* as without adequate support and communication with other service providers it was difficult to do anything else.

> *"I normally do the initial diagnosis and work up but then they would go to the hospital. They can get their eyes checked there you see and all that stuff." (GP102, USNC)*

4.3.2.2 *Capability vs. Availability of resources*

The lack of resources was highlighted as a barrier to greater primary care involvement in diabetes care. Despite consensus among participants that general practice was an appropriate setting for managing diabetes, some participants felt they were at a disadvantage to the hospital setting in terms of *"access to all the specialties involved"* (GP107, RSC). Those who delivered structured care to patients recognised the resource implications of their approach.

> *"It is very labour intensive and some practices would find it very difficult, well we find it difficult and we've 2 nurses, but particularly practices that have very little nursing resources or none, very, very difficult." (GP103, UGC)*

More specifically a number of participants felt general practice was 'capable with resources'. The use of the conditional tense in the following quote gives a sense of the untapped potential in general practice and the scope for improvement;

> *"GPs are competent and capable of doing it but because of manpower and infrastructural issues it's not being delivered to the standard that it could be" (GP106)*

- **History repeating itself**

The 2nd factor which influenced the balance of care was the tradition of referring all patients to the hospital specialist. One GP suggested the tradition of referring all patients to *"one tsar of diabetes"* was *"totally disempowering a whole generation of young doctors" (GP108, RGC).* Such traditions were being carried on by GPs in this study;

> *"I was in a 3 doctor practice and I was following the lead of the others, which was the historical thing that anybody with diabetes was referred to the hospital." (GP113, USC)*

- **Location**

The location of a practice had an influence on the balance of care as GPs in rural areas had little choice but to manage patients with diabetes given the distance from hospital services. The move towards primary-care based management was not a new phenomenon in rural areas:

> *"There are individual GPs who've been working away like mad…out in the west of Ireland y'know, single handed, who've been just doing it all the time. It's a special interest for them because they've been 100 or 150 miles from a clinic so they've had to do it. They've become the specialists" (GP103, UGC)*

- **Special Interest**

Finally the balance of care residing in general practice was related to a GP's interest in diabetes and therefore his/her willingness to take charge. As a practice nurse reflected;

> *"We do a very heavy workload for diabetics but that's because diabetes is one of our big babies here" (PN 104, RGC)*

As well as being a determinant of the balance of care, special interest also emerged as a facilitator of high quality care which will be outlined in the 2nd section.

4.3.3 Extent of sharing care

The third dimension of diabetes care delivery was the extent of sharing between settings which varied across GP experiences. Some practices were involved in a formal shared care scheme which comprised of a diabetes nurse specialist clinic in the practice once a month. Other GPs had more informal arrangements such as GP107 from a rural practice which was sharing care by *"supporting the hospital";*

> *"I suppose we do share care in that we do the blood monitoring for the hospital and we send them all with the patient. I suppose that's part of shared care that we're doing at the moment" (GP107, RSC)*

Other GPs were managing diabetes primarily in the practice with referrals to the hospitals for particular issues. GP103 had evolved from a formal shared care initiative to more structured care which meant *"virtually all their diabetes work is done in the practice"* (GP103, UGC). This quote reflects the interrelationship between the balance of care and the extent of sharing between settings. However there were instances where most of the care was being provided in general practice and participants did not perceive

themselves to be sharing management with the hospital-based team, which led to the separation of these dimensions.

> *"I know that in Dublin there would be combined care. I think that's a good idea but I don't think it's necessary if you're a well-trained doctor" (GP112, RGC)*

4.3.3.1 *Reasons for Referral*

Reasons for referral typically emerged when GPs were asked about the relationship with the hospital, suggesting this is a defining characteristic of that relationship. As Table 23 illustrates the historical context underlying the balance of care manifested itself in referral patterns; those who always went to the hospital continued to do so.

Referrals were occasionally based on a GP's feeling as a professional or their personal assessment of the case. The GP had often tried to manage the patient first but reached a threshold of expertise. In particular, there was a threshold of expertise and confidence around initiating insulin and managing Type 1 diabetes:

> *"…if we have difficult problems or we've people coming to the end of the line; we wouldn't be initiating insulin in this practice just yet, we're not at that level of…competence" (GP101, RSC)*

Table 23 Reasons for Referral to the Hospital-based team.

Reason	Quotes
Timing	"Clinically often they're not ill, so you don't automatically refer them" (GP109, RSC) "It's not coordinated, it's just referral as required" (GP111, UGC)
Problems/Complications	"We would use the hospital where it would be difficult to control cases" (GP112, RGC) "…if they have secondary issues like neuropathies" (GP114, USC)
Professional feeling	"You feel that you're not getting good control for all that you're doing, everything you think you should be doing, you're hoping that maybe sometimes they'll do better by sending them to hospital" (GP111, USC)
History	"…we inherited patients from another practice and they go to the clinic but we generally encourage them to come here (practice) anyway" (GP112, RGC) "If the patient's going to the hospital regularly they're not inclined to come here"(GP111, USC)

4.3.3.2 *Resisting referral*

Just as there were reasons to refer, there were reasons not to (Table 24). Reasons given by GPs for resisting referral included the perceived risk of losing of patients to secondary care. This rationale related to the degree of communication between settings. While this was the GP's choice, a more unsatisfactory fruitless referral situation was highlighted by a rural single-handed GP; you could refer to the diabetes nurse specialist but there was *"no room really"*.

Table 24 Reasons for not referring patients to the hospital

Reason	Quote
Patient considerations & preferences	"They don't like hospital clinics, because they sit all day to see a nurse or intern…whereas there is a good relationship between the GP and the patient here".
Patients lost to secondary care	"I try to keep the patient here (in general practice) as much as possible" (GP2, RCS) as there is a possibility of losing patient management to the secondary care services where communication was poor.
Better results in primary care	"The 3 nurses we have are very good, and their success in weight reduction is much superior to that of the hospital, their success in lifestyle changes are definitely superior to that of the hospital, so we don't really [refer]" (GP112, RGC)
Limited hospital capacity	"I mean they're certainly going to be overwhelmed if we send everybody up to them so I don't tend to do that" (GP114, USC).

4.3.4 Formal vs. Informal Initiatives

The final dimension of care delivery which emerged during analysis was the distinction between GPs involved in formal initiatives and those providing structured care *'off their own bat'*. This dimension related to a subset of proactive GPs who had a special interest in diabetes or were presented with an opportunity to develop care in their practice.

> *"In this part of the city in 1998, 3 of our small inner city hospitals closed and moved out to [place] so a group of GPs, perhaps 15 practices in all, formed a sort of partnership with the then Health Board to share some services like a podiatrist, a dietician...Subsequently this group of GPs and the Health Board then decided to enter negotiations with [hospital] and we started with educational sessions for ourselves and reasonably frequent meetings with the hospital people… We educated ourselves, wrote a set of guideline which we have from time to time updated." (GP103, UGC)*

The existence of formal initiatives shaped some GPs understanding of the terms such as 'shared' care and 'structured care' which will be explored in the next section.

Emergence of themes:

This section presents GPs attitudes to and understanding of models of care based on actual experience (e.g. involvement in initiatives) and perceptions of how models of care operate. Discussions about the balance of care between settings and how care was provided gave an indication of GPs' understanding of common terminology namely 'shared', 'structured' and 'integrated' care. Integrated care was proposed by some participants as an ideal model.

4.3.5 GPs' Understanding of Models of Care Terminology

Confusion of multiple meanings and uses

Firstly, the multiple meanings and interchangeable use of the terms was highlighted by one participant who suggested understanding *"depends on your own interpretation…you'd have to define that term [shared care] but all these terms…they mean different things to different people" (GP113, USC).* There were several examples in the data of ambiguous interpretations. For example GP5 (UGC) stated that there was shared care available to patients however multidisciplinary services from secondary care would be welcomed, calling into question the understanding and nature of the shared care experienced.

4.3.5.1 *Experience and Understanding of Structured Care*

At the start of this results section a structured approach to care was defined in terms of organisational features in the practice (registers, recall, nurse coordination etc.) as distinct from an ad-hoc approach. However GPs' understanding of 'structured care' also related to general practice-based management. As mentioned previously GP103 referred to structured care as meaning *"virtually all their diabetes work is done in the practice"*. Structured care also encompassed continuity and consistency of contact with the hospital and definite boundaries between the settings (GP113, USC).

> *"There doesn't seem to be any structured care, they're seeing different doctors and stuff like that." (GP15 UCG)*

Advantages of adopting a structured approach to care

Those providing structured care in the practice highlighted a number of benefits which overlap with the advantages of the general practice setting which will be outlined later in Part 2 (Table 25). Advantages of structured care in general practice included conveniences and continuity for patients.

Table 25 Advantages of adopting a structured approach to diabetes care

Advantage	Quote
Convenience	"It was much easier for them to come in and speak here in the surgery where it wasn't 20 miles in and the issues with parking and queuing up in the diabetic clinic for maybe 2 hours because things are running behind" (N104)
Continuity & familiarity	"There was also continuity because I'm here all day everyday so everybody that comes in knows me and they know that if they can't get to a clinic but they have a question they can pick up the phone so there's a familiarity about it and their comfortable" (PN104)
Improvements in monitoring & outcomes	"…meticulous care does improve health and prevent things like cardiovascular problems later….our podiatrist is always saying every…every amputation is preventable. I mean I don't think we've had any amputations since we've started this, it may be a pure coincidence but…" (GP103)

Challenges: time and resources

The most commonly cited challenges to providing structured care for patients were time and resources. Local initiatives were *"a great idea but need to be supported and funded"*. *"Simple sort of communication things"* between the practice and the hospital were also difficult therefore the practice faced the challenge of trying to avoid duplication or omission when providing structured care in the practice (GP103, UCG). Even those who had not undertaken structured care or joined a particular initiative were aware of the demands. GP107, who had developed structured cardiovascular disease management, had learned the pressure such initiatives can put on the practice;

> *"It took up so much time that [the nurse] could do absolutely nothing else, which puts a lot of pressure on the rest of the practice then because she wasn't taking bloods which meant I had to, which means I couldn't see the sick patients…" (GP107, RSC)*

These challenges overlap with the barriers to managing diabetes care in everyday general practice.

4.3.5.2 *Experience & Understanding of "Shared Care" Initiatives*

GPs involved in formal shared care schemes referred to features such as educational sessions, meetings with hospital teams, developing a set of common guidelines or a protocol within the scheme, sharing services and sharing a diabetes nurse specialist (GP103 UGC, GP108 RGC) (See Appendix XIII). The benefits of shared care arrangement included easier access to secondary care, thus the initiative was a facilitator to providing care.

> *"Now, if it turns out that he (patient with high blood sugar) needs to see someone, we can fast track him and get him seen by consultant within a week, because of this shared care arrangement." (GP13 RCS)*

There were also benefits for the practice involved. Shared care was considered a *"useful resource for up-skilling GPs"* but it also saved GPs time having *"70 diabetics managed to a large extent by others"* (GP108, RGC).

Extent of sharing in shared care

These benefits call into question the extent of sharing involved in 'shared care'. The potential downsides to having others provide care was that the GP could find him/herself disconnected from patient management;

> *"I think it'd be nice if their registrars came out here once in a blue moon to visit us, see how things are. Another weakness of the existing system is, the nurses do it and we don't interact with them afterwards. There isn't time to sit down and talk about the people they've seen, that's partly to do with the way we have it organised here" (GP108, RGC).*

The lack of interaction suggested that the GP was outside the care process. This impression was strengthened by the use of the word "they" in the following quote; *"They shouldn't expect their diabetic teams [to be] coming into my practice for free." (GP108 RGC)*

'Shared Care': "2nd best system" or best of both worlds

There were divergent opinions and understandings of shared care among the participants. One GP had a negative perception of 'shared care' as reducing general practice to *"a 2nd best system"*. This single-handed GP imagined care being delegated to GPs in a system *"whereby the GP sees the patients for the bloods and whatever, the initial diagnosis and that but then the hospital would be saying do this and do that you'd be under the thumb, GPs like puppets. We need to keep some level of autonomy."* (GP102, USNC).

However for other participants 'sharing' care represented the best of both worlds for practitioners and patients. From this perspective a shared model of care was not a system of hospital delegation but rather routine diabetes management in the practice with *support* from the hospital setting. The features of sharing care according to participants are outlined in Table 26 as well as the perceived benefits.

Table 26 Features & Benefits of Sharing Care

BENEFITS	FEATURE
Best of both worlds	**Expert opinion with practice based routine management**
▪ "I'd love to see more patients going through shared care. I think it's very *reassuring* when you're on your own in general practice to see what they can do as well and to have the benefit of renal physicians and specialists in the hospital setting" (GP114, USC). ▪ Shared care is a "good combination [because] we get the best of his annual updates and yet with the help of the nurses we manage them pretty effectively here" (GP108, RGC)	
Shared Responsibility	**Between the hospital, GP and the patient**
▪ "I would much prefer to share care, like with antenatal. So when a patient drops dead or [has an] MI or whatever, it's not all on my head…We share responsibility" (GP115, RSNC) ▪ "They see what they need to do in the hospital and I stay informed of what the hospital is doing…Under this model, the care is shared with the patient too, so the locus of ownership is shared and the patient is responsible too" (GP4, UCG)	
Seamless care	**Rather than continuous referral & discharge**
▪ "I would love a more formal shared care arrangement…but not with this thing of the patient being discharged to you and then if you want them seen you're referring them again…If you're worried about something you should be able to get them seen, that they haven't been discharged in the 1st place. Then if everything was going smoothly and there were no problems, maybe those people who were still being seen in the hospital maybe once a year for type 1 diabetics or even every 2 years for a type 2." (GP111, UGC)	
Communication	**Compared to antenatal care, in particular the shared record of care**
▪ "…since it's working so well in that [antenatal care], why can't it work for diabetes in general practice? If there's a piece of paper, a chart that the patient carries, I see what on that chart I need to do, they see what they need to do in the hospital, and I stay informed of what the hospital is doing and what I should next do, what's necessary for the patient" (GP4, UCG)	

4.3.6 Ideal Model of Care: greater sharing, not either/or care

Greater sharing between settings was proposed by GPs as the ideal relationship with the hospital or perfect balance of care between settings. This was also referred to as increased integration between settings. As reflected in the quotes above (Table 22) the optimum model for diabetes care would combine the strengths of both settings, outlined as follows:

> *"2 points of access so people have got a day-to-day support network and then they've got somebody acute who's a specialised person looking into their care" (PN104, RGC)*

> *"The ideal would be that every diabetic would be under consultant care or would have a consultant look over them from time to time and then the GP would do the fine tuning in between times but the consultant would oversee the overall thrust of care" (GP106, UGC)*

The emergent theme was one of defined joint involvement between consultants and GPs rather than an either/or situation;

> *"If you only deliver care in acute services then people are left floundering for 6 or 9 months in between…but equally if you only see them in the community and they don't have a link of some description with the hospital when they run into a problem its sometimes very difficult to get somebody in quickly because they're not part of the system" (N104, RGC)*

There were *"reservations"* about managing diabetes in general practice alone based on the scale of the illness today "*the sheer complexity of diabetes and all the complications" (GP115, RSNC).*

4.3.6.1 *Attitudinal challenges to integrating care between settings*

GPs own perspective on the need to share care between settings and their experience of patients' attitudes suggested potential challenges to the ideal model of care.

- **Is sharing really necessary? – 2 anomalies**

Two GPs felt that sharing care was unnecessary but both for different reasons. On the one hand, GP112, from a rural group practice, felt that combining care with the hospital setting was *"a good idea"* but *"unnecessary if you're a well trained doctor"*. Conversely GP102, a single-handed GP from an urban practice, felt the hospital was the most obvious setting of diabetes care and that shared care was a threat to GP autonomy;

"They say about patients going into the hospital and all that but then what else would they be doing really" (GP102, USNC).

- **Patients' understanding of and attitudes to the model of care**

In addition to their own preferences, GPs were cognisant of patients' attitudes towards the different care settings which could act as a barrier to care arrangements, whether trying to share care between settings or trying to structure care in the practice. These positive and negative attitudes were probably related to a patients understanding of their care:

"…it can often be difficult for the patient to see the need to come back for a review if they don't understand its part of a structured care programme" (GP106, UGC)

"some people who would, frequent DNA's of the hospital, kind of felt a bit like 'hang on their on my back now you're on my back too'…And you were sort of saying 'well if you're not attending them and I do understand why, 10 minutes of your time every 6 months is just going to keep things in check'…" (Nurse 104, RGC)

However equally GPs spoke of the patients preference for the GP setting (GP103, p7.2) which could act as a barrier to sharing care as patients don't see the need to go to the hospital. Although in favour of sharing care with the benefit of specialist input from the hospital, GP114 pointed out;

"The only problem is the patients don't see it that way and don't understand why they need to go to clinics all the time….they want us to do everything in the primary care setting which is understandable" (GP114, USC).

This section outlines the factors identified and discussed by GPs' as barriers and/or facilitators to delivering high quality care to patients with diabetes. A number of factors helping and hindering care were raised initially by GPs during discussions about the routine management of diabetes. These themes were followed-up and expanded upon when participants were presented with the prompt containing a list of 8 topics identified during the GP survey as influential factors. This section is organised around the 8 potential barriers and/or facilitators as well as the additional factors raised by participants.

4.3.7 Barriers & Facilitators to Optimal Diabetes Care

Emergence of Themes

Barriers and facilitators occurred at multiple levels within the health system and had knock-on effects as illustrated in Figure 24. It is important to note that the absence of barriers did not equate to the presence of facilitators as highlighted by the following quote from a GP;

"…there were no barriers, there were just no incentives." (GP112, RGC)

Furthermore the absence of a particular factor was often a barrier for GPs and consequently its presence would be a facilitator. Thus barriers were also 'would be' facilitators. For example practices with a nurse talked about the enabling role of nurses in providing structured systematic diabetes care. However, the absence of a nurse was a barrier to providing care and a 'would-be' resource.

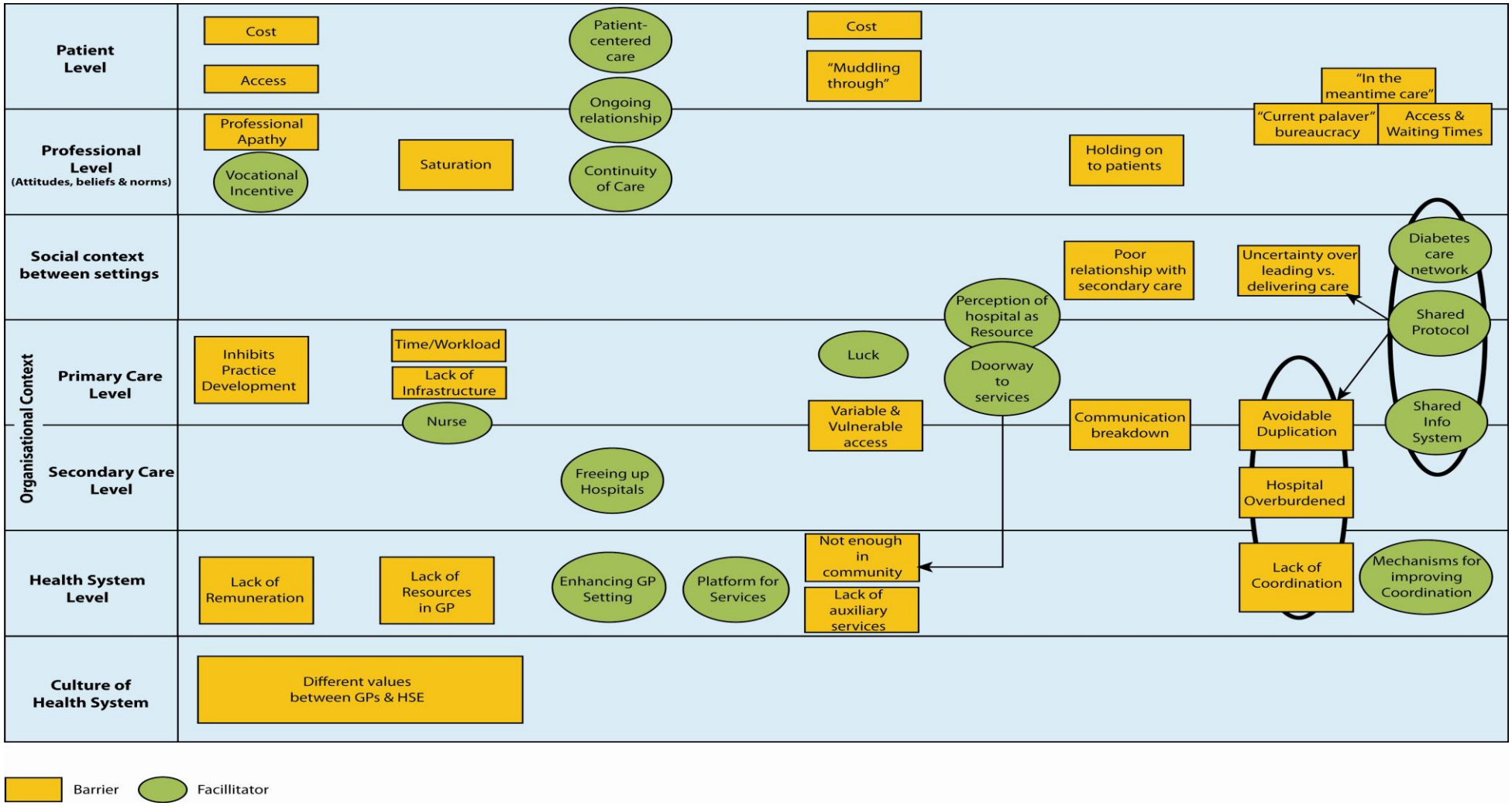


Figure 24 Barriers & Facilitators to Delivering Quality Diabetes Care

4.3.8 Lack of Financial Incentives & Remuneration

Emergence of themes

The lack of remuneration/financial incentives was one of the factors which received the most attention during interviews as a barrier to care delivery in both group and single practices, across urban and rural areas. At the time of interview remuneration for diabetes care was *"non-existent"* for most GPs in Ireland. Participant had varying opinions on the merits of pay-for-performance payment. Despite the method of recompense it was widely agreed that the lack of remuneration impeded diabetes care and led to barriers at other levels of the system including stunting practice development, imposing a cost barrier on patients and creating a sense of apathy among professionals. Some GPs made the distinction between financial incentives and those incentives which relate to the patient or professional satisfaction. Financial incentives and remuneration will be discussed in tandem with each other followed by an outline of the other incentives driving GPs.

4.3.8.1 *"Whether you like it or not general practice is a business"*

Remuneration was discussed synonymously with financial incentives. Occasionally, GPs were not comfortable citing remuneration or financial incentives as a factor influencing the development of care using phrases such as *"I hate to say it but…"* (GP114 USC, GP102 USNC, 105 UGC, GP106 UGC). GPs may feel they *should* be motivated by other factors. There were varying opinions as to how important remuneration or financial incentives were. A small number of GPs did not expect remuneration as they felt providing diabetes care was part of their remit as general practitioners [GP13 RCS, GP9 RCS, GP5].

> *"I think it's [diabetes] just part of treating people, so I don't think it's [incentives] a barrier" (GP109, RSC)*

Moving along the scale, GP1 felt that *"incentives would help*" but were not necessary, while GP9 suggested it was *"debatable"* whether remuneration would facilitate care provision. At the other end of the scale remuneration was marked as "*the 1st incentive that comes to anyone's mind in general practice"* (GP111, UGC) primarily because general practice is a business (GP114, USC, GP104, RGC) and the money has to come from somewhere.

> *"Unfortunately whether you like it or not general practice is a business and it has to pay bills" (GP114, USC)*

Hence, from a business perspective providing diabetes care in general practice was a financial disincentive. Even with a *"small payment"* provided as part of a formal initiative, the development of a systematic structured approach to care resulted in *"a financial loss"* for the practice (GP103, UGC). Another GP described taking on the primary management of diabetes as *"pro bono"* work (GP112, RGC), the Latin phrase which translates as "for the public good". This suggests that for those who have developed a systematic structured approach to care in their practice, the lack of remuneration was outweighed by other incentives which will be presented later.

4.3.8.2 *Financially incentivizing care – pros, cons and concerns*

There were concerns about financially incentivising diabetes care in general practice and differences of opinion about the most appropriate method of recompense. GPs were mostly familiar with performance-based remuneration and concentrated their opinions in this area. Participants drew on familiar schemes such as antenatal care (GP111) and Heart Watch (GP 113, 101) as possible models for remunerating diabetes care. These models are performance-based remuneration models. Another proposed option was skewing GMS payments to reflect the workload associated with diabetes (GP106), in particular for the annual review of patients (GP RSC). There were divergent opinions as to whether financially incentivizing care would have a positive or negative effect on diabetes management (Table 27). The main concern was that performance based remuneration would pervert or *"corrupt"* the provision of care (GP1 UCG, GP12 RCG).

> *"…the worry is that once you incentivize it that other things that you can't incentivize get lost or diminished in the process" (GP106, UGC)*

It could create a ripple effect throughout chronic disease management whereby all chronic illnesses would have to be incentivised.

Table 27 Advantages and Disadvantages of a Pay-for-Performance Model

ADVANTAGES
"Straight-forward" method of payment
"if you do it you get paid, if you don't do it you don't get paid…it's a set amount of care… and only when all 10 or 12 items are completed or a proportion [you get paid]" (GP111, UGC)
Worked for other types of care
"things like flu vaccines and payment for vaccinations, that's national…antenatal care…because there's quite a straight-forward way of claiming remuneration" (GP111, UGC) "if the diabetes patient was flagged in some way, particularly by payment and targets, for instance we get paid for accounting for 95% of our children that are vaccinated" (GP4, UCG).
Worked in other countries
"Similar to the framework quality thing in the UK…if you recorded blood pressure or the glomular filtration rate or whatever and you can show that you've done that in your diabetics in the past year that you should get financial incentive or reward" (GP106, UGC)
DISADVANTAGES
Ineffective for providers & patients
"I look at the way the UK's doing it and it isn't working…it's not good for doctors and the patients aren't any healthier so I don't think it's a good way of doing it." (GP107, RSC)
Risk of scamming the system
"…the real keen boys who are getting the sugars down…inappropriately low…using insulin to bring down the haemoglobin A1c more could, in theory, be killing them" (GP112, RGC) "…you'll get the sly boys who do well. And there'll be guys giving a very good service, and there'll be guys giving a middling service but the guys who give the middling service, in theory, could be getting paid more" (GP112, RGC)

4.3.8.3 *Lack of remuneration creating further barriers in the system*

According to participants the lack of remuneration created both physical and attitudinal barriers to care deliver. The ramifications of were conceptualized on 4 levels; patient, professional, organisational and system level (Figure 25). This illustrates how a barrier can create or exacerbate problems at other levels of the health system.

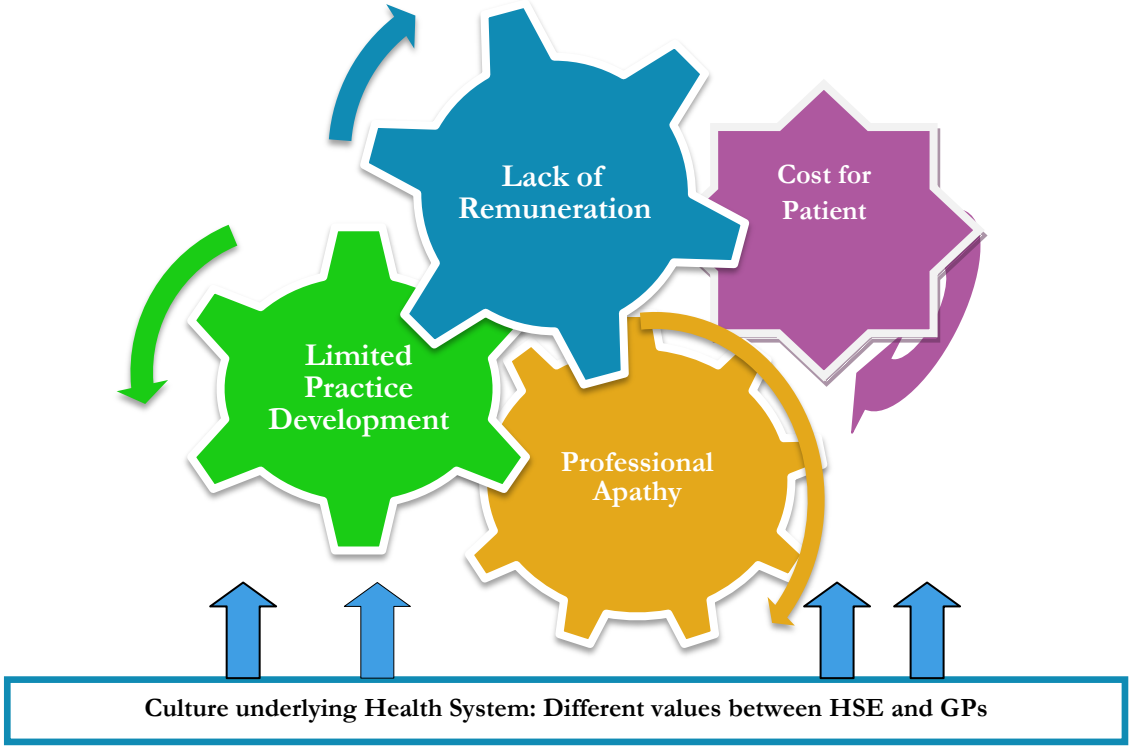


Figure 25 Impact of a lack of remuneration at different levels of the health system

- **Financial Barriers at the Patient Level**

Firstly there was a cost for some patients to receive regular diabetes care in the general practice setting. One single-handed GP felt he had no choice but to pass on the cost of care to patients.

> *"I mean if we're getting no recognition and no incentive and no remuneration or anything to do this work, I'd be mad in the head to… keep doing it unless I charge the patient and I don't like doing that but I don't have any choice" (GP101, RSC)*

There was a sense of relying on patients' understanding that this work was valuable and that *"somebody has to pay",* the doctor couldn't provide it *"just because I want to"* (GP101, RSC). The cost could deter patients from attending general practice for their diabetes care, creating an access barrier to this setting. Providing a medical card to all patients with diabetes, which would entitle them to free GP care, was suggested as a way to remove this financial disincentive (GP3, RSC).

- **Impeding Practice Development at an organisational level**

The lack of remuneration also had a limiting effect on practice development (GP114, USC). Those who were providing care on an ad-hoc basis felt there was no incentive *"to do more"* (GP115, RSNC). Another single-handed rural GP highlighted the *"disincentives in the system"* as "*a barrier that needs to be repaired"*, relating to the fact that 90% of his patients with diabetes were General Medical Scheme patients for whom he was paid a capitation grant each year regardless of the intensity or quality of care. This had financial implications for his practice and the manner in which care was delivered. There were limited incentives at a practice level, both in terms of finance and resources, to improve the way care was delivered to patients:

> *"Incentives are a barrier. At the moment care is opportunistic but if there were incentives for me to hold a clinic that would help. We could keep flow charts and I'd get remuneration because there is none and this takes a lot of time, manpower, secretarial time, nurse time, and at the moment there's no incentive to do that." (GP5, UCG)*

- **Apathy at a Professional level**

The lack of remuneration created *"bad feeling"* among GPs at a professional level (GP110, RGC) with GPs perceiving themselves as being taken advantage of by the health system (GP102 USNC).

> *"There's no real recognition for it, which is important, because I think that if things do come down on us, things like the flu vaccine, which is a minor point, we'll sort of say 'fine', but it'll show apathy and then it'll be 'okay, we'll see our diabetics once a year now', because we have to end up making money elsewhere." (GP112, RGC)*

As the last quote suggests the lack of remuneration for diabetes could have a negative influence on GPs willingness to take on other patient groups or care procedures. It also suggests that recompense reflected recognition in the health system. GPs felt the lack of remuneration was a sign of the lack of value placed on chronic disease management and the work carried out in general practice. The lack of recognition was particularly disheartening for GPs providing the majority of routine diabetes management in their practices in a structured way, in some cases off their *"own bat"* (GP101 RSC, GP112 RGC, GP110 RGC). There was no *"encouragement"* to provide more and better services.

"In essence, if I may say so, this a reasonable service we're offering here, we're not getting paid for it" (GP110, RGC)

"Nobody asked us to do it and now that we are nobody really thanks us for it" (GP112, RGC).

- **Cultural difference in health system: different values among GPs & the HSE**

As Figure 24 illustrated the absence of remuneration was seen to reflect the different values among GPs and HSE which created the barriers above the surface.

"It's typical of the HSE that things that we value highly we don't get paid for so it's really your own interest" (GP101, RSC)

According to participants the difference in values were also reflected in the current GP contract which does not support comprehensive chronic disease management and preventative care.

"I would love to see the care of all chronic illnesses recognised as a core part of our health system and general practice is really the only place that it can be done efficiently or economically but our present contract doesn't reflect that…Whatever the current recession, we need, and I believe the country needs a new contract which recognises and rewards good care of chronic illnesses" (GP103, UGC)

The difference in values was conceptualised as a cultural dimension because it speaks to the tradition within the Irish health system to focus on acute reactive medicine as opposed to preventative medicine or chronic disease management. While policy documents refer to chronic disease management in the community, there was a lack of tangible support for these proposals. For example the GP contract was marked as an ongoing *"bone of contention"* in relation to the proposed implementation of an integrated model of care which would see General Practice being responsible for providing the majority of diabetes care (GP13, RCS). The HSE "*needs to back up their policy of shifting from secondary care to primary care"* (GP12) relating to the earlier theme of general practice being at a disadvantage in terms of resources and access to services.

4.3.9 Motivations beyond money: "vocational" incentive

Participants made the distinction between financial *"disincentives"* of providing diabetes care and other incentives which were *"vocational"* or personal. Table 28 outlines the aspects of these incentives including the motivations such as a sense of professional duty and personal experience. The GPs quoted in the table below had developed an organised structured approach to diabetes management both formally as part of a local initiative and informally. Hence, in a subgroup of GPs the vocational and personal incentives appeared to be overriding the financial disincentives. Similarly GP 13 (RCS) felt *"personal gain"* was the entire incentive for providing diabetes care.

> *"We feel that we've improved the service that they've [patients] been given, so that was the incentive, but that's the only incentive" (GP112)*

Perhaps these were the types of incentive that participants felt they *should be* motivated by as opposed to monetary factors. As GP112 surmised; *"we are doctors after all"*.

Table 28 Aspects of personal and vocational incentives

Personal Incentives	
Personal satisfaction	"I get a joy out of thinking we do a great job…there's the incentive for me, that's what counts" (GP108, RGC)
Personal experience	My own father was in hospital 7 or 8 years ago. He was on the ward and there were 7 other guys, it was a vascular ward, and they were all diabetics. Some of them were in for 8, 12 weeks, or 16 weeks, incredible. At the same time I read somewhere that if you can get, is it, a 1% drop in the HbA1C, reduces the complications by 25%.So that kind of struck a chord with me..." (GP110, RGC)
Vocational Incentives	
Job satisfaction	"If we can get the older diabetics some better control, we'd be doing some good...so from a personal, job satisfaction professional point of view that would be a huge incentive for me" (GP110, RGC)
Seeing improvement	"I love to see all these nice normal HbA1cs coming back" (GP110, RGC)
Patient Feedback	"We're starting people on insulin who really need it and they feel so much better. [Patients say] 'my energy's back up'...so it's very rewarding, you get a lot of good feedback from patients" (GP103, UGC) "I get encouragement from the patients because I think they have seen that [we emphasize prevention], they buy into that and hopefully care is good" (GP101, RSC)
Personal Value on prevention	"Depending what your attitude is and your enthusiasm [for] preventative stuff, which to me is just as important if not more important and it's enjoyable" (GP101, RSC)
Professional Duty	"...the international evidence is such that we felt duty bound to offer as tight control as we can for patients" (GP103, UGC)

Other Incentives

GPs referred to other incentives for providing care including being motivated by the potential in general practice to provide a lot of diabetes care (GP13); practical support for practices such as making a dietician available to the practice (GP111, UGC, GP107, RSC), financial support for education and training (GP15, RCS) and a *"clinical incentive"* to encourage GPs to manage patients in the practice;

> *"If you admit and refer very few [to the hospital], hence you're keeping your care out in the practice, once again there is no incentive. That's where a reward system should come into the thing. If you use your resources well, when you ask for use of other resources [referral to hospital], you should be given preferential use of them, because you are using them appropriately" (GP112, RGC)*

However there were doubts expressed about rewarding behaviour such as referral or the performance of certain tasks.

4.3.9.1 *"Pockets of Interest"*

As previously highlighted the theme of vocational incentives was notable among GPs providing structured routine care in their practices or involved in particular initiatives (GP101, 103, 112, 108, 110). However GPs acknowledged that special interest was limited to *"pockets"* and *"you can't expect all GPs to be desperately keen on it"* (diabetes) (GP103, UGC). The *"real bunch of keen ones"* were well known to one another.

> *"Some GPs are really into diabetes…If you talk to Dr Y he is super organised and really interested…I see a lot of psychiatric patients and foreign nationals…Diabetes is definitely Dr Y's thing" (GP102, USNC).*

It is arguable that beyond this group, remuneration and financial incentives would be the main facilitator to providing high quality care in the practice and therefore the biggest barrier to engaging all GPs at present. There aren't enough GPs who are interested in diabetes and *"…there are no incentives to motivate them" (GP3, RCS).*

4.3.10 Barriers & Facilitators to Integration

Emergence of themes

Originally this theme was defined as 'relationship with hospital' however it was subsequently sub-divided to reflect the multidimensional nature of the relationship between general practice and the hospital setting (Appendix XIII). Each dimension was considered a separate theme:

- The actual relationship with hospital (model of care) vs. desired: how care is organised between settings as outlined in Part 1.
- The nature of the relationship between settings; positive or negative relationship with consultants and the hospital-based team acting as a barrier or enabler to care (social context within system relating to collaboration and teamwork)
- Barriers to interfacing and integrating; issues of coordination and communication (organisational context)

The latter two components will be dealt with in this section as barriers or facilitators to delivering diabetes care.

4.3.10.1 *Nature of the relationship between health care providers*

The nature of the relationship between the GP and the hospital consultant and/or team was gleaned from discussions about interactions with the hospital and referring patients. In some instances a positive relationship was facilitating the delivery of care. A number of GPs referred directly to a good relationship with the hospital based team [GP5, 6,7, 13, 14] including those GPs providing structured care in their practice [GP101 RSC, GP13, 14, 6]. The hospital was perceived as a resource for GPs providing care as well as a *"doorway to services"*. However in other cases the relationship between the health care providers, and more abstractly the settings, was a barrier to integration.

Hospital as a "resource" and a doorway to services (F)

A positive relationship with the hospital team enabled the provision of care in the community as specialist services were a "resource" for GPs. GP12 (RCG) stated that advice from specialist hospital consultants *'would be'* a major facilitator in delivering care in general practice. Having the support of hospital expertise was particularly reassuring for single handed GPs (GP115, GP11 SNC, GP3 RCS, GP114 USC).

"It is very reassuring when you're on your own in general practice to see what they can do as well and to have the benefit of renal physicians and specialists" (GP114)

A rural single-handed GP stressed the hospital was *"an essential support"* to GP management as diabetes care could not be provided without hospital involvement (GP115, RSNC). This GP tried to maximise the benefit of the available expertise by doing the blood work in advance of patients' visits so that if she had a concern the specialist could address it at the upcoming visit. For GPs involved in shared care programmes (GP13, 6), the supportive relationship with the hospital enabled GPs to manage diabetes on a large scale in the community. The advantages to the relationship between settings included fast-tracking patients to specialist care and facilitating GP management of Type 1 insulin adjustment.

The other dimension to the hospital as a resource was as a doorway to auxiliary services. Some practices were *"still"* reliant on hospital for access to services such as retinopathy screening and foot care which was *"the main advantage of the hospital visit"* from one practice nurse's point of view.

"Poor Relationship" between professionals

Some GPs did not have a constructive relationship with the hospital based team which was a barrier to delivering care. For example GP3 found specialists in the hospital difficult to pin down and felt it would be hard to take part in formal shared care, especially *"with the power struggle between primary care and secondary services"*. Two factors emerged which appeared to shape participants relationship with the hospital setting; losing patients to secondary care and poor communication.

- ***Holding on to patients***

Part of the power struggle was the conscious effort to retain patients as GPs were wary of losing patients to 'the system'. A minority of GPs conveyed a sense of wariness about the sharing diabetes care having experienced specialists holding on to patients. As discussed previously, one of reasons why some GPs resisted referring patients from primary care into the hospital was the risk of losing the patient to secondary care (Part 1). On the other side of the boundary GP13 (RCS) also experienced the hospital system refusing to 'let go' of patients from secondary care to primary care;

"Once they go into the hospital system, they stay in the hospital system, stay there more often actually. And so I need to be extra vigilant with them as they get more concentrated attention in our GP setting" (GP10, USC)

Therefore some GPs' attitudes and wariness towards secondary care providers was influencing the care pathway for patients.

- ***Poor Communication***

The sense of mistrust and wariness among some GPs was also fuelled by poor communication between the settings. In some instances poor communication was synonymous with a poor relationship (GP15, RCS).

"It's [care] is disjointed, hospitals letters don't come out at all and there are no recordings of bloods or exams in general". Because of this *"there's definitely tension between GPs and hospitals, with us and the diabetes clinic." (GP10, USC)*

The following quote also illustrates the pressure and tension within the system creeping into communication:

"The letters that have come from the hospital recently would…sound more and more irritable to me because they seem to be under a lot of pressure" (GP106, UCG).

What constitutes good communication; open, reciprocal and continuous

During the interviews carried out by this researcher, participants occasionally raised the issue of communication of their own accord; usually to illustrate a broader point (e.g. GP106). When prompted the common response of contact via referral letter suggests referral letters equate to communication.

"It's good I mean they certainly send us a lot of detail…But I think patients are kind of divided into, if the patients going to the hospital regularly they're not inclined to come here." (GP111, UGC)

The *"standard letter"* included information on parameters, a brief narrative on patients progress and *"what the future plan is"* (GP113, USC). However, this GP typically referred patients to the hospital for routine management so there was little sense of engagement with, or indeed consultation on, the plan. It was more an FYI than two-way communication. Two-way communication was referred to by those who had phone contact with the hospital consultant for particular patients when necessary (GP101

RSC/ GP107 RSC). These GPs appeared to have a close working relationship with the consultant referring to them by name rather than "they".

Co-operation and a more open relationship whereby specialists were approachable would improve the relationship between settings (GP12, RGC). GP113 (USC) called for continuous communication between settings to improve care and facilitate integration; *"not just a single meeting, a dialogue"*. Indeed communication systems were one of the suggested facilitators to integrate care between settings which will now be outlined.

4.3.11 Lack of Coordination at the Primary-Secondary Interface

Emergence of themes

While the nature of the relationship was positive for a number of GPs, barriers arouse in relation to the coordination and integration between settings. As one GP summarised the relationship was *"accessible but not structured"* (GP115, RSNC). There were a number of symptoms of the lack of coordination and organisation within the system including waiting times, overburdened hospitals and *"in the meantime"* care. These consequences were barriers in and of themselves.

4.3.11.1 *Lack of coordination within system*

Lack of coordination between settings was identified by GPs as a barrier when discussing their relationship with the hospital setting. The historical remnants of the separation of acute and community services were seen as the root of current coordination difficulties;

> *"…it isn't really to do with communication, it has to do with the whole system really, and it hasn't ever really been properly coordinated or funded. I think that any mess that's in the health system really historically goes back 30, 40 years in my experience. There has never been a proper management of medical, nursing community coordinated care…ever in this country" (GP109, RSC)*

The lack of coordination within the system had a knock on effect on the integration between primary and secondary care settings reflected in the confusion and lack of clarity around sharing care and roles of responsibility. A number of GPs felt there was no sharing between settings and instead care was disjointed (GP10 UCS) while other GPs were unclear about what was expected of them in terms of diabetes management;

"…I'm still not sure where the hospital ends, it's not clearly defined. We need to…there needs to be a clear definition as to what the hospital is going to do, what we're expected to do" (GP113, USC)

The recall process as an example of the lack of coordination

The process of recalling patients was a stark reflection of the lack of coordination between settings. For example, GP106 (UGC) indicated that patients were recalled *"by the system" "as the hospital deems appropriate"* with problems referred to the hospital in the meantime. The GP concluded *"that's as much of a protocol as there is"*. Thus the process appeared one-sided and was not collaborative or even consultative. This picture suggests that patients were managed in both settings but rather independently of each other. Similarly, GP111 (RGC) felt care was not really shared as the hospital brought back the patient until such time as they perceived no problem. The patient *might* return to the GP but there was no sharing of information in the meantime. GP12 reiterated this point stating that cooperation with secondary care services was lacking and hinders comprehensive care. Even within shared care initiatives coordination between settings could be difficult;

"The difficulty has been in coordinating the half yearly reviews and the annual reviews with the nurses here because they go to annual review in the clinic and 6 monthly here I think" (GP108, RGC)

4.3.11.2 *Symptoms of the Lack of Coordination*

The following sub-themes are categorised as delivery-level manifestations of the lack of the coordination in the system. Each symptom of poor coordination was a barrier in itself for patients and providers trying to navigate the system. This reflects the entwined nature of barriers and facilitators throughout the health system illustrated in Figure 26.

- **Hospitals "Overburdened"**

One of the main symptoms of poor coordination was the overburdened hospital clinics which could not meet the demands of growing patient numbers. This led to poor access to specialist expertise for both GPs and patients. GPs were acting as gatekeepers when referring patients with diabetes. For example GP114 referred to 'keeping' the hospital for "*complicated cases"* suggesting the hospital was used as a finite and valuable resource.

"I mean they're certainly going to be overwhelmed if we send everybody up to them so I don't tend to do that." (GP114, USC)

GPs acknowledged the burden on the hospital setting and the insufficient manpower including endocrinologists in Ireland to meet the demand. Highlighting the barriers was not about a proportioning blame.

"Consultants just don't have time, they can't see everybody. It's just not possible. They're doing their best…I've no complaints about their service at all" (GP113, USC)

- **Leading vs. Delivering care**

The lack of coordination was reflected in and further exacerbated by the delegation of care within the hospital. A distinction emerged from the GP perspective, between care which was *"consultant-led rather than consultant delivered"* (GP10) with nurses and intern staff delivering most of the care. GP106 also made the distinction between consultant-led and consultant-delivered care;

"The care that's delivered should be consultant-delivered but not just consultant-led…There is no point in sending somebody to the clinic and having a relatively inexperienced SHO just bringing them back in 3 months and not answering the particular query you have" (GP106, UGC)

This theme resonates with the view of the consultant as a resource whose expertise were valued by the GP. The situation may also be consequence of the insufficient consultant endocrinologists in Ireland. The issue of who was delivering care in the hospital setting was also noted by patients and impacted on the continuity of care.

"I mean most of the patients wouldn't see the consultant probably…they'd see the junior doctor. Some of them might have been attending the clinic for 2 or 3 years and never seen a consultant. That's what they tell me…I haven't studied that to be verifying that" (GP113, USC)

The dichotomy between leading and delivering care further suggests a lack of clarity and coordination around the overall responsibility for patients' care (Appendix XII).

- **Barriers to Access: Waiting Times**

As a result of the overburdened hospitals and the inadequate staffing, GPs often experienced difficulty accessing secondary care services both in urban and rural areas [GP3 RSC, GP4 UGC, GP11 (USNC)]. This lack of access hindered care in general practice just as it enabled care in areas where the hospital was seen as resource. Hence better access to secondary care was identified by a number of GPs as a potential 'would be' facilitator [GP7 UCG, GP3 RCS, GP1 UCG, GP4 UCG].

> *"There's a massive diabetic clinic in the hospital but care is not better. It's difficult to make appointments, get access to services, especially when it's urgent" (GP10, UCS)*

The issue of waiting times was raised by a number of GPs however there was significant variation between lengths of waiting time experienced. This experience was not unique among urban or rural areas or among group or single-handed practices. One urban-based GP had noticed that waiting times have lengthened substantially;

> *"I notice that they're pushing them [reviews] out further and further, the reviews would have been 6 months some time ago…its gone to 2 years" (GP113, USC)*

In one rural area in the South, a GP referred to a *"short wait"* of up to 6 weeks (GP107, RCS) compared to another rural area in the South West (GP110 RGC) where patients could be waiting a *"couple of months"* to be seen in the hospital. One factor which appeared to determine the length of the wait was the severity of the patient. If a patient had a serious problem they would usually be seen quite quickly but patients with less serious issues could be *"waiting for ages"* (GP113, USC).

Uniquely, a GP involved in a formal shared care initiative, felt a waiting time of 6-9 months was *"no harm"* as patients were taken care of in the local diabetes programme (GP108, RCG) and were prepared and educated when it came to their hospital appointment. However in areas where no such programme exists, waiting lists could be harmful.

- **"In the meantime" care**

The lack of coordination and integration between settings was reflected in the theme *"in the meantime care"* (GP113, p2.1). The phrase "in the meantime" was used to define the

unknown period of GP management between hospital reviews and emerged on a number of occasions in relation to the tenuous link between hospital and GP care. For example GP105 (UGC) described his practice as providing care *"in the meantime"* of clinic visits; initiating treatment, giving dietary advice and monitoring while waiting. Given the lack of consultation about responsibilities and boundaries between settings, GP113 (USC) 'supposed' *"that we're to pick them up in the meantime",* that is between reviews, but *"there's been no communication, there's been no meetings, there's been no working group… it's just sort of left like that".*

There were varying opinions as to whether the uncertainty of *"in the meantime"* care was problematic or detrimental. As mentioned previously, GP108 (RGC; involved in a shared care scheme) felt the waiting time was *"no harm"* because *"in the meantime"* patients were being cared for by the local programme. Patients were worked up, educated, introduced to a glucometer, on medication with good metabolic control. Thus a "*prepared patient"* arrived for his/her hospital appointment.

However this level of support and early structured management was the exception rather than the rule. Other patients were *"falling through the net"* and not attending either setting for management leading to the development of irreversible complications (GP110, RGC). The quote below from a Practice Nurse illustrates the uncertainty for providers and patients created by *"in the meantime"* care and the lack of coordination within the system;

> *"If you could say to them [patients] 'look this is your diagnosis, this is what we're going to discuss and over the next 2 weeks you're going to meet A, B, C and then we have a base line of everything covered from day 1 and you know exactly where you are, you're on a springboard ready to jump. As opposed to… saying 'stand on the spring board for about 2 months and then we'll jump you into that and then 2 months later you* ***might*** *get called for your eyes and 2 months later you* ***might*** *get called for your feet', in which time they may have had a problem with their feet and they're not quite sure how they should have dealt with it…" (Nurse 104, RGC)*

While this practice was providing structured nurse-led diabetes management it was on the initiative of the GP rather than a formal scheme, and perhaps such initiatives continue to struggle with the lack of structure in the system as a whole.

- **Boundaries & Bureaucracy: The current "palaver"**

The lack of clear boundaries and bureaucracy between settings was described by one GP as the current *"palaver"* which epitomised the consequences of uncoordinated care. While it was related to the multiple components of diabetes management and the number of disciplines involved it also surrounded simple tasks such as checking cholesterol;

> *"…at the moment it's a big palaver if you check cholesterol, get it to the patient to bring into the hospital and it gets lost in the process lots of times and then it seems incredibly wasteful of effort and time and resources." (GP106, UGC)*

Patients too got *"caught up in administration and bureaucracy of the hospital system"* (GP10, UCS). GP108 highlighted the impact of the "palaver" on patients;

> *" they spend the last precious days of their lives going around from out-patients to out-patients, confused as to who to believe, and in the ideal world, the GP service would be coordinating and making sure it doesn't happen too much,…then they get lost in the follow-up…it gets so complicated" (GP108, RGC)*

This was the only direct reference to the GPs taking responsibility for coordinating care between settings *"in the ideal world"*. This theme illustrates how the lack of coordination between settings led to bureaucracy around service delivery and ultimately confusion and wasted time for patients.

- **Avoidable Duplication**

Closely related to the palaver of navigating the health system was the potential for avoidable duplication. GPs providing structured care in the practice were very much attuned to the potential duplication of care and were actively trying to avoid it. GP112 (RGC) felt the hospital was a duplication of care almost, given the standard and structure of care being provided in the practice. Thus while the consultant and nurse was available to them, the GP felt they didn't really need it in most cases. In contrast one Practice Nurse felt powerless against the duplication as the practice needed the hospital to access auxiliary services;

> *"Unfortunately they still have to be seen in the hospital annually because for things like retinopathy screening and podiatry care, there isn't one single unit where you*

could refer them…they have to go through the clinic, there's a bit of duplication that goes on there that could be avoided" (Nurse 104, RGC)

The risk of duplication was linked to communication difficulties as the infrastructure was not in place to facilitate shared communication in an accurate and timely fashion. In this instance the responsibility for avoiding duplication was assumed by the GP and problem was owned by the practice however this may not always be the case.

"one of ***our*** *problems is to make sure that they don't have 2 annual eye tests in different places or…have all their bloods done a fortnight apart…Those simple sort of communication things but they are still difficult" (GP103, UGC)*

4.3.11.3 *Mechanisms for improving coordination and integration*

As outlined in section 1, sharing or integrating care was perceived as the ideal model to facilitate comprehensive management of diabetes. GPs proposed a number of mechanisms to improve integration which would enable communication and coordination between the settings, namely a shared protocol and shared information systems. A shared protocol would address avoidable duplication and clarify the roles and responsibilities of each setting. A shared information system would minimize duplication the "palaver" in the system.

- **Developing a shared protocol**

GPs felt there was *"room for"* a protocol in diabetes care (GP106, UGC). There were a number of proposed dimensions to such a protocol and GPs drew on their experiences of the national protocol for antenatal care to illustrate their ideas (GP101 RSC, GP106 UGC, GP109, RSC);

"…the kind of protocol you have with maternity care where there would be a common chart held by all diabetics and that the patient would carry it from the hospital to the GP so it's clear when cholesterol was last checked…" (GP106, UGC)

The protocol would provide clarity around the remit of GPs and the hospital-based team, answering the call for more formal boundaries of responsibility called for some GPs;

"…it would be nice if it was more formal, some kind of protocol drawn up as to who we should send and who we shouldn't send" (GP110, RGC)

"where an integrated guidelines are drawn up where everybody knows what is going on…what's happening, whose responsibility is what and…then you would know the best use…the resources are best used" (GP113, USC)

Remuneration and databases could be integrated as part of a national protocol or *"contract"* (GP101, RSC) creating a standard system for funding and providing diabetes care in Ireland.

- **Shared information systems**

Shared information systems were also suggested as facilitator of the coordination between settings (GP108, RGC) and would *"make a difference"* to care delivery (GP103, UGC). As GP106 suggests, such a system would put the patient in the centre of care;

"…They [all health care providers involved] could feed into that…It would be kind of patient-focused rather than having its primary focus in hospital or a particular place" (GP106, UGC)

An internet based system whereby you could view *"vacancies"* online and make an appointment would be a vast improvement on the current letter-based referral system (GP105, UGC). And there was a sense that this change would be possible given the technology available and learning from other countries.

"The way forward in my view would be to take these systems (hospital and GP systems) but get them integrated into one [software program]…and I heard of an experience where in Denmark, they had several systems and all of the IT developers of the different computer systems were hoodwinked into taking a jolly…somebody turned the key in the lock and left them there, on the understanding that they weren't getting out until the individual systems could talk to each other. In Ireland we only have two systems. Somebody needs to turn the key on those two" (GP108)

This suggestion came from a GP who gave diabetes nurse specialists from the hospital access to his practice computer system to update notes and make recommendations; such is the current requirement for updating and sharing information between practitioners.

- **Building a diabetes network to facilitate integration**

Continuous dialogue when integrating settings was previously highlighted as characteristic of good communication required in the system (GP113, USC). Part of this

dialogue could be an annual meeting of all health professionals involved in diabetes care for patients in an area which '*would be'* beneficial, especially for a rural community. This in turn would *"improve awareness which will improve care"* (GP9).

4.3.12 The General Practice setting as a facilitator within the system

The General Practice setting was proposed as a facilitator of care delivery, having a positive effect on the health system as well as the patient. The benefits of this setting put forward by participants reflected the sense of the untapped potential in general practice (Table 29).

> *"I certainly would…underline the value of primary care physicians as a resource in terms of managing the national diabetic problem" (GP114, p13.1)*

Table 29 Advantages of the General Practice Setting

Advantage	Quote
Freeing up the hospital	"A lot of work regarding review and monitoring can be provided in the general practice setting which does not need to be done in hospitals and that's the advantage of GP I think…" *(GP5, UCG)* "People from this area would have to travel to [regional town]…The waiting list for out-patients is already huge. There was a good while there, there was no diabetes specialist, it was only sort of dabbled in by the generalists." (GP101, RSC)
Continuity of contact	"Its local, its small, it's not intimidating, there's no stigma associated like going to a special clinic and they see the same nurses and doctors each time" (GP108, RGC) "They see the same doctors all the time; more importantly see the same nurses all the time" (GP112, RGC) The "biggest enabler for change in general practice is that there is continuity of practice and care" (GP16, UCS)
"Ongoing relationship"	"patients tend to be friends more than anything else" (GP4, UCG)
Patient-centred setting	"they (hospital) only provide a service; it's not patient-friendly at all" (GP10, UCS)
Patient preference	"It's definitely the wish of patients for local services nearby" (GP12, RCG)
"A platform for primary care workers"	"I have the premises, the computer system, I have the insurance, light, I even have the patients from which young doctors and diabetic nurses and dieticians and psychologists can work…and work as close to the patients home as possible" (GP108, RGC)

4.3.13 The HSE: A Help or a Hindrance

There was divided opinion on the role of the HSE in delivering care. Previous themes around the lack of coordination in the system suggested an over-bureaucratised system. The opinions of GPs towards the HSE centred on the concept of efficiency within the organisation;

"There's a big improvement in efficiency in organisation since the establishment of the HSE…There is a choice of three hospitals for patients and then we're also linked into Health One". (GP13, RSC)

This theme of the HSE as a positive change and a facilitator of care delivery emerged during one interview (MOM) and was not evident in the data collected from other GPs or by the other researcher (SMH) thus it is an important anomaly illustrating the different experiences of the health system across professionals, in particular locales or for particular conditions. This positive experience was in contrast to the view expressed by another rural GP where the new structures of the HSE had a negative impact as it now took "*5 meetings to make a decision*" (GP112, RGC). Furthermore the changes in the structure of the health system and layers of bureaucracy alluded to by GP112 were stifling change. This GP had witnessed a shift from a once *"receptive"* and flexible system to layers of bureaucracy;

"You can see it now, in the quality of community care, very poor. It used to be if we were running a diabetic audit, we'd ring up the North Western Health Board, you'd speak to the person, not particularly medically involved but a good manager, and they'd say 'that's a good idea, send us up a letter and we'll push it to the whole [area]'…they were good, very receptive…but it's gone to hell now" (GP112, RGC)

Thus the HSE as a system could be a barrier to initiative and as a consequence a barrier to change. While both comments centre on efficiency, the first GP is referring to delivery while the second GP is referring to making changes in the system.

4.3.14 Auxiliary Services: "Not enough of them and too hard to access"

Emergence of Themes

The themes in relation to support services typically emerged during discussions about the provision of care. Access to services and the availability of community services were a barrier or a 'would be' facilitator to the provision of care. Some GPs were satisfied with an individual service in their area such as the dietician, eye specialist, or foot specialist. Services fell along a scale from good to bad or bad to worst in some cases reflecting the variability of availability. Thus, few GPs had access to a complete package of care for their patients with diabetes. Participants referred to being *"lucky"* to have access to services suggesting the availability of services was a bonus rather than the norm.

"Not enough of them and too hard to access" was how one GP summed up the situation in relation to support services for diabetes patients (GP108, p8.4). This statement encapsulates the 2 key barriers facing GPs.

A. Lack of services in the community (not available at all or not enough)
B. Problems accessing the services which are available

4.3.14.1 *Lack of services in the community: relying on hospital*

Support services were described as *"abysmal"* (GP114, USC) and *"nonexistent" (PN104, RGC)* in some areas. The lack of services in the community left GPs at a disadvantage to the hospital setting (GP113, USC) reiterating the theme of GPs being capable of providing care with the proper resources. Although GP102 was relying on the hospital for *"finer details like eyes and feet",* and was satisfied with this arrangement, there was a sense that the hospital could provide what he could not therefore it was the most logical setting for managing diabetes.

A number of other GPs were also relying on hospitals for access to support services and for some this access was the main advantage of the review visit in the hospital (PN104, RGC/ GP115, RSNC). This dependence was seen as one of the main barriers to community-based diabetes care;

> *"I think that's the barrier to the services as a community-based thing running properly, because it means you have to access the acute services to get somebody in" (PN 104)*

As a result of this dependency on hospital services, the lack of coordination and its manifestations in the health system were also a barrier to accessing support services. For example when discussing access to dietetic services GP109 (RSC) referred to the hospital as a *"fortress"* and used the example to illustrate the lack of *"inter-connectedness between services"*. The reliance on the hospital also led to waiting lists for services hindering early intervention and management (GP106, UGC/ PN104, RGC GP115, RSNC).

> *"I had somebody recently whose…who had very poor eyesight due to diabetes and we couldn't get a community podiatrist to see her…at all. I mean it was about 2 years or something they told me the list was, that she wasn't a priority" (GP106)*

Outreach services facilitating care provision in rural areas

The lack of community services was a particular challenge for the elderly, as highlighted by GPs from rural areas (GP15 RCS, GP9 RCS, GP109 RCS). This patient group, who cannot travel far, would benefit from outreach services which did not exist in their areas. For example one rural GP praised the provision of a dietetic outreach service which benefited patients in terms of time and convenience (GP110, RGC). The service was established by the dieticians themselves demonstrating the initiative among different providers with the system of diabetes care.

4.3.14.2 *"Patchy" Access: variability & vulnerability*

In addition to the lack of community services in some areas, where services were in place their availability was often limited, in both urban and rural areas (GP104, RGC/ GP105, UGC/ GP114, USC/ GP115, RSNC/GP15 RCS, GP3 RSC, GP9 RSC, GP7 UGC, GP5 UGC, GP6 USC]**.** Services available to general practitioners and their patients ranged from good to bad. *"Patchy"* was a term commonly used to describe the availability of services in the community. This adjective reflects both the variability and the vulnerability which characterised services in the Irish Health System at the time.

The variability of services fell along a scale from good to bad to worst. Some GPs were satisfied with a specific service such as the dietician or foot specialist in a given area. In particular those with access to a retinopathy screening programme were very positive about the level and organisation of the service (GP111, UGC/ GP112, RGC, GP8 RCG, GP11 USNC]. Few GPs had a total package of services in the area therefore the availability was conceptualised as being along a scale from good to bad to worse reflected in the following quote;

> *"The waiting lists are way too long. Now dietician isn't the worst. I mean I think foot care is probably the worst" (GP106, UGC)*

A rural based GP also referred to a scale as eyes were described as *"harder"* in terms of access compared to services for diet and feet which were both conveniently located in the area (GP107, RSC).

Another feature of the services, where they did exist, was the level of vulnerability arising from the recruitment embargo in the health system and the risk of funding cuts due to the growing economic recession. This theme was reflective of the policy position in 2009/2010 within the government to freeze recruitment in the public sector due to

the economic climate. The vulnerability of services usually resulted from maternity leave or retirement as these health care professionals were not replaced by the HSE due to the recruitment embargo. This phenomenon was experienced in rural and urban areas.

> *"…some things are good and some things are bad. Foot care is not particularly good…it's a bit random…dieticians were good, we had a community dietician and then she went on maternity leave and she wasn't replaced so now again it's a bit patchy at the moment" (GP111, UGC)*

Patients left "muddling through"

The barriers to availability and access have a negative impact on patients as highlighted by a number of GPs. One urban-based GP referred to families *"muddling through"* to provide care for family members with diabetes (GP106, UGC) while a Practice Nurse based in a rural area described newly diagnosed patients being left on their own *"for two and a half months once their diagnosis kicks in"* waiting for access to a dietician to assist and advise on the necessary lifestyle modifications (PN104, RGC). The financial barriers for patients, because of insufficient services in the community, were also recognised by GPs. Many patients had to attend private service providers due to long waiting lists or the unavailability of services in the community.

On occasion the GP was not aware of what was in place (e.g. GP115, RSNC) which is itself a barrier for patients. In such cases comprehensive diabetes care is dependent on the GP to organise a service or dependent on proactive patients showing initiative to seek out appropriate care;

> *"The nurse checks and reminds them about taking care of their nails. Otherwise I've nothing formally organised…its basically up to themselves…most of them do nothing I would suspect, some of them are probably going to a chiropodist off their own bat, how often I couldn't say" (GP110, RGC)*

4.3.14.3 *"Lucky" to have access to services*

Luck appeared to be a factor which facilitated the provision of a comprehensive diabetes service in general practice as those who had access to services referred to their practices and patients as *"lucky"* recognising and acknowledging the unique position they were in (GP110 RGC, GP107 RSC). For example in reference to short waiting lists for auxiliary services, one participant said patients were *"rather lucky…it's unusual"* (GP103 UGC).

In some instances access to auxiliary services was an upshot of initiatives to develop care locally or within the practice. For example a GP from a formal scheme providing structured care in his practice was *"in a loop with other services"* but attributed this network to *"the closure of local hospitals and the opportunity of starting this south inner city partnership"* (GP103 UGC). Another GP involved in a formal shared care initiative was confident about the way services were organised: however he appeared more detached from the process as services were delivered through the hospital (GP108, RGC).

> *"Podiatry has to go through the hospital, eyes…I suppose, that works pretty much…I know others criticise it but the way that it's organised now, they do get their eyes done regularly, they do get their podiatry, I think, when necessary and its well organised" (GP108, RGC)*

Other practices had built up structured care in their own practice and as a result had local arrangements in place for patients. A Practice Nurse, who represented this experience, had developed a *"rapport"* with local foot services which she cited as a facilitator of care delivery as opposed to dietetics where it was more difficult to pin-point a contact, again reflecting the variability.

> *"…If ever I'm stuck and somebody comes in…and we're not happy, I can ring up there and say 'I have this patient I'm really not happy with, will you see them as an asap' and they will. Because they know that we're not sending every person up there with that. And that is excellent because we have good rapport with them."*

4.3.15 Resources, Time and Workload

Emergence of Themes

During interviews GPs discussed resources, time and workload in tandem with each other, reflecting the interconnection between the factors. Most GPs referred to these factors as barriers to optimal delivery. However there was a sense of inevitability about the challenges of time, workload and resources hence these factors were not the dominant topic of discussion during interviews. In particular GPs who had developed an organised structured approach care tended to gloss over these barriers or discuss how they overcome the challenges.

4.3.15.1 *"People like diabetic nurses are worth their weight in gold"*

As mentioned in the previous section, the presence of a nurse emerged as a facilitator in the coordination and delivery of structured systematic diabetes care. This theme was reiterated during the latter section of the interview as having a nurse was cited as a resource for the practice and the patient;

> *"Probably the biggest advantage really in diabetes in recent years, has been the diabetic nurse, she has been the single best thing to happen to diabetes from the management point of view." (GP109, RSC)*

Both Practice Nurses and Diabetes Nurse Specialists (DNS) were perceived as integral to the delivery of care, the common feature being *"somebody designated to diabetes management"* (PN104, RGC). From various GP accounts, it appears the nurse enabled care in several ways. The nurse's role in coordinating recall and regular review was outlined in the 1st part of the results section. In some areas the DNS facilitated coordination and communication with the local hospital setting (GP8 RCG, GP7 UCG). Improvements in quality of patient care were attributed to enhanced nurse-led services both in the practice and in the local hospital (GP1 UCG).

> *"We're lucky now, I think I'm lucky this nurse that does this [diabetes clinics] also does the heart watch so this is a very easy side move for her" (GP110, RGC)*

Funding to recruit nurses as a resource for the practice was highlighted as a 'would be' facilitator and current barrier particularly for single-handed practices which could not afford to employ another nurse (GP10, UCS, GP105 UGC, GP114, USC).

4.3.15.2 *Lack of Resources and Infrastructure in Primary Care*

Most GPs acknowledged the lack of sufficient resources to deliver optimal care however many did not elaborate on the point. The resource which was most challenging in general practice was *"infrastructure"* (GP107). Infrastructure related to both staff and premises which were often mentioned in tandem. IT structures and support were also singled out as insufficient for optimal care delivery. Those who had sufficient resources cited them as a facilitator (GP110 RGC, GP113 USC) while those without cited them as *"limiting"* factor (GP105 UGC, GP114 USC).

> *"…you need staff dedicated to do that job which means you need a room for them to work in, you need equipment and you need access to referral centres like ophthalmologists and chiropodists…infrastructure. Pie in the sky I know." (GP107, RSC)*

More specifically, resources were cited as a barrier to the shift in diabetes care to the community setting. As mentioned previously GPs felt they were at a disadvantage to the hospital setting due to the lack of resources in primary care. GPs felt they were capable of providing more diabetes care in general practice but the *"support"* was not in place to enable that.

> *"…until the resources…the protocols and the structure are there I'm not going to unilaterally move to start doing it…There needs to be a deliberate shift" (GP113, USC)*

> *"They want us to do everything in the primary care setting which is understandable… as much as possible it would be nice to be supported to be able to do that but it would mean more staff and that inevitably brings in things that would limit staff which would be incentives and remuneration" (GP114, USC)*

The last quote illustrates the interplay between barriers and facilitators evident throughout the findings.

4.3.15.3 *Time is "always a barrier"*

Time was a thread running throughout the narratives on providing diabetes care and has already been referred to a number of times in this results section. The issues around time were two-fold; the importance of timing in diabetes management and the time pressures facing GPs (See Appendix XII). The former concept related to the importance of early intervention and timely review which has been highlighted in relation to waiting times for access to the specialists and for access to auxiliary services. The latter theme of a time barrier was an obvious issue for GPs in terms of volume of patients seen in their daily practice, the specific demands of providing diabetes care and competing demands from other patient groups. For GPs time was *"always a barrier"* (GP111, UGC) reflecting the inevitability of certain barriers. More specifically time was a *"cost"* of providing diabetes care (GP101, RSC), a sentiment echoed by other GPs [GPs 13 (RCS), 15 (RCS), 2 (RCS), 16 (UCS) and 11 (UnonCS)].

"You'll always find time"

However a number of participants were not held back by this barrier, particularly the sub-category of practices that had initiated and developed a structured approach to diabetes care. Their can-do attitude may have been reflective of their enthusiasm for diabetes care. Delegating care was one method for overcoming the time barrier. For

example GP6 (UCG) referred to good staff resources to deal with the time spent on diabetes care so it worked well in the practice. Another GP acknowledged the lack of time for *personal* engagement but delegated care to the nurse;

> *"I personally would like to have more time to devote to diabetes care myself. It's been on my list of things to do for the last 2 or 3 years, to sit down with Nurse P and actually review with her what she 's doing" (GP110, RGC)*

Being *"overstretched"* was excused as due to '*our'* organisation within the practice (GP108, RGC) or the patient-doctor ratio in the practice (GP110, RGC). These GPs owned and took responsibility for the time barrier and tried to overcome as opposed to just bemoaning it.

Dedicated Time: advantages & disadvantages

A distinction has been made between dedicated time within the daily practice to deliver diabetes care and dedicated time to organise diabetes care. A number of single-handed GPs wanted dedicated time to coordinate care for patients (GP101 RSC, GP113 USC, GP13 RSC). This was an extra time demand in addition to provision and the use of the word *"devote"* implied a personal dedication to the task;

> *"You really need to* ***devote****…an afternoon session, a day a week or a day a month or a day a fortnight…to try and coordinate it…its time consuming that's the biggest barrier for us" (GP101, RSC)*

The demands of organising care also include coordinating with the hospital setting as evidenced by one single-handed GP who did not *"have time or resources to do or look for shared care arrangements".*

In contrast GPs' opinions were divided over dedicated time to deliver care. For some dedicated time to deliver diabetes care to patients would be a facilitator (GP13, RCS). Diabetes clinics were perceived to be the *"ideal"* scenario (GP16, UCS, GP106 RGC) and preferable over hospital-based clinics (GP14 UCG). However even the 'ideal' could generate problems. Clinics *"may not be the best use of resources"* such as space and nursing time. Holding special clinics during the day had implications for both the practice and the patient as other patients could not be seen during that time. It also placed restrictions on the patient with diabetes;

"…in an ideal world you would have [a] dedicated clinic in the practice for your diabetic…but then of course…diabetics have to fit their lives in as well and Thursday afternoon that you've decided to do your clinic might not be [suitable] for the patient so I mean there are time constraints for the patient and the doctor" (GP106, UGC)

4.3.15.4 *Workload reaching saturation in general practice*

Workload was a growing barrier in general practice as *"a huge amount more bloods are being done"* for example. While the sheer volume of patients with diabetes and the *"overwhelming workload with type 2 diabetics"* presented a significant challenge to care delivery in general practice, similar to time management, some practices were tackling the workload effectively and efficiently. In particular planning and organisation were essential to managing the *"heavier workload"* created by managing diabetes in a systematic structured way (PN104, RGC). Another participant referred to *"staggering care"* to make it more manageable (GP16, UCS).

While many GPs referred to the workload as a barrier within the practice, it is also system-level barrier as more and more aspects of health care were being moved to the community. As a setting general practice was becoming "saturated", this could limit its capacity to assume primary responsibility for diabetes care.

"I think general practice is quite willing to take on…well we always have been willing to take on more and more stuff that is primary care-based [and] bring it out of secondary care but we're saturated now" (GP110, RGC)

Other factors influencing the provision of diabetes care

Finally one of the main facilitators of optimal care delivery proposed by participants was the provision of education and training for health care professionals (Table 30). Education was seen as one way to foster interest in diabetes among the wider profession (GP112 RGC, GP107 RSC). However the cost of pursuing an interest was too high for some GPs at present.

"I think when you're interested in something you will attend courses to do it so I think more available education would be good. Time to go and do things that are not going to cost you, for me to go and take a day off means I have to get a locum and every time I get a locum its €400 or €500" (GP107, RSC)

Table 30 Other Barriers & Facilitators referred to by GPs

B/F	Factor	Explanation
F	**Public Health Policy**	"Society needs to ban food ads, to stop the greed people are feeding into" (GP11, UnonCS).
F	**Guidelines**	"Now we have national guidelines, we've local guidelines…we've ICGP protocols. So I think every GP in the country knows how to best care for patients with diabetes" (GP103, UGC) "We're following the guidelines more closely trying to get people closer to goal. So you're more aware of what you should be doing not that you actually get it right but you're kind of more aiming towards something" (GP107, RSC)
F	**Advances in medicine**	"We really have monitoring processes in place now. We also have medicines there that were never there before…it is a good time, to start a protocol because there are things that can be done at a practical level" (GP109, RSC)
F	**Patient Awareness**	GP4 (UCG) noted that patient awareness of diabetes and their family history has improved in recent times and was a facilitating factor when providing care.
B	**Unrealistic Clinical Targets**	GP1 (UCG) stated that the need for perfection on A1c levels was a barrier to satisfactory care.
B	**Polypharmacy**	According to GP 6 (UCG), as it was difficult for patients to deal with this and difficult for GPs to communicate to patients, due to time and workload constraints, especially in the elderly population group.

4.4 Discussion

4.4.1 Summary of Findings

The results of this study capture the complexity and variability which characterises the delivery of diabetes care in Ireland. This qualitative study was conducted as a follow-up to the national survey of GPs to elaborate on the organisation and delivery of diabetes care in general practice and explore perceptions of the barriers and facilitators to providing optimal care in that setting. The analysis delineated four dimensions of diabetes care delivery. Firstly there was a continuum within the practice from *"ad-hoc"* to structured systematic care. Secondly, there was a varying balance of care between GP-led management and hospital-led management which was influenced by the interest of the GP, the location of the practice, the availability of resources and the historical context of care. Another continuum which emerged from the data was the extent of sharing diabetes management between the practice and the hospital-based team. The relationship between the settings was synonymous with referrals. Reasons for referring patients to the hospital included reaching a professional threshold of expertise and the development of complications which required specialist input. However, participants also gave reasons for resisting referral of patients into the hospital including the apprehension of losing the patient to *"the system"*. The final dimension of care delivery, which related to a subset of interested GPs and Nurses, focused on practice involvement in formal local/regional initiatives to improve diabetes care or proactive efforts within the practice to develop a structured approach to care, categorised as informal initiatives.

Previous studies have categorised factors influencing diabetes care at the level of patient, provider and organisation/system (180, 181). This study unpacked further layers of health care delivery, identifying factors relating to the relationships between providers and the culture underlying the health system. The main barriers to optimal care delivery from the general practice perspective were system-level deficiencies such as the lack of remuneration, insufficient services and lack of coordination between settings. These issues had a ripple effect throughout the system at an organisational, social, professional and patient level. For example the lack of remuneration for diabetes care created a sense of *"apathy"* among health care professionals but also led to out-of-pocket costs for patients.

The preceding surveys of GPs (Chapter 3) and consultants suggested a lack of formal coordination between settings reflected in the lack of routine discharge, shared protocols or joint meetings (161, 170). The qualitative findings illustrate the negative effects of the lack of coordination in the system including the bureaucratic *"palaver"* around service delivery, the uncertainty for patients and providers of *"in the meantime care"* and *"overburdened"* hospital clinics. The flooded hospital system led participants to highlight the capacity and benefits of general practice as a setting for diabetes management. This potential was untapped due to the lack of infrastructure, deficient access to services and insufficient resources to provide high quality care. Time was highlighted as a significant barrier in general practice. However, some participants adopted a more proactive attitude towards overcoming this almost inevitable challenge.

4.4.2 Barriers to Delivering Optimal Diabetes Care

A number of the barriers to optimal diabetes care delivery highlighted in this study were brought to our attention in 2001 in national primary care strategy 'Primary Care; A New Direction'(182). 'Inadequacies' in primary care in 2001 included poor primary care infrastructure, fragmented services, lack of availability of certain professional groups, poor liaison between settings and the failure to fully realise the potential of primary care to ease the pressure on secondary care (182). Similar barriers to diabetes care provision have been highlighted in a surveyed conducted in UK. The barriers identified, including inadequate access to auxiliary services and secondary care, were ranked with inadequate access to dieticians and chiropody perceived as a greater barrier in the UK than access to ophthalmology (164). There was a similar though unconscious rating of auxiliary services by participants in this study, along a scale from good to bad to worse. There was not an urban/rural divide in terms of access to services rather participants highlighted the dearth of services in primary care compared to the hospital setting. Until this balance is rectified, proposals to shift care to the community will not be viable.

The results reflect the overlapping spheres of the Chronic Care Model (CCM): community resources and policies, the health system, the practice, the professional and the patient. The consequences of barriers and facilitators throughout the system are congruent with an underlying assumption of the CCM that different components of chronic illness care are interdependent. Innovation and development is unlikely to occur at practice level if chronic disease management is not prioritised in the health system (84). GPs in this study perceived the lack of financial support and encouragement as an

indicator of the lack of value placed on primary care chronic disease management, concluding that there was *"no incentive to do more"*.

4.4.3 Incentivising Diabetes Care

The lack of remuneration or financial incentives for chronic disease management was one of the principal barriers to providing optimal diabetes care in general practice according to participants in this study. However opinions were divided about the most desirable model of remuneration. Evidence on the best way to remunerate health care professionals is inconclusive and the rigorous evaluation of different payment structures is fraught with methodological difficulties (183). In the preceding survey over half of the GPs favoured a mixture of capitation grants and fee for service, while less than 25% supported target-driven payment as remuneration for diabetes care. The qualitative findings presented in this chapter revealed concerns about target-driven payment, including the risk of diminishing non-incentivised aspects of care and the potential for health care professionals to scam the system. These concerns have been raised in relation to the Quality Outcomes Framework (QOF) in the UK which links additional payment to performance and quality in general practice (184, 185). Research using QOF data has shown a reduction in quality among aspects of care not linked to incentives as well as a decline in the continuity of care (186, 187). Such unintended negative consequences compound the contradictory evidence base underlying the impact of pay-for-performance structures (188).

4.4.4 Role of personal and "vocational" incentives

In light of the inconsistent evidence on financial incentives, Marshall and Harrison (2005) contend that *"something more than personal financial gain is driving professional behaviour"* (p5) (189). This proposition is supported by the results of this study which highlighted the activities of *"keen"* GPs who developed an organised approach to diabetes care, in the absence of adequate remuneration and in some cases at a financial loss to the practice. This subgroup of GPs referred to personal and *"vocational"* incentives including personal satisfaction and a professional *"duty"*. Internal incentives such as these are known as intrinsic motivation; an activity carried out because it is inherently satisfying as opposed to externally rewarding (190). There is evidence to suggest that intrinsic motivation can be *"crowded out"* by external rewards particularly performance-based rewards by diminishing self-determination and self esteem (191). This is somewhat similar to the concerns expressed in this study that financial incentives could corrupt

care and cause a ripple effect for incentivizing all chronic disease management. The self-determination to manage other chronic illness may be undermined by the financial rewards received for diabetes care. However the subgroup of *"keen"* GPs did not anticipate the potential negative impact of remuneration on their own personal motivation. Policy-makers deciding on the ideal payment structure for healthcare should consider the context (183) and the alignment of values between the professional and the organisation (189). According to the results of this study, there is a mismatch between the values of the HSE and those of GPs in terms of the contribution of primary care and the value of chronic disease management.

Two levels of internal incentives were identified in this study; personal incentives and *"vocational incentives"* however a framework for worker motivation proposed by Franco et al (2002) illuminates further distinctions in the results (192). Drawing on theories from economics, psychology and sociology, Franco et al identified determinants of worker motivation at the individual level, organisational level and cultural level. According to the framework, individual level determinants include goals, values, self concept (self efficacy & evaluation of competencies) and the experience of outcomes. In this study the subgroup of interested GPs' conveyed a sense of competence and confidence in their ability, referring to the feeling *"that we've improved the service"*. Furthermore GPs referred to their personal experience of the complications of diabetes as an incentive to act and the personal value placed on preventative medicine.

According to Franco's framework, organisational determinants of motivation include organisational structures, communication processes and organisational support such as adequate resources and efficient service delivery. A number of GPs emphasised infrastructure and resource deficits as impediments to providing optimal care although they acknowledged the appropriateness of the general practice setting for diabetes management. This suggests that organisational determinants were the dominant influence over individual motivation for some GPs. The success and perceived benefits of formal initiatives, including access to auxiliary services, illustrates how intrinsic motivation to improve care coupled with organisational support can lead to changes in the practice. However, the framework does not account for the dominance of one type of motivation over other, as appears to be the case for those GPs who developed care *"off their own bat"* without financial incentives. Participants suggested remuneration was necessary for widespread engagement in diabetes care as intrinsic incentives were

limited to *"pockets of interest"* and were insufficient to motivate all health care professionals.

4.4.5 Elucidating models of care

As suggested by one participant in this study the terms surrounding the models of care *"mean different things to different people"*. Both shared care and structured care involved similar features to enhance the delivery of care but the terms also had local connotations. Structured care was characterised by organisational and professional features such as patient registries and local arrangements to access services, reflecting some of the components of effective chronic disease management proposed by the Chronic Care Model (193). The allocation of tasks between the GP and the nurse which evidence in the data is also considered a key part of the practice delivery system (69). However, unique to this context, participants associated the term structured care with general practice-led management. In light of descriptions of structured chronic disease care in the literature and the participants' interpretation of the term, structured care could be considered as an organised and systematic approach adopted within the practice to provide diabetes care to the majority of patients.

Formal shared care initiatives were also associated with organisational and professional features including shared education sessions, referral protocols and sharing the expertise of a Diabetes Nurse Specialist, a characteristic of formal shared care initiatives in the Netherlands (128). The perception of shared care, as a "*good combination*" of the benefits of primary and secondary management was in stark contrast to the unique perspective of shared care as a means of demoting general practice to a second best system delegated to by hospitals. The conflicting positive and negative views of shared care schemes have previously been raised in relation to sharing cancer care between primary care physicians and specialists (194).

4.4.5.1 *Sharing care to enhance coordination and integration*

Participants identified greater 'sharing' of care between settings as a facilitator to diabetes care provision using the term interchangeably with 'integrated care'. Shared care arrangements and the numerous permutations (e.g. transmural care, disease management, integrated care pathways) have been described as mechanisms to achieve greater integration (171, 195). In this study 'sharing' care combined attitudinal components, such as a sense of shared responsibility, and behavioural components such as common records and protocols for referral and discharge. Shared protocols to clarify

the realms of responsibility in each setting and integrated information systems could reduce the uncertainty of *"in the meantime care",* limit *"avoidable duplication"* or the alternative of patients *"falling between two stools"*. These system-level interventions are in keeping with the WHO definition of integrated care as a concept *'bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care and rehabilitation and health promotion'* (171).

As opposed to either/or care, the focal point of sharing management in this study was two points of access for the patient combining the best of both worlds; access to and support from the expertise in secondary care with the balance of care in general practice for routine management. However, it is important to identify and highlight the unique opinions on the need for joint involvement. One participant perceived *"no need"* for hospital involvement while another felt the hospital was the natural setting for diabetes management given the availability of services and expertise. Anomalies such as these are often brushed over in quantitative research (196) but in this study they highlight the need for flexibility within a national model of care to allow for lack of interest but also capacity to manage the majority of patients in general practice. Originally the report from the Expert Advisory Group for Diabetes (2008) prescribed the number of patient visits required under an integrated model of care (1), however the working definition of the model has since been modified to allow for professional judgment and discretion. Integrated care now encompasses the majority of patients' visits taking place in general practice with review in the diabetes centres, the frequency of which depends on patient need (142). Flexibility depending on local circumstances does not negate the need for clarity surrounding the realms of responsibility highlighted in this study. Responsibility for coordinating care needs to be assigned to prevent wasteful duplication and gaps in care which could prove costly for the patient (197).

4.4.6 Strengths & Weaknesses

In this study qualitative research refers to a set of methods rather than a rival paradigm associated with a particular philosophical perspective (198). The Framework approach was a pragmatic way of analysing the data as there were pre-specified aims and particular information requirements to inform the establishment of a national diabetes register. It also facilitated analysis within a restricted time frame and the transparent approach to data management allowed the researchers to understand and assess the analysis of their colleague (175). The latter advantages of the Framework approach

could be framed as a criticism; is it more of a data management tool rather than a method of analysis? There is no single agreed method of analysing qualitative data which is an open and evolving process. Looking across the various methods and writers, there are several similarities between the coding processes of different approaches although different terminology are employed (178).

Health Services Research has tried to move on from the justification or defence of qualitative methodology towards enhancing the quality of these methods (198). Triangulation is a common technique for demonstrating the rigor and quality of a study and in this instance triangulation of analysts was employed. Like many aspects of qualitative research methodology, the merits of involving more than one analyst are debated (199, 200). In addition to the reality of group research projects, a team of researchers can bring breadth and depth to the findings (22, 201) and is often considered an implicit form of inter-rater reliability (179). Inter-rater reliability was also applied explicitly in this study involving an independent researcher. Applying the term or concept of reliability to qualitative research is contentious in itself. Inter-rate reliability is seen by some as a habit of quantitative research adopted without question of its appropriateness (202). However the technique is appropriate in the context of semi-structured interviews whereby all participants are asked broadly the same questions in the same order with data coded at the end of the collection period. Nevertheless there is a risk of over-simplifying codes and themes to facilitate independent checking. In this study inter-rater reliability was utilised on the initial codes following the first wave of analysis to minimise this risk.

The focus of this study was on the organisational and structural barriers and facilitators of optimal diabetes care based on the findings of the national survey of GPs. Patient-related factors such as attitudes to diabetes and adherence have also been conceptualised as barriers and facilitators to care provision (181). GPs highlighted potential barriers and facilitators from the patient perspective including the familiarity of care provided in general practice and the out-of-pocket costs associated GP care which has been previously identified as a barrier to access (203). Further research should be conducted with patients to garner their views on the factors influencing provision and examine the similarity or disparity between the different perspectives.

This study advances our understanding of the interaction between the barriers and facilitators involved in providing optimal diabetes care. Previous studies purport to

demonstrate relationships between barriers and facilitators however these connections may not necessarily emerge from the data itself and often issues are superficially corralled into patient, provider and system level issues. While there were differences in categorisation of barriers, similar challenges to diabetes management were found in other studies. For example a study conducted in Canada identified the lack of capacity for computerised recall as a physician-level barrier. While the authors of the Canadian study refer to the *'serendipity'* of patients returning to the practice as a barrier, a number of GPs in this study were purposeful in their avoidance of reminders in order to evoke a sense of responsibility among patients (181). There is a balance to be struck between the organised approach of regular recall and review and the onus on the proactive patient to actively manage their own illness and care.

The barriers and facilitators identified in this study are rooted in the context and peculiarities of the Irish health system, such as the part played by 'luck' in securing access to services in the community. However the similarity of barriers and facilitators identified across studies adds weight to the argument that structural and organisational factors influence the provision of high quality diabetes care in general practice (164, 181, 203). There is scope for a meta-synthesis to be conducted on the barriers and facilitators to provision, to develop and understand the full extent of the evidence base (204). A number of the barriers have implications beyond diabetes care and correspond to issues facing the wider primary care setting (205). Consequently there is ample opportunity to learn from other settings and countries in terms of how to overcome these barriers.

4.4.7 Conclusion

The key ingredients of effective diabetes care highlighted in 1982, organisation and enthusiasm, emerged in this study of GPs' experiences of diabetes care provision and their perspectives on the barriers and facilitators to delivery. Given the policy focus on increasing the role of primary care in chronic disease management, there is a need to understand the current challenges to delivery in this setting. Reorientation of care must be accompanied by the reorganisation of support and resources. Internal incentives and enthusiasm are drivers of change for a pocket of health care professionals however this is not sufficient for widespread engagement of GPs in diabetes care delivery (206). Health systems need to invest in infrastructure to support and enable health care professionals to make high quality care attainable rather than aspirational.

5 Attitudes to Engaging in Quality Improvement in General Practice

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Abstract

Aim: The aim of this study was to explore attitudes and openness to engaging in quality improvement in general practice. The examples of developing a national diabetes register and conducting routine audit were utilised to elicit attitudes towards improvement at a practice and population level.

Methods: A purposive sample of 29 GPs and 2 Practice Nurses (nominated to represent the practice) participated in semi-structured interviews. Participants' practices varied by (a) location (rural/urban), (b) size (single-handed/group practice) c) extent of computerisation in the practice. The topic guide focused on 5 subjects, 2 of which are dealt with in this chapter: experiences of change in the health system at a local and national level; attitudes towards quality improvement activities in particular the development of a national diabetes register and engaging in audit in the practice. Analysis was conducted using the Framework approach.

Results: The findings suggested a sense of inertia toward quality improvement activities, particularly at a national level. This attitude was strongly influenced by previous experiences of change in the health system which was used as a cautionary example. Change initiated at a national level was seen to be *"imposed"* on general practice and did not meet the needs of the practice or patients. In contrast participants referred to positive experiences of change within the practice and at a local level, facilitated by a *"practice ethos",* leadership and special interest. Participants expressed wariness and scepticism towards the development of a national diabetes register. The main advantage was *"knowing the numbers"* for epidemiological purposes and there were concerns that this innovation would drain resources from other priorities.

Conclusions: This study illustrates the link between previous experience and the growing sense of inertia towards future quality improvement. The sense of inertia also stemmed from the competing demands of delivering routine diabetes care in a system with limited resources. The culture which facilitated change within the practice is absent at a national level. In line with the concept of civic professionalism, quality improvement needs to be considered part of the job. This requires a shift in professional culture and investment in an infrastructure to support participation.

This study will be submitted to the International Journal for Quality in Health Care

5.1 Introduction

The struggle to reform healthcare worldwide has led to growing recognition of the need to understand the nature of the system we are trying to change and the context in which that change will take place (207). Many experts now contend that understanding the context in which quality improvement flourishes or fails is as important as generating evidence of the effectiveness of different strategies in the field of quality improvement research (18, 19). A review of quality improvement strategies targeting organisation and provider behaviour in diabetes found that effectiveness was dependent partly on clinical context but also other contextual factors such as the beliefs and attitudes of professionals (8).

5.1.1 Organisational Culture in Healthcare

One contextual factor which is receiving increasing attention in health care is the notion of organisational culture. There is a lack of consensus on the definition of organisational culture with two main conceptualisations: organisational culture as something an organisation is (defining characteristic) versus organisational culture as something an organisation has (attribute) (208). The distinction has implications for policy and research as the latter definition suggests potential to create, change and manage this independent variable to improve quality (209). In an effort to find middle ground, Davies et al suggest organisational culture is an organisational variable which emerges from sharing between colleagues including beliefs, attitudes and behavioural norms in an organisation (208). Similarly Donabedian describes a quality culture in healthcare as the prevailing set of values, attitudes and beliefs about the importance of quality, who is responsible for ensuring it and what methods are acceptable and unacceptable for obtaining it (28). The interest in organisational culture in health services research is based on the assumption that culture and performance are related. There are few rigorous evaluations of the link between culture and performance in health care given the problems of definition and measurement (210) however there is some evidence to suggest culture is associated with the effectiveness and quality of care (211, 212).

5.1.2 Role of Health Care Professionals in Quality Improvement

Involving all health care professionals in quality improvement is a remnant of the Total Quality Management philosophy (TQM) which has influenced the evolution of health care reform. According to the TQM approach developing a quality improvement culture requires a wider commitment to quality among staff at all levels of the

organisation (78, 213). From experience studying quality improvement in the US and the UK, Berwick and colleagues have concluded that health care professionals are key to the success or failure of quality management depending on their willingness to learn, accept and adapt to changes in practice (163). For example the beliefs and attitudes of the health care professionals can act as a source of resistance to wider change and initiatives can fail without 'buy in' from frontline staff (209). With the growing focus on cost effectiveness and efficiency in the health system, it is imperative to understand the perspectives of those whom we expect to adopt and adapt to change, before developing and implementing quality improvement initiatives.

5.1.3 Beliefs and Attitudes towards Quality Improvement

Three levels of organisational culture have been suggested: underlying assumptions, beliefs, attitudes and values, and observable behaviour and structures in an organisation (214). Focusing on beliefs and attitudes, a number of theories from the field of health psychology hypothesize a relationship between attitudes, beliefs and behaviour (215). For example the Theory of Planned Behaviour has previously been applied to predict the management of Type 2 diabetes in primary care (216). However few studies have sought to identify or understand the attitudes and beliefs which could influence engagement in quality improvement and fewer still have applied a theoretical framework to understand the success or failure of implementing change (217). Among the exceptions, Spooner et al (2001) sought to identify the reasons for participation in quality improvement among GPs in England (218). The findings suggested that a desire to improve care, financial incentives, maintenance of professional autonomy and professional pride were sources of motivation driving participation. A more recent qualitative study of practitioners' views on quality and efforts to achieve it in the hospital setting, found that the healthcare system was perceived as a source of barriers to high quality care while quality was perceived as a function of the professional's skill, knowledge and motivation (219). Professional commitment has also emerged from quantitative analysis of the factors associated with the implementation of change in chronic disease management (220).

5.1.4 Improving the Quality of Care in Ireland

There is a lack of information concerning engagement in and openness to quality improvement in the Irish health system. Although the national guidelines for diabetes management promote patient registration, recall and regular review as part of

comprehensive diabetes management (17), evidence suggests that such strategies to enhance the delivery of care are not widely adopted in Ireland. The survey of the organisation of diabetes care in general practice presented in Chapter 3 found that almost one quarter of GPs did not maintain registers, use guidelines *or* engage in formal recall of patients for review (170). A follow-up qualitative study found that efforts to enhance the organisation and level of diabetes care in the practice were limited to *"pockets of interest"* among GPs. This is indicative of the level of the wider engagement in quality improvement in the Irish health system as initiatives are often *"sporadic and individually driven"* (79). It is important to identify the factors which drive and deter health care professionals from making necessary changes in their practice. Qualitative research is particularly useful for identifying and understanding the barriers to practice change. This approach to research, which studies phenomena in their natural setting, provides an opportunity to explore the contextual issues to be considered when making changes (173).

This qualitative research was undertaken as part of a programme of research to inform the development of a national diabetes register. Prior to developing and piloting a national register a study was conducted to understand the experiences and attitudes of general practitioners towards change in the health system. In this study the proposed development of a register was utilised as an example of an initiative to improve the quality of care and outcomes at a population level. The study also examined attitudes to conducting regular audit, a function enabled by routine patient registration, as an example of quality improvement within the practice.

5.1.5 Aims & Objectives

The overall aim of this study was to explore GPs attitudes and openness to engaging in quality improvement. The specific objective of this study was:

1. To identify and understand attitudes to the development of a national diabetes register and the use of audit as examples of mechanisms for quality improvement at practice and population level.

5.2 Methods

The design and methodology outlined in Chapter 4 was also used to generate the results presented in this chapter. Hence the sampling technique, participant recruitment, interview procedure, data coding and analysis, and data credibility described in detail in the first qualitative study presented in Chapter 4 (Section 4.2.), also apply to this chapter.

The following three topics from the semi-structured topic guide were the basis for emergent themes presented in this Chapter:

- How have things changed locally and nationally
- Attitudes to the development of a national diabetes register and engaging in audit in the practice.

5.3 Results

The results section is organised into 2 parts. Section 1 presents the themes relating to participants' experiences of change at local or practice level, as well as previous experience engaging with national-level programmes to improve services. As a means of eliciting attitudes to engaging in quality improvement, participants were engaged in discussion about the establishment of a national diabetes register, a population-level strategy to improve care, and engagement in routine audit, a practice-level improvement strategy. The emergent themes are presented in section 2. Participants referred to barriers to quality improvement such as time and money which overlapped substantially with the barriers to optimal provision hence these themes are outlined briefly.

Section 1: Previous experience shaping future attitudes

Emergence of themes

During the interviews GPs spoke about experiences of and attitudes towards change in Ireland at local, regional and national level. Previous experience of change appeared to have a positive or negative influence on attitudes and openness to future quality improvement initiatives. A number of GPs spoke about existing programmes within the health system or recent changes at a national level and the need to learn from their mistakes. Conversely positive experiences usually at a local level were put forward as templates for future change. Changes within the practice, particularly becoming more structured in diabetes management, illustrated the drivers of change at the local level including the role of local pioneers and a practice ethos of trust and teamwork. Hence there was a notable contrast between attitudes towards change at a local and national level. While highlighting the negative aspects of previous change, participants also offered examples of positive experiences which could counteract such difficulties in the future which led to the development of Figure 26.

Special interest emerged as an enabler of quality improvement for a subset of participants as it did in the previous study of factors facilitating the provision of diabetes care. While the lack of remuneration was not a barrier for a select group of GPs with a special interest it was recognised as a barrier to wide-scale change. The lack of financial incentives and the top-down direction of change could contribute to GPs sense of being *"taken advantage of"* within the system. This apathy could be addressed by involving clinicians at an early stage in the decision making and development process.

5.3.1 Enabling change in the practice: ethos, leadership and interest

A number of participants recounted experiences of change in the practice including developing a structured approach to diabetes care either independently as a practice (PN104, GP112) or by joining a formal local scheme (GP103, GP110). Other practice changes included becoming computerised (GP113) and merging into a group practice (GP108). These experiences revealed some of the enablers of change within the practice or at a local level (Figure 26).



Figure 26 Enabling change within the practice

Practice "ethos" = trust and a shared goal.

An emergent theme among GPs who had adopted a structured approach to care or become involved in a local initiative was the *"ethos"* within the practices which supported change and improvement (Appendix XIII). This ethos stemmed from the relationship and interaction between the GP and the nurse or other members of the practice staff.

> *"Everyone is very cooperative, we get on well together and I'm sure if I was to sort of suggest it [making changes] and run with it, I don't think there'd be any barriers" (GP111, RGC, p5.2)*

A supportive practice ethos enabled improvements in diabetes management and facilitated delegation and nurse-led delivery. This theme was particularly strong throughout one practice nurse's account of setting up structured diabetes care in the practice;

> *"When I came in (the GP) was saying that he was very proactive, getting into the prevention rather than cure issues like diabetes and asthma, and how did I feel about taking over clinics in those areas so that we were specialising in those areas. I was delighted to be…you know that that's what we all*

want. So I was given the time and the freedom and the access to things to be able to do it." (Nurse 104, RGC, p5).

There were two features to the practice ethos identifiable from the above quote; trust between members of the team and having a shared goal *("what we all want")*. Another GP who had made efforts to organise the delivery of diabetes care referred to staff buying into the new approach and the common aim driving their efforts;

"At the end of the day it's all about the patient and minimizing problems down the line. And everybody…buys into that fact that if you do stuff now and stick to the guidelines…you can stop the problems…everyone buys into that and gets on with it" GP101, RSC, P5.1)

Practices which had delegated the coordination of care to nurses demonstrated a sense of trust and confidence in their ability to deliver care which was implicit in the outline of care given by participants;

"There's a lot of support from the doctors because if somebody's coming in to see me and I'm saying this isn't working or I'm not happy with how this is going, they're more than happy to take my word on it and pull them through [to see them]" (Nurse 104, RGC, p6.3)

"They [diabetes nurse specialists] have access to [the practice computer]…they can put details in the health system. We give them access…They act responsibly, we've known them for many years and they are very committed…If I didn't trust these ladies it'd be a different kettle of fish (laughs)" (GP108, RGC, p14.1)

Leadership- a pioneer for change

In many of the accounts, the practice or GP had undertaken a structured approach to diabetes care off his/her *"own bat"*. However participants also referred to *"pioneering"* individuals (GP108, RGC, P8.1), including GPs and specialists, who had developed the formal diabetes schemes;

"There are 2 or 3 key movers. There's a couple of GPs who are really trying to move it along" (GP110, RGC, p8.2)

Furthermore it was suggested that GPs have the necessary skills and respect to engage colleagues in schemes and initiatives, a role which could be expanded to increase buy-in in future quality improvement initiatives;

"I think people of my age, mid fifties, in the UK…are being put into positions where they are heading up schemes and programs and they can speak the language and have the recognition and respect of other GPs in the area. That's good, there needs to be more of that…They are good at networking and bringing people together" (GP108, P18.2)

Interest in Improving Care

The previous analysis (Chapter 4) found that personal and professional incentives emerged as the motivation for delivering diabetes care in general practice in the absence of financial incentives. These reasons were also driving participant's interests in improving care. GP13 (RCS) talked about his perseverance in making changes in the practice; *"keeping it going- being stubborn"* was a major driver of improvement.

5.3.2 Previous Change in the Irish health system; a cautionary tale

Participants' accounts of previous experience of change within the health system revealed a sceptical attitude towards change at a national level. This attitude was conveyed through a number of subthemes including the sense of changes being *"all talk with no action"* and the proliferation of pilot projects and the imposition of changes from the top down. There was also a sense of frustration and resignation with the implementation of ideas which were *"good in principle"*. There was an emergent negative attitude towards change at a national level.

5.3.2.1 *"All talk no action"*

The discourse around diabetes care both in policy circles and in the HSE was frustrating and disillusioning, described as *"all talk and no action"* (GP8 RGC). This sentiment was echoed by GPs in reference to other changes in the health system, particularly in relation to the promise of extra services and IT developments which were *"mooted many years ago [but] never paid for" (GP103, UGC).*

"I know there was talk about designing a common package and they're talking about rolling that out throughout the country but…" (GP106, P6.3, RGC)

"Podiatry is non-existing in the community…there was talk at one point that there was going to be a mobile unit coming out but it's never (materialized)" (Nurse 104, p14.1)

Another common example used to illustrate the lack of action was the development of primary care teams to provide multidisciplinary care for patients in the community;

"We were promised a whole range of services through the primary health care teams, but they have really fallen…Like the cervical screening thing, it was a good idea and then they're not resourced properly and they just fall into the sand" (GP112, p9.3, RGC)

5.3.2.2 *Proliferation of pilots*

The theme of "*talk with no action"* was connected to the lack of follow-up on ideas and projects within the health system, particularly IT projects. One practice nurse spoke of yet another IT project between the hospital and general practice which initially *"had great speed and then it sort of died a death and nothing really happened with it"* (PN104, RGC, P8.2). Similarly GP15 referred to a smart card initiative which would enable GPs to download information but again the GP witnessed the project *"die off"*. The common language here suggests a lack of sustained interest in the projects. One participant suggested this lack of follow-through was reflective of the wider culture in Ireland;

"Because in Ireland we don't…we just think short-term. We never think long-term…they launch pilot projects and then that's it, they are never followed up and there's so many examples of that" (GP113, USC, p11.2)

The previous experience of ideas which were not followed through had a direct impact on attitudes towards a national diabetes register as illustrated by the following quote from a sceptical GP;

"It's an idealistic approach, and I'm afraid…, in my lifetime anything idealistic has never come to fruition, I mean not even once…Sometimes people get into the idea of the ideal…and I mean everybody would like these things…In practical terms, they never work and haven't worked in the past…but that doesn't mean you should stop hoping for it" (GP109, RSC, p14).

There is risk of tiring health care professionals with ideas which never materialise and pilots which never take off, leaving them sceptical and indifferent towards future quality improvement initiatives.

5.3.2.3 *Learning from past experience: "Caution with the example of Heart Watch"*

In terms of developing an organised model of diabetes care, participants drew on previous experience of chronic disease management initiatives in general practice. In particular participants highlighted the strengths and weaknesses of an initiative established to develop a structured and organised service for patients with heart disease within primary care. Opinion was divided on the extent to which the structure of this initiative should be applied to diabetes care (Table 31). Some felt the programme*, "which has proven very successful"* for the management of heart disease, was *"a model worth looking at"* for diabetes (GP105, UGC) and could offer a viable *"template"* for developing a national register (GP4 UCG, GP8 RCG, GP16 UCS). The skills developed from the implementation and running of the programme could transfer easily to a diabetes management program. Conversely, while others felt it was *"good in principle"* there were issues with the implementation of the programme in practice. Some participants Heart used this programme as a warning of what not to do when developing a disease management programme for diabetes. Both groups felt there were valuable lessons to be learned from this experience.

> *"I hope they don't use Heart Watch as their immediate template, because I think it will be a very arduous system. I think they should look at the benefits or the good points of it and restructure it to make it much more user friendly" (GP112 ,RGC, P19)*

Table 31 Dived opinions on the strengths and weaknesses of a national program for the management of heart disease in primary care and the potential for diabetes care.

Strengths	
Proven effectiveness	"It's excellent. And I think the evidence is there…to show that they have reached…the targets are reached within the framework of a Heart Watch type set up" (GP106, UGC, P4)
Transferability	"What the heart watch patients get done isn't that much different to what diabetics need, in terms of the bloods they get done and the advice they get about smoking, blood pressure, exercise and diet…it gives you this little list…there's great incentive and remuneration in that too." (GP110, RGC, p19.1)
Standardising and improving care	"…the advantage of is like a Heart Watch type programme…the advantages of that are clear for everybody to see. And if we can standardise protocols and guidelines that everybody buys into that and that everybody does it at regional and national level…outcomes…can only be better" (GP101, RSC, p6.1)
Weaknesses	
"Cumbersome"	"…you have to fill in information that can't be automatically transferred from our software system, so we have bloods that come in online, goes on to the patient chart. Then we have to hand-transfer them across to the thing. Now it's nonsense" (GP112, RGC, p12.2).
Not user-friendly	"…very boring and longwinded and very repetitive…it wasn't a bit user-friendly" (GP101, RSC, p7.2)
Bureaucratic	"If you equate our management of diabetes care to the completely over-structured method of Heart Watch…we would actually fear any system that would involve general audit or payment methods would be very bureaucratic" (GP112, RGC, p8.2)

When change is not improvement

Participants' attitudes towards this initiative suggested that change was not always perceived as an improvement. Furthermore 'implementation' of the new programme did not guarantee use as a number of participants developed their own system for cardiovascular management before and after the introduction of the scheme;

> *"I think it's a good idea but we were doing it…we find it much harder to do than what we used to do and we were doing more. So now the Heart Watch that has been superimposed…they want so much repetitive work…Its more difficult when its structured badly… it's twice the amount of work that it used to be, for as good as if not slightly lesser service"" (GP112, RGC, P9)*

Another GP developed his own protocol for cardiovascular risk assessment despite having access to the Heart Watch programme, suggesting a duplication of efforts;

> *"…it's [my system] just not as frightening [in terms of length and amount of information required] as the Heart Watch. And I find that user-friendly, I use it a lot now…" (GP101, RSC, p8.3)*

Similar themes emerged in relation to the implementation of the national cervical cancer screening programme including *"over bureaucracy"* (GP112, RGC, p13.1) and the cumbersome

nature of running the programme in the practice. This programme, which was in its infancy at the time of the interviews, involved a patient register however there were doubts as to whether this was a beneficial development leading to wariness about a potential diabetes register.

> *"It's not a perfect system…it seems to be falling over because it seems to be costing itself to run the register, it seems to be getting in the way of delivering the health care…so I'm not sure a register would help if it did that" (GP114, USC, p12.1)*

5.3.2.4 *Resistance to top-down change*

Another theme relating to previous experience, which was raised in relation to the heart disease initiative, was the direction of change. Initiatives were perceived to be developed and implemented from the top-down as opposed to bottom-up. As a result participants felt that change did not reflect the needs and priorities of clinicians delivering care.

> *"The problem is it's worked from the non clinical people in to the clinical people rather than the clinical people working out, and I think that's important" (GP112, RGC, p19.1)*

Participants referred to change being *"imposed"* upon general practice. The language used in the following quote conveys the perceived threatening and intrusive nature of change from 'above'. It also suggests early resistance to changes which are *"imposed"* rather than discussed and negotiated.

> *"There is a* ***force*** *from primary care and from tertiary care and from the powers that control the purse strings to have a computer E-health travel down the way and* ***impose*** *itself eventually* ***on primary care****. This is doomed. It needs to go the other way. It should start here and work that way back up the line." (GP108, RGC, P11.2)*

A number of participants expressed concerns about impending changes which were perceived to be orchestrated by 'others' including the transferring of insulin initiation to GPs (GP106) and *"taking away"* out-of-hours services (GP102). To some participants change was perceived as something which happened *to* general practice, outside of its control, reinforcing the idea of change as threatening:

> *"One thing that concerns me is that* ***they're*** *looking at the volume of blood tests going into labs and I think* ***there's a move afoot*** *to separate [the work] the hospital lab gets every day, just let them do the hospital stuff and then maybe have two or three*

dedicated labs around the country for GP bloods… [That] is a slight worry down the road. (GP110, RGC, p7.3)

Taking advantage of GPs

One participant likened the direction of change to big brother which creates a *"stand-off"* with the GP. As a result of the top-down direction of change and the lack of remuneration, GPs may feel they are being taken advantage of;

"GP practices are often so overworked and overloaded that when something comes down and it's said like this is what you have to do, there's a big kind of 'hang on a minute, we're not paid for this, we're already doing this and this and there's a big kind of stand-off." (Nurse 104, RGC, p25.2)

This was also a perception attached to participation in research as one participant perceived the National Diabetes Register Project to be about "*what can we get a GP to do for diabetics?"* rather than what was best for the patient *(GP109, RSC, p8.3).* This perception could be compounded by the lack of follow-up or implementation on pilot projects.

5.3.3 Widespread engagement requires remuneration and involvement

Based on previous experience participants made suggestions on factors which would promote engagement in quality improvement in the general practice setting. Firstly the lack of remuneration for taking on new aspects of care (e.g. increased involvement in routine diabetes management) or implementing new initiatives fuelled the perception that GPs were taken advantage of. The remuneration for participation in Heart Watch was one of the main advantages of the initiative. This issue was highlighted in the previous study as a barrier to providing optimal care in everyday general practice but was also raised as a consideration for the development of a national diabetes register. It was seen as particularly necessary to engage practices without a special interest;

"it's a factor that needs to be considered if this register is to be rolled out because we have an interest already in diabetes care but other practice may not" (GP6, UCG)

Reflecting the economic and political context of the interviews, GP110 (RGC, p19.4) felt that funding had delayed the development of diabetes care in Ireland up to now and would certainly do so for the foreseeable future given the current financial climate.

Secondly participants emphasised the need to involve clinicians in decisions which affect practices to garner support and engagement in change. This bottom-up approach could

counteract the sense of apathy towards initiatives. One proposed alternative was to introduce changes through professional associations as a way to increase engagement:

> *"…a way to get around that [resistance] may be to bring it [change] in through support groups like the Practice Nurse Association or Community Nurses Association, or the local GP meetings…Maybe bring it in so that everybody feels that they were part of making the decision as opposed to it [being] told to them" (Nurse 104, RGC, p26)*

In particular in relation to setting up a national diabetes register, GP112 felt *"It would need to be liaised…the planning would need to be with clinicians and a sensible manager".*

5.3.4 Learning from previous experience

Participants used their previous experiences as cautionary examples of implementing change in practice, highlighting the potential for those developing diabetes care to learn from the mistakes of other programmes. The themes also highlighted the features of change which lead to scepticism and wariness, namely top down change which does not meet clinical or practice needs and therefore does not represent improvement. This attitude was compounded by a perceived lack of follow-through on ideas and initiatives. In contrast participants highlighted positive experiences of implementing change within the practice, revealing enablers of the process including ethos, interest and leadership. Other factors which could promote wider engagement and *"buy-in"* included remuneration and involvement in decisions-making. Participants' accounts were littered with references of what to do and what not to do, which led to the development of the model in Figure 27 which illustrates how potential pitfalls may be counteracted by those implementing change in the future.

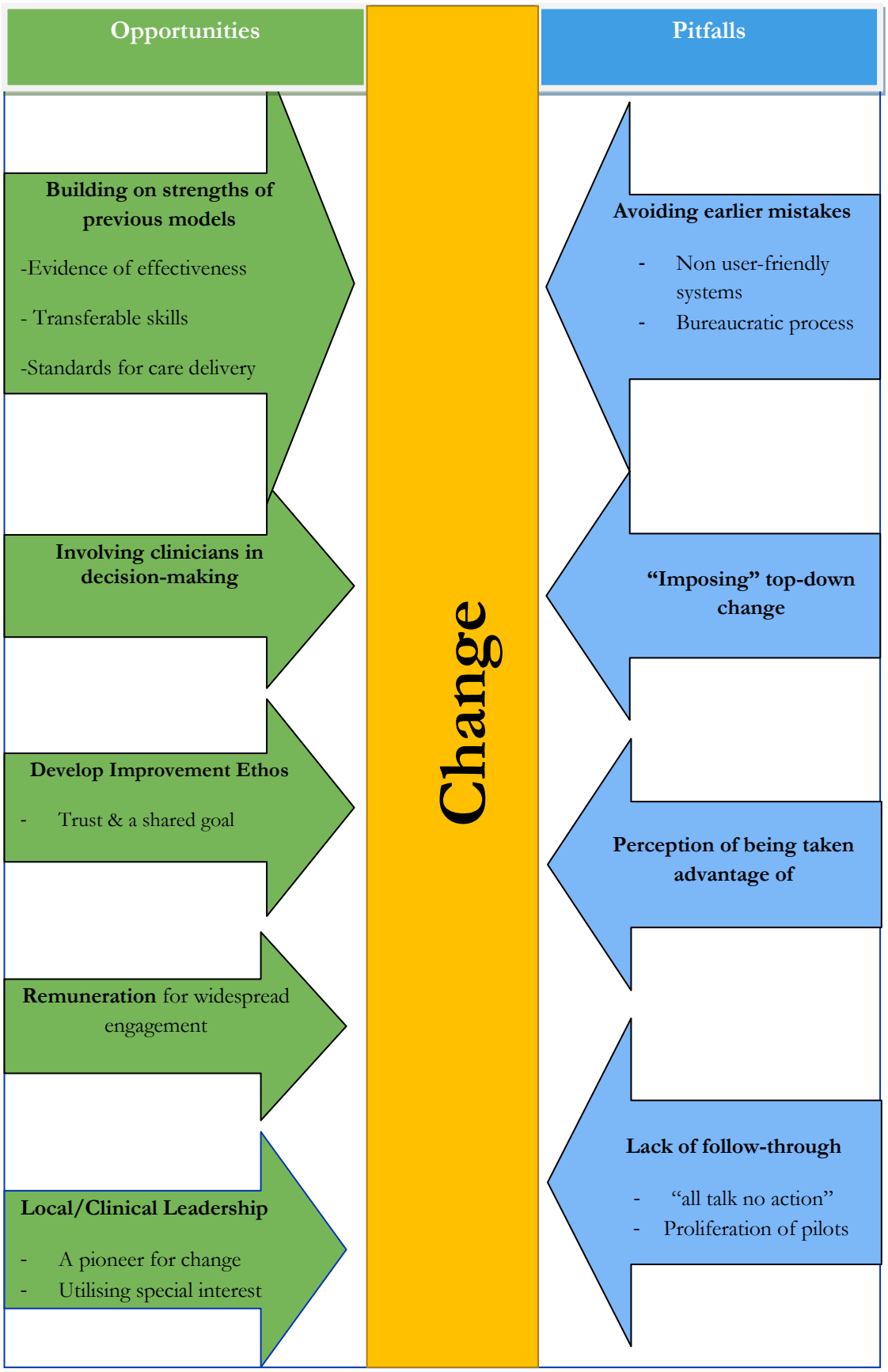


Figure 27 Maximising existing opportunities and counteracting previous pitfalls.

Emergence of Themes

Participants were asked about their attitudes to developing a national diabetes register, an example of a systematic population-based quality improvement initiative. Participants were open to the 'idea' of a national register however attitudes were tentative. They were undecided about the advantages and use of a national register for their individual practice and patients. Preferences varied in terms of whether a register should be maintained at regional or national level. Indeed some participants questioned what additional benefit of having a register at national level. They had given little consideration to the features of a register in terms of key indicators and coding issues. A number of challenges or prerequisites were identified before setting up a register suggesting it may not be a priority for GPs in terms of providing and improving diabetes care in their practice at this time.

5.3.5 Establishing a National Register: important but not a priority

The common thread running through most responses towards a national diabetes register was 'it's a good idea but…' There was support and openness towards the concept of a national register however it was not the number one priority for GPs when thinking about necessary improvements in diabetes care.

> *"I think it sounds like a great ideal…[but] money might be better placed in some other way" (GP114, USC, p10.2)*

A number of subthemes reflect this position. Firstly GPs were uncertain about the benefits of a national register for GP management and patients in their practice. The advantages which were put forward were typically at a national level e.g. research and planning, unrelated to the management of patients. Secondly there were mixed opinions on whether the register should be national or regional. A number of GPs were in favour of a national register that would have data available at a regional level. These attitudes are most likely shaped by previous experience of national level programmes as previously outlined. The enthusiasm and engagement of GPs in the potential initiative was constrained by the logistical challenges highlighted at practice level as well as prerequisites which "would" need to be in addressed before a register could be developed. Hence there was reserved support based on the satisfaction of several other requirements. Finally participants highlighted some concerns about the potential negative impact of a national diabetes register on the way care

is delivered in general practice including the administrative burden such as system could place on the practice. Again the influence of past experience could be seen running through these themes.

5.3.5.1 *Weighing up advantages locally and nationally*

While participants were in favour of the concept or the idea of a national register they were hesitant about the practical benefits for clinicians and patients. Initially participants were silent and unsure of the advantages of a national or even regional register. A number of GPs questioned aloud what the possible benefits would be (GP107 RSC, GP108 RGC, GP111 UGC, GP113 USC, GP115 RSNC).

> *"What would that…, say at a regional level what is the benefit of it, what's the use of it?" (GP111, UGC, P8.3)*

After initial uncertainty, participants perceived the main advantages to be at a national level for planning and research (Table 32). The most *"obvious"* advantage of a national register was to provide information on prevalence which was considered more of a research priority than a clinical priority.

> *"How would it benefit? Just to see how many?" (GP107, RSC, p8.6)*

> *"Mmm [Silence]. I suppose we would know how many diagnosed cases we had in Ireland but apart from that…I don't know what else it could be used for" (GP102, USNC)*

Table 32 Advantages of a National Diabetes Register

Advantages of a National Diabetes Register for Diabetes	
'Knowing the numbers'	"It would be great obviously if they had some demographic information so we could know the incidence, the true incidence of diabetes" (GP105, UCG, p7.1)
Epidemiology & Research	"From a statistical point of view it would give good information about how many people we've got out there registered with the disease" (PN 104,RGC, p19.4) "I think research is important, that's its main advantage" (GP108, RGC, P16.1)
Planning & resource allocation at a national level	"If you had a national register you could then nationally plan…which areas are under resourced" (GP103, UGC, p10.2) "It means financially we can put the resources in the right way…From resourcing things properly, it would be much easier to make an argument to government [for services]" (PN104, RGC, p20.1) "I suppose a national one would give much more information… or locally at HSE level, decisions could be made as to how much funding could be diverted to diabetic care" (GP110, RGC, p15.1)
Quality assurance	"I think it would be possible to meet the targets more clearly if you had a national register" (GP106, UGC, p12.1)
"Sensory signal" to increase awareness of diabetes	"…it's a good trigger. I mean typically if you look at swine flu, when you get statistics thrown out that this is the number of people in hospital & this is the age group, it makes you more aware that when you've got a 24 year old coming in as opposed to somebody of 69/70, that you're thinking in a different direction… you're more aware and tuned in" (PN104, RGC, p21.3)

Participants questioned the specific advantages of a national register for patients and the practice. Those participants who maintained practice registers highlighted the advantages of a *practice* register in organising care facilitating activities such as identifying the number of patients, targeting interventions towards that group and ensuring the completeness of care (e.g. GP113, USC, p8.2). There was a sense of ownership and therefore responsibility to register a practice's *"own"* patients:

> *"If I have my own diabetics registered on my own computer here…isn't that all I really need to (do)" (GP110,RGC, p15.2)*

However the benefit of a national register to the individual patient with diabetes was called into question. Participants focused on *"how it would make a difference to an individual patient that their information is on a register" (GP113, USC, p9.1).*

> *"I wonder if Mr. Blogs comes into me and I say I'm going to put you on a regional register and he's gona say 'what's that gona do for me'" (PN104, RGC, p20.2)*

5.3.5.2 *Regional versus national register: a question of control*

Participants expressed different preferences in terms of the development of a regional register or a national register. A number of participants were in favour of a national register with regional capabilities i.e. data available for each region. Regional-level information was perceived to be of more use than national data, reflecting participants' primary interest in their own area and their body of patients.

> *I'm not sure how useful on a national basis all that [information on key indicators] would be. I definitely think on a regional basis that would be really useful" (GP103, UGC, p13.1)*

When asked about her thoughts on a national register, one GP (GP115, RSNC), felt it could be helpful for planning as *"we were waiting a long time for a dietician in the community",* taking the topic back to local issues in that rural area (p5.3). Some participants argued for *"local, individual services"* (GP108, RGC). Drawing on experience of national level change, participants conveyed a sense of wariness towards centralised services which were beyond their control;

> *"Take the cervical smear cytology thing [screening programme], they're already showing signs of rowing back their commitment to that. So there you are, economic whim of the government, and suddenly, we won't keep it going the same way anymore, so it's better to have it local. In practice, or area, as in the County X... It smacks to me of central power" (GP108, RGC, p16.2)*

Conversely another GP used the example of the cervical screening programme to emphasize the need for a national register as regional efforts were considered *"too piecemeal";*

> *"I think of the experience from cervical check and breast check and all the various screening programmes, it's too piecemeal, too much duplication of effort without any clear cut benefits unless you've implemented it at national level" (GP106,UGC p13.3).*

5.3.5.3 *Concerns & conditions before setting up a national register*

The finer details of developing a register did not appear to overly concern the participants. Most had not considered which indicators they would like included on the register for example. This lack of concern with the detail of the initiative was in contrast with the concerns and conditions surrounding the development and wider implementation of a national register. The concerns presented in Table 33 were reflective of the unstable

environment in which health services were being provided at the time. The concern that data from a national register would be used to take away services stemmed from the downgrading or 'reconfiguration' of care from smaller locations to larger centres.

Participants also outlined a number of prerequisites that would need to be in place before a register could be established and a number of conditions the register would have to satisfy. One of concerns about the initiative related to the logistics of developing a register in the absence of complete computerisation in general practice and the varying degrees of computer usage within practices:

> *"I don't think everyone is computerised so that would be a big challenge. For me it's a press of a button and I can give you my list of diabetics in 5 minutes…Even if they are [computerised] what percentage of them are actually using those kinds of programs. In a lot of places I worked before they were just using the computer to print prescriptions. So they didn't even have their diabetics registered as diabetics" (GP107, RSC p9.1)*

Paradoxically the lack of computerisation was not considered problematic by *non-computerised* GPs and was not perceived as a barrier to their involvement in a national diabetes register;

> *"This is my style. It suits me and I enjoy how I do it. And I think me patients like it as well…But I would like to see us having a place in anything that would develop, that's why I was keen to meet with you. I think we have a role in it and would like it to be considered" (GP115, RSNC, p4.2)*

Another concern was the *"fluidity of the practice population"* in Ireland as it is not obligatory to register with one GP or practice. The following quote sums up the overarching position of the participants; a register was perceived as a positive and necessary development but…

> *"…the only way to deliver the standard of care the patient deserves would be to have a diabetic register* ***but*** *in Ireland we've the whole issue of the fluidity of the practice population, nobody knows what their practice population is so you're trying to shoot a moving target" (GP106, UGC, p5.1).*

Participants used tentative language when outlining the prerequisites that would need to be in place before a register could be established and conditions the register would have to satisfy (Table 33). The caution and uncertainty reflected previous negative experiences of change and a growing sense of wariness and inertia towards ideas for improvement.

Table 33 Concerns & conditions regarding the establishment of national diabetes register

Concerns	
Risk of diverting resources	"I've no problem with it but on the other hand if it's something like 6 sheets have to be filled in every time somebody new was diagnosed as diabetic...it's all about balance. It can't be a burden and in particular it can't be an administrative burden" (GP111, UGC, p9.1)
Being used to take away services	"That's the flip side (to planning). It's exactly what happened in [local hospital]; they looked at how many surgical cases we had there and not they are pulling our surgical services. " (GP107, RSC, p9.2)
Conditions	
Universal Patient Registration	"I don't see how that can work ***until*** you've got a GPs practice registered as well...You can't be responsible for something until you know for definite it is your ***realm of responsibility***" (GP106, UGC, p12.3)
Driven by clinical aims	"It ***depends*** on the layer of bureaucracy that goes with it...***As long as*** the its aims are not too high falutin', as long as they're very practical and clinically sensible" (GP112, RGC, p13.2)
Perceived practical value	"What we would want is that it ***would be*** useful for those using it and those providing care, so it would not be seen as something just for research, because I don't think that would engage health professionals" (GP113, USC, p8.2)
Benefit to patients	"It ***would have to*** have some benefit to the patient because otherwise you'd be continually chasing people with sticks trying to get them into the system." (GP114, USC, p11.1)
Planning	**"If** it were to be done, it should really be done with a lot of thought into what's the best way to do it..." (GP109, RSC, P8.3)

5.3.6 Engaging in Audit- a special interest

Emergence of Themes

Similar attitudes emerged towards audit as a mechanism for quality improvement within the practice. Firstly there was limited involvement in audit among participants and even less experience of auditing diabetes care specifically. However those who had experience of conducting audit reported on resulting changes in practice. Some participants referred to auditing individual patients' care whereas this could have been more accurately described as a case review of an individual patient's progress. Again time emerged as the main barrier to engaging in audit as well as lack of training. Participants felt the main benefits of auditing care were to increase awareness within the practice and to ensure consistency of care. There was resistance among some GPs to what they perceived as *"tick the box"* management, related to the concerns regarding target-based remuneration outlined in the previous study.

5.3.6.1 *Limited use of audit in practice*

Participants had different interpretations of auditing care, referring to a review of cases on an individual basis and an inspection of care delivered to a group of patients. In the former case, participants' descriptions appeared to be more of a case management exercise. Few participants referred to auditing the care of groups of patients (e.g. patients with diabetes). Only one GP raised the issue of audit independently during his account of how diabetes care was provided at the outset of the interview (p2 of transcript) suggesting it is considered part of the overall care process. In most instances however it was non-existent or sporadic rather than a continuous process of quality assurance.

> *"Once [we had an audit], when we were becoming part of the Diamond project. They came out and they had a look at; firstly how often our patients were being called in [to the hospital], what type of things we were asking them, whether we were kind of covering everything they would cover in a clinic" (PN104, RGC, p9.2)*

The use of the word *"they"* suggests a lack of ownership over the audit process as it was not conducted for the purposes of the practice but for the purposes of a hospital-led project. This contrasted to the sense of ownership reflected in the participant's account of how the GP and Practice Nurse reviewed patients' care before establishing a structured approach to delivery. This was not referred to as an audit however:

> *"I culminated a list [of patients] with [the GP] and we went through each one to see whether they visited the hospital on a regular basis, how well controlled they are, what we could do*

from a recall point of view or whether we could take over a large abundance of their care" (PN104,RGC, p1.2).

5.3.6.2 *Audit as a professional aspiration rather than routine practice*

There were mixed attitudes towards audit as part of care. Some participants were open to the process as a quality assurance mechanism but hadn't had time (GP110, RGC, p10/ GP108, RGC, p8.2/ GP113, USC, p4.3). Uniquely one participant felt strongly that auditing care was part of the professional role of a doctor.

"You cannot defend, morally defend, not doing an audit. You just can't. You can't call yourself a real doctor I think, until you do that" (GP108, RGC, p8.2)

This was a strong opinion from a proactive GP heavily involved in providing diabetes care as a member of a formal initiative. Another participant also spoke about audit as part of a professional role but as *"a level we aspire to"* rather than a part of routine practice. It was described as part of the *"intellectual ideals"* of general practice however in reality there are competing pressures of time and having to pay the bills (GP110, RGC, p10.1). This relates to attitudes which emerged in relation to patient registration; greater prioritisation of and commitment to individual patient care than patients' as a group or population.

5.3.7 Audit leading to change and improvement

Those who had engaged in routine audit highlighted the benefits of this quality assurance activity (Table 34). In contrast to the advantages of a national register, the benefits of audit were within the practice. It was another example of the positive experiences of engaging in change within the practice. In particular the results of audit had highlighted areas for improvement. In some instances the results of audit generated interest in improving care and were a motivating factor behind changes in practice. Finally audit ensured a consistent standard of care was delivered to patients across locations.

Table 34 Advantages of engaging in audit in the practice

Advantage	Quote
Increasing awareness	"I do a lot of audits within the practice, things like blood tests; where we do blood tests and patients don't follow up on it. It was quite surprising how many people came in for bloods and didn't follow them up. So then we put in a plan of action to phone them if they hadn't phoned after 3 weeks" (GP107, RSC, p3.5) "By auditing you realise that…ok you assumed everyone would be on aspirin and indeed that wasn't the case so it was a good idea to do that" (GP112, RGC, P19.2)
Driving Change	"Really it was an audit of our MIs and seeing there were a lot of secondary things that we could have managed better. So we looked at the target group and just tried to get them better controlled. And also my nurse has an interest, she's a cardiac ICU nurse, her interest was in cardiac care so we tried that first" (GP107, RSG, p6.4)
Ensuring consistency	"I think it's absolutely important because you could have one practice doing fantastic things and another just falling short and then you've got a patient living in this place not getting as good as here…I think you have to have audit across the board to make sure everybody's standard is the same. And also to make sure people are being given the same advice…" (PN104, RGC, p10.1)

5.3.8 Concerns and Conditions for Audit

Similar to attitudes towards registration, there were certain concerns and conditions which dampened participants' enthusiasm for engaging in audit. The issues were not only raised by those who were not engaging in audit but also those who had previously cited positive experiences. Again there was a logistical concern regarding data entry and the consistency of human behaviour. The GP in the following quote monitored care with an 'audit mindset' suggesting quality improvement needs to be part of routine practice:

> *"Data entry is very important if you're going to be collecting data [for audit]...we're fairly careful in using [the computer software] terms because I do a lot of auditing and recall...I enter it with audit in mind at the end...But not everyone is thinking when they first enter it. And you see it with locums as well when they are writing notes they write short hand, some kind of code that makes sense to them." (GP107. RSG, p10.5)*

5.3.8.1 *Balancing consequences of audit*

The main conditions related to incentives or encouragement to conduct audit. Participants felt that *"unless there is really good motivation and reward at the end of the day it's just too much time" (GP107, P3.3).* However there were differences of opinion as to the governance of audit and the consequences of this quality improvement activity if standards of care were not met (Figure 28).

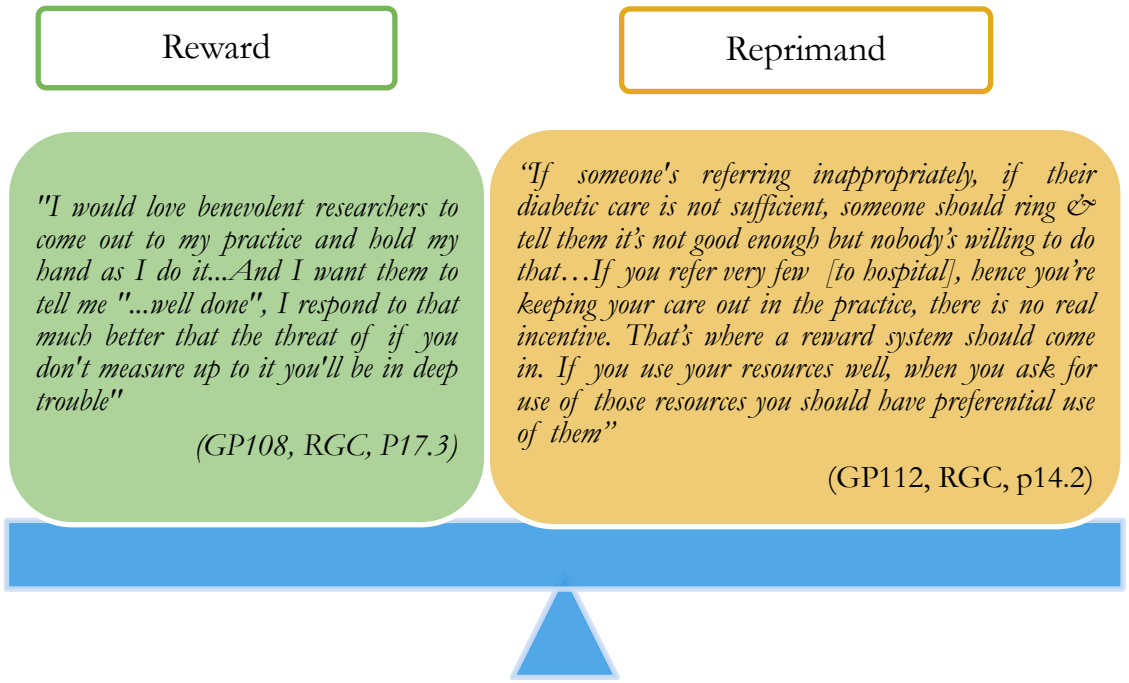


Figure 28 Balance between rewarding and reprimanding audit performance

5.3.8.2 *"Ticking Boxes"- quality assurance as a threat to autonomy*

Concerns about the use of audit within the health system as a means of monitoring and remunerating care reflected wariness of efforts at a national level to improve care. The issues were highlighted by participants in the previous chapter in relation to the merits of a pay-for-performance model of remuneration for diabetes care. Monitoring diabetes care through audit was described as *"tick the box"* management and was perceived to place all the responsibility on the GP to meet targets which in some cases were not achievable:

> *"…take vaccinations, it only takes 1 or 2 families who are not going to vaccinate to completely upset your whole system…I don't think much of a system that kind of puts the responsibility on to me…" (GP111, UCG, p12.1)*

Furthermore monitoring diabetes care nationally through a national registry for example was seen as threat to doctor autonomy. One participant highlighted the risk of disempowering health care professionals through this type of quality improvement activity:

> *"Quality of care... you've got to get the balance between disempowering…,If I'm just a monkey filling in boxes, there's no autonomy, no decision making powers, you've got to follow* ***their*** *protocol which has been laid down by the National Registry perhaps…That's one of the disadvantages, it disempowers me, makes me less enthusiastic and I just feel like I'm just*

a teeny little unimportant piece…I don't get the same enjoyment out of managing it [diabetes]" (GP108, RGC, p17.3)

This quote highlights the lack of ownership felt by the GP in this situation. It also reiterates the importance of the direction of change when developing and implementing initiatives. There is a balance to be struck between quality assurance as a threat or a tool for high quality management.

5.4 Discussion

This study explored attitudes and openness to quality improvement initiatives in general practice, through the narrative of previous change experiences and potential future involvement in quality improvement. This study was part of a qualitative phase of research undertaken by the National Diabetes Register Project (NDRP) to inform the development of a national register. The findings illustrate how previous experience can shape attitudes to and enthusiasm for future quality improvement initiatives. Previous experience of change in the health system was used as cautionary examples for those seeking to reform diabetes care as participants highlighted the pitfalls and problems developing and implementing change at a national level. There was a contrast between the positive experiences of initiating change within the practice, enabled by a *"practice ethos",* local leadership and special interest, and changes *"imposed"* upon general practice. Previous experience contributed to the wariness and scepticism towards the development of a national diabetes register. Firstly there were doubts about the benefits of a population-level initiative such as a national register to individual patients and practices. While there was tentative support for the concept participants were keen to highlight the conditions and concerns surrounding the establishment of a national register. Similarly while participants emphasised the benefits of conducting audit within their own practice, there was concern about the use of performance information to monitor or judge the quality of care in general practice on a wider scale.

5.4.1 Attitudes influencing interest in future improvement initiatives

The results of this study conducted in Irish general practice suggest health care professionals' attitudes can influence openness and enthusiasm for future change. This finding is in keeping with the relationship between attitudes and behavioural intentions proposed in a number of psychological theories. For example, Ajzen's Theory of Planned Behaviour suggests intention to act is shaped by attitudes, perceived social norms and perceived behavioural control (221). In turn attitudes are influenced by expected outcomes. The attitudes of participants in this study suggest a low expectation of successful change in the Irish health system given previous experience. Scepticism is a common response to proposed innovations to improve the quality of care stemming from the perceived similarity of old and new efforts to improve care, efforts which are often at odds with what doctors think is important (70). Participants in this study emphasised the need to learn from the past mistakes, particularly when developing disease management systems for general practice. In the past the lack of correspondence between systems for cardiovascular disease management and the needs of the practice meant that in some instances GPs were forced to create their

own patient management systems or reverted back to original ways of organising care. This experience illustrates that change does not always lead to the increased efficiency and improvement expected.

Another source of scepticism revealed in this study was the empty promise of change in the health system and the proliferation of short-term pilot projects leading one GP to comment *"nothing in my lifetime has ever happened"*. The exasperation and perceived lack of follow-up on pilot projects has serious implications for health services research in Ireland as it may pose a barrier to recruiting health care professionals as participants and engaging these professionals in the development and implementation of quality improvement interventions in the future.

5.4.2 Participation in the development and implementation of change

Personal commitment and a desire to improve care have been identified as factors which motivated primary care professionals to participate in quality improvement initiatives (218, 222). Similar themes emerged in this study as participants referred to having a special interest and receiving *"buy in"* from other members of staff in the practice as enablers of change in the practice. In contrast national-level initiatives were described as being *"imposed"* on general practice which generates a *"standoff"* between health care professionals and management. A lack of ownership over initiatives introduced from outside the practice, reflected for example in the continued use of the word "they" by participants, can act as a source of inertia towards change and improvement (209).

Participation, through involvement in design and implementation, is one of the key strategies for managing resistance among those expected to accept change according to Kotter and Schlesinger, experts in the field of change management (223). Participants in this study wanted more involvement in the development of quality improvement initiatives and promoted it as a way to increase interest and engagement in change among health care professionals. Participation is particularly useful when initiators of change do not have all the information they need to implement change (223). The health care professionals who participated in this study highlighted a number of pitfalls and prerequisites to inform the development and implementation of a national register including the need for universal registration at general practice level and the importance of developing a system which is user-friendly and clinically relevant to GPs.

Another factor to be considered prior to implementation is the characteristics of the innovation itself. The perceived advantages, utility, complexity and risks could help or hinder

implementation (68, 224). In terms of the innovation explored in this study, a national diabetes register was considered to be of little advantage to people with diabetes and of limited utility in the general practice setting. In addition, there were concerns that a national register would divert resources from other priorities or that resulting data would be used to downgrade services in the light of previous experience of 'reconfiguration' in the Irish health system. This expressed wariness towards change in the national health system suggests a real lack of trust between those initiators and implementers of change.

5.4.2.1 *Priorities in Diabetes Care*

As mentioned previously, different assessments of the needs of an organisation can lead to resistance towards change (70). The sense of inertia towards the development of a national diabetes register among participants in this study contrasts to the impetus placed on a register as a pillar of comprehensive diabetes management in research and policy circles. This contrast suggests a discrepancy between the values and needs perceived by policy makers and researchers and those prioritised by health care professionals delivering services on the ground. According to participants the main use of a national diabetes register was as an epidemiological tool to *"know how many"* people had diabetes in Ireland. However, experts in the field of quality improvement suggest this is just a starting point as without knowing and tracking the patient population, we cannot monitor and improve the health status or care experience of patients and we cannot adequately plan to meet the needs of the population (225). Yet given the deficiencies in local services and barriers to providing routine care in everyday practice highlighted in the previous study, the establishment of a national register was not a priority for those interviewed. According to Coiera (2011) inertia towards reform is a natural response in the face of such competing demands and any intervention will struggle to succeed in a system which is 'over-constrained' regardless of its merits (207). The success of an innovation in the presence of such inertia requires the supply of new resources to meet additional demand. Hence for a quality improvement intervention to succeed in the Irish health system there is a need to address the barriers to provision highlighted in Chapter 4.

5.4.3 Developing a quality culture in Ireland

Questioning the benefits of a national register for their *"own"* patients, participants revealed the tension between population-level change and the needs of individual patients sitting in front of GPs and nurses day after day. The shift in the traditional concept of professionalism towards civic responsibility addresses this tension, as it extends the accountability of the

health care professional from the individual patient to the community of patients as a whole, as well as potential patients in the future (206). An essential part of 'civic professionalism' is the commitment to quality of care and quality improvement. The involvement of health care professionals is *"not simply desirable but also essential"* (71). The emerging concept of 'civic professionalism', which posits quality improvement as a commitment and responsibility of all health care professionals (206), resonates with the principles to the industrial style Total Quality Management (TQM) (78, 213). At present quality improvement in Ireland is not viewed as a 'civic activity' embedded in the organisational and professional culture of the health system, but rather a special interest pursued by *"pockets"* of professionals.

One approach to changing the organisational culture in health care is to draw on existing strengths in the health system (226). One of the strengths highlighted in this study which enabled change was the *"practice ethos";* a sense of trust between members of the team and a shared goal to improve patient care and outcomes. Hence quality improvement activities were valued within the practice and *"everyone buys into that"*. The 'practice ethos' which emerged in this study relates to the definition of culture proposed by Donabedian which described culture as the prevailing set of values and beliefs about the importance of quality and who is responsible for ensuring it (28). Another enabler of change at a local level was the presence of local pioneers of change who initiated schemes and improvements within the practice and wider community. Interventions involving opinion leaders can lead to improvements in evidence-based practice in both primary and secondary care however the exact role of a leader is not clearly described in studies (227). Over the last two decades improvements in diabetes care in Ireland have largely been led from the ground up by 'local champions'. However developing a culture of quality improvement requires leadership at all levels of the health system (228).

The values and attitudes which influenced the practice ethos in this study are just one articulation of a culture of quality improvement in health care. Another level of organisational culture is the 'artefacts' or observable manifestations of a culture (214). In healthcare this could refer to incentive structures or technology for monitoring and assessing performance to facilitate engagement in quality improvement (208). This level of culture requires funding and investment and is currently missing in the Irish health system. Widespread participation in quality improvement can only be expected when an infrastructure is put in place to support it, including IT systems for data collection and information sharing, incentives and continuing professional development (229).

5.4.4 Strengths & Weaknesses

One of the most useful qualitative interviewing techniques is the use of concrete experiences rather than abstract notions when eliciting attitudes from interviewees (177). The proposed establishment a national register was a useful interview tool for eliciting views about population-based change and change at a national level. However as there was limited engagement in quality improvement activities beyond sporadic audit within the practice setting, it was more challenging to elicit attitudes towards other improvement strategies such as benchmarking and the use guidelines. While there was overlap between the barriers and facilitators to delivering and improving care such as remuneration and having a special interest, this study highlights the subtle distinction between the activities which few other studies have highlighted (222). As Berwick contends that being a better doctor and creating a better system are two different jobs each with its own skill set (230).

This is one of the first studies to explore the context of change in the Irish health system and attitudes to quality improvement. The findings of this research are timely as there are imminent changes proposed for general practice including the current health policy proposal to provide free GP care for all patients as part of universal health insurance. Diabetes care in Ireland is also in transition as the National Working Group for Diabetes, under the Clinical Care Programme, set about implementing a national retinopathy screening programme and a national model of integrated care.

5.4.5 Conclusions

This study highlights how previous experience can shape attitudes towards future plans for quality improvement. There is a growing sense of inertia towards change at a national level. This sense of inertia also stems from the competing demands of delivering routine diabetes care in a system with dwindling resources. The culture which facilitates change within the practice is absent at a health system level. In line with the concept of civic professionalism, quality improvement needs to be considered part of the day job. This requires a shift in professional culture and investment in an infrastructure to support participation.

6 The Quality of Primary Care-led Diabetes Management: a Bottom-up Approach to Improvement

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Dr. Velma Harkins

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Abstract

Aim: The aim of this study was to assess the quality of structured Type 2 diabetes management in three primary care-led initiatives in Ireland, a bottom-up approach to improvement in a country with minimal incentives to promote the quality of care.

Methods: A purposive sample of three initiatives, engaging in regular audit, participated in this study. Data on processes of care and intermediate outcomes were available for 3010 adult patients with Type 2 diabetes. Results were benchmarked against the national guidelines for the management of Type 2 diabetes in the community, results from an audit of shared diabetes care in Ireland, and results from the National Diabetes Audit (NDA) for England (2008/2009) and the Scottish Diabetes Survey (2009).

Results: The recording of clinical processes of care was similar to results in the UK however the recording of lifestyle factors was markedly lower. Recording of HbA1c, blood pressure and lipids exceeded 85%. Recording of retinopathy screening (71%, n=1872) was also comparable to England (77%) and Scotland (90%). Only 63% (n=1263) of patients had smoking status recorded compared to 99% of patients in Scotland while 70% had BMI recorded compared to 89% in England. A similar proportion of patients in Ireland and the UK achieved clinical targets. Thirty-five percent of patients (n=948) achieved the national target for HbA1c of ≤6.5% (<48mmol/mol) compared to 25% in England. Applying the NICE target for blood pressure (≤140/80mmHg), 54% of patients reached this target, 6% lower than the level of achievement among patients with Type 2 diabetes in England (60%). Approximately half of patients with Type 2 diabetes were categorised as obese (>30kg/m^2) in Ireland (n=1060) and Scotland (54%).

Conclusions: This study demonstrates what can be achieved by proactive and interested health professionals in the absence of national infrastructure to support high quality diabetes care. The quality of primary care-led diabetes management in the three initiatives studied appears broadly consistent with results from the UK. The challenge facing health systems is to establish quality assurance a responsibility for all health care professionals rather than the subject of special interest for a few.

This study has been accepted for publication in BMC Health Services Research

6.1 Introduction

6.1.1 Increasing the role of primary care in diabetes management

The persistent gap in the quality of health care has been attributed to the inability of health systems, which are oriented towards acute episodic care, to meet the needs of patients with complex chronic conditions (10). It is now widely accepted that this hospital-heavy model of care will not cope with the future burden of chronic disease and as a consequence health care systems are examining ways to reorganise services with growing emphasis on the role of primary care (11, 13).

A common feature of the reorganisation of health systems in developed countries is the shift of chronic illness care such as diabetes management from the hospital setting to the community. An important proviso of this transfer is that care in the general practice setting is structured, planned and integrated (1). A systematic review found care in the community was as good as or better than hospital-based care alone in terms of mortality rates, HbA1c concentrations and loss of patients to follow up when it was structured with intensive support for GPs (231). In the qualitative study of the barriers and facilitators to optimal diabetes management presented in Chapter 4, GPs suggested the potential of general practice was stifled by the lack of resources and insufficient access to support services.

6.1.2 Providing Structured Diabetes Care in the Community

Structured care interventions have been described as a series of *'multifaceted disease management strategies'* (p8) (133) and typically involve a combination of organisational, professional and patient level interventions. A systematic review of multidimensional professional and organisational interventions to improve the quality of diabetes care demonstrated a positive impact on the processes and outcomes. Combining patient education with these interventions and enhancing the nurses' role led to improvements in patient outcomes however outcomes beyond measures of glycaemic control tended to be neglected (14). Another trial of structured primary care involving diabetes registers and input from 'local physician champions' had a impact on processes and outcomes of care for patients with Type 2 diabetes (111). Structured care can also have a positive impact on psychosocial outcomes as demonstrated by two studies conducted in Ireland. Significant improvements were identified in treatment satisfaction and well-being as well as process measures, following an intervention delivering structured shared diabetes care to patients with Type 2 diabetes (138). Furthermore an observational study examining the relationship between models of care and quality of life, found that patients with diabetes receiving structured care

in general practice reported better quality of life compared to patients under a traditional or mixed model of care (20).

6.1.3 Reorganising Diabetes Care in Ireland

The adoption of a structured approach to diabetes care in general practice is the exception rather than the rule in Ireland. As illustrated by the survey of diabetes care in general practice presented in Chapter 3 of this thesis, care is often ad-hoc with limited adoption of strategies to enhance organisation such as patient registries or formal recall systems (170). Approximately half of the GPs surveyed reported using guidelines with fewer still referring to national guidelines for diabetes management in the community. Access to essential support services such as dietetics and retinopathy screening was inconsistent with multiple providers of services.

Within this opportunistic system, there are a number of 'islands of excellence' providing comprehensive systematic care for patients with diabetes. There are currently ten initiatives ranging from shared care arrangements (139), to structured care initiatives set up by GPs, to more recent initiatives which are mainly characterised by the appointment of a diabetes nurse specialist. Similar to shared care arrangements in the Netherlands (7), shared care in Ireland is characterised by *'joint participation between hospital consultants and general practitioners in the planned delivery of care'* for patients with diabetes (141). This joint participation is facilitated and supported by a Diabetes Nurse Specialist.

Structured care has connotations with primary care-led diabetes management in Ireland as illustrated by the findings of the qualitative study of diabetes care presented in Chapter 4. Three initiatives pioneering a structured approach to diabetes care in the community have engaged interested proactive health care professionals in a bottom-up approach to improving the quality of care and patient outcomes. Through the dissemination of regular audit reports, each group has independently contributed to the evidence base for structured primary care-led diabetes management in Ireland (137, 140, 232). The aim of this study was to profile the performance of this group of 'champions' against that of the national system of diabetes care delivery in the UK where care provision is supported by a dedicated policy framework, population-based retinopathy screening, robust IT systems and a financial incentive structure to promote quality assurance.

6.1.4 Aims & Objectives

As part of the aim to examine efforts to bridge the quality gap around diabetes care at practice and policy level the objective of this study was:

1. To assess the quality of structured Type 2 diabetes management in practices with a special interest in diabetes, a bottom-up primary-care led approach to improvement, and to compare the performance to that of a national system of diabetes care (UK).

6.2 Methodology

6.2.1 Design

This cross sectional study was based on data from primary care-based initiatives across three regions of Ireland; the Diabetes Interest Group Cork (DIG) in the South of Ireland, the HSE Midland Area Diabetes Structured Care Programme and HSE North East Diabetes Watch.

6.2.2 Sample

6.2.2.1 *Practices*

A purposive sample of three primary care initiatives participated in this study. Three of the most well-established primary care schemes were chosen, all of which conducted and disseminated regular audit. There are currently 10 diabetes initiatives in Ireland, however most did not engage in the routine collection and analysis of audit data at the time. Although a purposive sample of schemes was used, within each scheme all practices took part in the audit (n=63). The sample represents a small proportion of the total number of GPs in Ireland (approx. 1%), reflecting the special interest in improving diabetes care.

Participating practices were from a mixture of urban and rural areas and included single-handed and group practices. All practices provided structured care to patients with Type 2 diabetes in the general practice setting, which involved continuing professional education, incorporating guidelines, maintaining practice registers and engaging in regular audit and feedback. Each practice employed a Practice Nurse. Some patients were also attending secondary care as required. Specialist input was provided in one initiative by a Diabetes Nurse Specialist while the other two initiatives were coordinated by a Diabetes Nurse Facilitator. Practices also received administrative and audit/research support to manage the initiatives.

Two of the three initiatives financially reimbursed general practices for their involvement in the scheme. In the Midland Area Diabetes Structured Care Programme, practices were reimbursed for Practice Nurse time or through participation in the Heart Watch Programme, the disease management programme for cardiovascular disease. GPs involved in Diabetes Watch were paid per patient visit and also had an annual target to achieve in order to receive a bonus payment. Practices involved in the third initiative, the Diabetes Interest Group, did not receive payment in any form for participation.

Prevalence

It was not possible to calculate the prevalence of Type 2 diabetes in this sample as it is not mandatory in Ireland for patients to register with a single general practice; therefore we lack a reliable population denominator. The prevalence estimates for each region from the Institute of Public Health (IPH) (39), are comparable with the estimated national prevalence and the prevalence of Type 2 diabetes in Scotland and England (Figure 29).

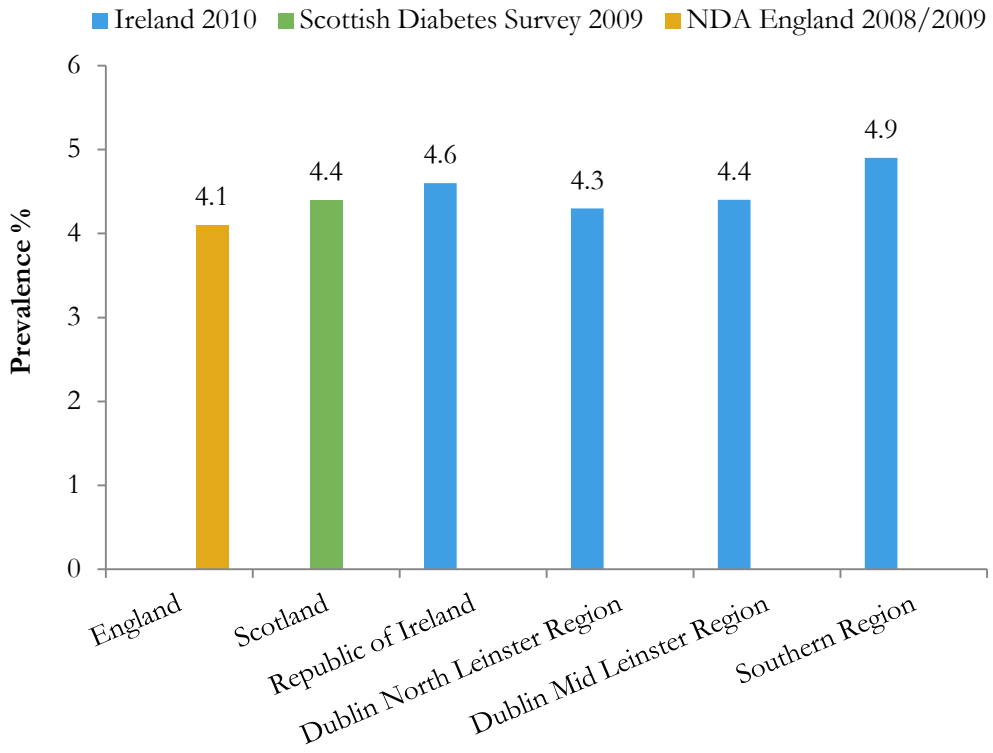


Figure 29.Estimate of population prevalence for Type 2 diabetes in adults in 2010

6.2.2.2 *Patients*

Adult patients (≤18 years old) with Type 2 diabetes who were registered with a participating practice were eligible for inclusion in the analysis. Type 2 diabetes was defined on the basis of standard clinical and blood glucose criteria (12). Patients with Type 1 diabetes and Pre-diabetes were excluded from the analysis.

Due to the large number of patients enrolled in the HSE Midland Diabetes Structured Care Programme (>3000), a random sample was selected from each practice and included in the overall analysis. A sample size of 1168 patients (51%) was calculated using glycaemic control (HbA1c level) as the outcome measure with a confidence level of 95% and a difference of 2%. In a previous audit, the mean HbA1c for the total

sample was 7.6% and the 95% confidence interval was ± 0.11% which equates to ~1.5%. Data were available on 989 patients with Type 2 diabetes (47.1% of total sample) which was 97 patients less than the determined sample size as a number of patients recorded on the database as current had died, left the practice or had been transferred to a nursing home.

6.2.3 Data Collection

Data collected between late 2007 to early 2009 (≤12 months in each area) were collated into a single dataset for analysis. All data were collected manually by practices themselves or by the DNS/Diabetes Nurse Facilitator (Table 35). Data sources included the patient's clinical notes (electronic and paper), letters in the clinical notes regarding outpatient appointments in hospitals and referrals to other services (chiropody/podiatry, retinopathy, dietetics etc).

Table 35 Data Collection across the 3 Initiatives

	HSE Midland Area Diabetes Structured	Diabetes Interest Group	Diabetes Watch
Number of practices	28 GPs	12 GPs	23 GPs
Number of patients	989 (47%)	1006	1015
Data collection period	Nov 08-March 09	Dec 07-May 08	Jan 08-Dec 09
Data Collection Method	Diabetes Clinical Nurse Specialists	Diabetes Nurse Facilitator	Excel datasheets completed by practices at each visit & submitted to Diabetes Nurse Facilitator
Sample	Random sample from each practice	All patients registered with participating practice	All patients who attended 2nd visit during 2008

As there was slight variation between the three primary care initiatives regarding the data collected, a comparison exercise was conducted to determine common data (Appendix XV). All data collected was based on the previous 12 months. Table 36 shows details of variables common across all three initiatives.

Table 36 Common dataset across 3 primary care-led initiatives

Demographics	Process of care	Intermediate Outcome of Care
Gender	Recording of HbA1c	HbA1c
Age	Recording of Blood Pressure	Blood Pressure
	Recording of Body Mass Index	Body Mass Index (BMI)
	Recording of Total Cholesterol concentration	Total Cholesterol concentration
	Recording of LDL Cholesterol concentration	LDL Cholesterol concentration
	Recording of HDL Cholesterol concentration	HDL Cholesterol concentration
	Recording of smoking status	Smoking Status
	Retinopathy screening in past year	
	Foot Assessment in the past year	
	Treatment with statin/aspirin	

6.2.4 Comparators

National Comparison

The national guidelines for diabetes care in the community, *"A Practical Guide to Integrated Type 2 Diabetes Care"*, were used to define the optimal standard of care in Ireland (17). The guidelines set targets for the achievement of outcomes and the relevant cut-off points are indicated in the results section. Data were also compared to the results of the most recent audit of shared care in Ireland completed by the East Coast Area Diabetes Shared Care Programme (ECAD) (139). This enabled a comparison between two models of care; primary care-led structured management and shared care between GPs and the hospital based team. Established in 2001, the ECAD shared care scheme involves 11 GP practices and 3 hospitals. The most recent audit was based on data from 261 patients with Type 2 diabetes. Data were collected from the GP practices and entered onto an excel spreadsheet by the GP, Practice Nurse, DNS or dietician, similar to data collection in the Diabetes Watch Programme.

International Comparison

Comparisons were drawn with the National Diabetes Audit (NDA) for England for the corresponding period of 2008/2009 (233). This is the largest annual audit of diabetes

services in the world with over 1.5 million people with diabetes included, 75% of the diabetic population in 2008/2009. All primary care trusts in England (n=152) contributed data from the majority of GP practices in England (71%, n=5920). The NDA 2008/2009 data are contained on the NDA "Dashboard" where data represent Type 1 and Type 2 diabetes combined. The published executive summary report contains some results stratified by type of diabetes and where available figures for Type 2 diabetes are reported. Data from the National Diabetes Audit for Wales were excluded from this study as results were based on data from 31% of practices in Wales, and therefore were not considered representative.

The quality of care provided by primary care initiatives in Ireland was also compared to results from the Scottish Diabetes Survey (234). The population level survey is published annually by the Scottish Diabetes Survey Monitoring Group. It collates nationally agreed data submitted by 14 NHS Boards incorporating both primary and secondary care. Diabetes registers, held by each health board, are the main source of data for the survey. Results from 2009 were chosen as data were stratified by type of diabetes allowing for direct comparison with Type 2 diabetes management. Data on recording and outcomes were similar across the 2008 and 2009 Scottish Diabetes Surveys (234). In 2009 over 220,000 people were included in the survey, of which 87.4% had Type 2 diabetes.

6.2.5 Data Analysis

Data were entered into PASW Statistics (Version 18) for coding and analysis. Standard descriptive statistics are used throughout the report. Categorical data are presented as number and percent as appropriate. Continuous data are presented with standard measures of central tendency and dispersion: mean, standard deviation, median, interquartile range (IQR; range of values between 25^{th} and 75^{th} percentile) and range. Standard parametric and non-parametric test (T-test and Mann-Whitney U test) were used to compare the distribution of continuous variables in independent groups. A number of continuous variables were classified into risk categories according to the targets specified in national guidelines (17). In addition HbA1c levels were broken down according to the risk categorisation proposed by the ICGP (235). BMI results were categorised according to the WHO cut-off points (236). There were missing data on a number of variables ranging from 6% non-recording for blood pressure to 36% for smoking status. Where this occurs, the figures represent the recorded data.

6.3 Results

Following the collation of data from 3 primary care initiatives, data were available for 3,010 patients with Type 2 diabetes from 63 General Practices.

6.3.1 Characteristics of the study participants

6.3.1.1 *Age and gender*

The profile of patients in this sample was similar to that reported in the National Diabetes Audit for England (NDA) and the Scottish Diabetes Survey. Of the 3,010 patients, 56.5% were male (n = 1,701) (gender unknown for 0.4% of the sample, n = 11) comparable to Scotland where 54.6% of patients were male. This gender breakdown was also consistent with patients enrolled in shared care (57% male). Data on the gender breakdown of patients included in the NDA for England was not available.

The mean age of patients was 65.7 years (SD=12.2) comparable to an average age of 65 years among patients in the ECAD Shared Care Programme. Over half the patients were aged 65 years or over (56.5%, n=1691) compared to 70% of patients with Type 2 diabetes in Scotland. Twenty-five percent of people included in the NDA for England were less than 40 years old. Figure 30 presents the age distribution of all patients stratified by gender. There was a statistically significant age difference between males and females receiving structured care (64.7 vs. 67.1, p<0.001).

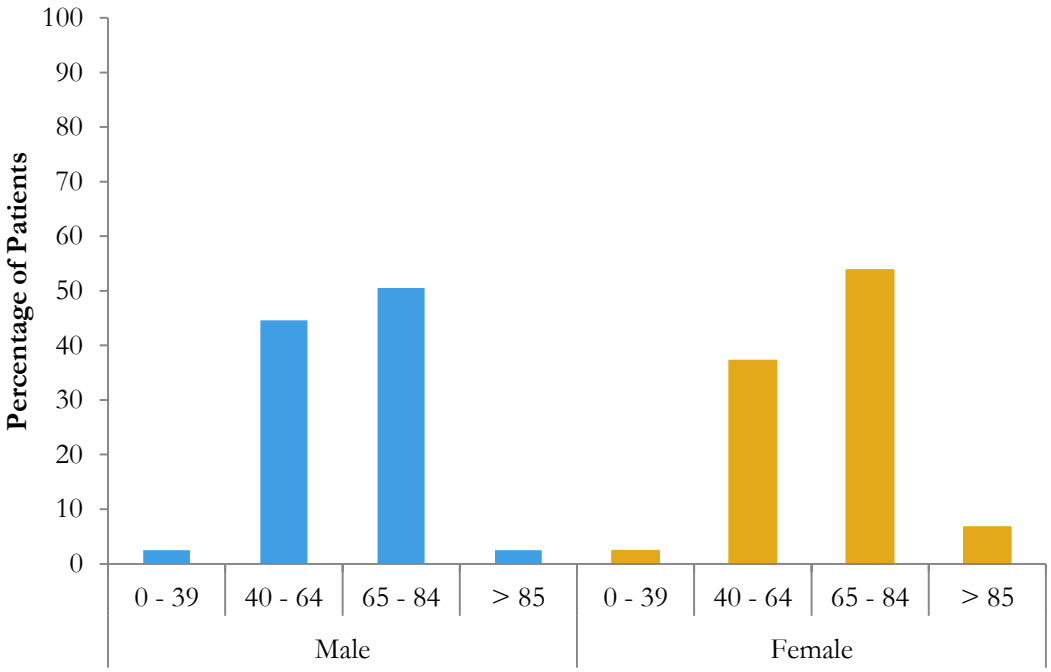


Figure 30 Percentage of patients in each age category by gender

6.3.2 Recording Processes of Care

The recording of processes of care among practices in the shared care model was marginally higher than structured care practices with the exception of retinopathy screening (43% shared care vs. 71% structured care, n=1872). Table 37 benchmarks the level of process recording in structured care practices against levels in shared care practices and results from the UK. Process of care recording for clinical outcomes compared favourably to audit results in England and Scotland. However recording of lifestyle factors was lower. Recording of Body Mass Index (BMI) was 70.4% compared to 90% in Scotland and 89.2% England. Only two of the three initiatives collected information on the recording of smoking status. Among these practices (n=1995), smoking status was recorded for 63% of patients (n=1263) compared to 99% recording in Scotland.

Table 37 Process of care recording

	Three Primary Care Initiatives Ireland		Shared Care Scheme Ireland	National Diabetes Audit England † T1 & T2 DM	Scottish Diabetes Survey T2 DM
	% (n)	95% CI	% (n)	%	%
HbA1c	90.2*(2714)	89.0-91.2	95 (247)	91.7	89.9
Blood Pressure	93.5 (2814)	92.5-94.3	96 (249)	94.1	95
Total Cholesterol	92.2 (2776)	91.2-93.2	Fasting Lipids 94 (246)	90.3	87.7
LDL Cholesterol	86.5 (2604)	85.2-87.7		-	-
HDL Cholesterol	84.9 (2554)	83.5-86.1		-	-
Smoking Status‡ (n=1995)	63.3 (1263)	61.5-65.4	87 (228)	86.8	99.3
BMI	70.4 (2119)	68.7-72.0	70 (182)	89.2	90.0
Retinopathy screening	71.2 (1872)	69.4-72.9	43 (111)	77.3	90.0
Foot assessment	64.6 (1481)	62.6-66.6	84 (220)	82.9	78.8

*4 DW pts with HbA1c = 0.1 were removed from analysis.

‡Smoking Status only recorded for DIG and HSEMA

†Data obtained from National Diabetes Audit Dashboard for England represent T1 & T2DM combined

6.3.3 Outcome Measures

6.3.3.1 *Glycaemic Control (HbA1c)*

The mean HbA1c value for the sample was 7.1% (54mmol/mol) (SD=1.3). There was no statistically significant difference in glycaemic control between males and females (p = 0.795). The mean HbA1c for patients involved in structured care was slightly higher than that of patients enrolled in shared care (7.1% vs. 6.8%). The mean HbA1c for patients with Type 2 diabetes across the 14 NHS Boards in Scotland was marginally higher (7.3% or 56 mmol/mol).

Over one third of patients with Type 2 diabetes (35%, n=943) reached the national recommended target for HbA1c (<6.5% or <48mmol/mol), compared to 25% of patients in England. Table 38 illustrates the stratification of patients into three HbA1c risk categories. Twenty-eight percent of patients with Type 2 diabetes (n=769) were in the high risk category (>7.5%) compared to 36% of patients with Type 2 diabetes in Scotland.

Table 38 HbA1c Risk Categories

	Primary Care Initiatives Ireland % (n=2718)	National Diabetes Audit England† %	Scottish Diabetes Survey▲ %
Low Risk (<6.5%/<48mmol/mol)	34.7 (943)	25.02	63.8
Medium Risk (6.5 – 7.5%/48-58mmol/mol)	37.0 (1006)	37.8	
High Risk (>7.5%/>58mmol/mol)	28.3 (769)	37.2	36.1

†Data obtained from NDA Dashboard represent Type 1 and Type 2 diabetes combined

▲In the Scottish Diabetes Survey HbA1c data were categorised as <7.5, (7.5-9.0) and >9.0

6.3.3.2 *Blood Pressure*

Thirty-seven percent of patients (n=1025) reached the recommended target for blood pressure in Ireland (≤130/80mmHg). The target in the UK in 2008/09 was ≤140/80 for patients without eye, kidney or vascular disease. Applying this target 54.4% of patients in the sample reached the target compared to 60.2% of patients with Type 2 diabetes in England.

Forty-three percent of patients (n=1209) met the current recommended target systolic blood of ≤130mmHg. Applying the cut-off of ≤140mmHg for systolic blood pressure

from the Scottish Diabetes Survey, 69% of patients in Ireland achieved this target compared to 74.6% of patients in Scotland. The mean systolic blood pressure for patients in Ireland was 136.3mmHg (SD=16.6) with no significant difference between males and females (p = 0.786). This was similar to the average systolic blood pressure recorded among patients in the ECAD Shared Care Scheme (137mmHg, n=232).

The mean diastolic blood pressure was 77.2mmHg (SD=9.3). Again there was no significant difference between males and females (p = 0.373). This average was similar to levels recorded among patients enrolled in the shared care scheme (76mmHg, n=232). Seventy-two percent of patients (n=1980) reached the national recommended target for diastolic blood pressure of ≤80mmHg. Comparable data on diastolic blood pressure were not available for England or Scotland.

6.3.3.3 *Lipid Profile*

The mean total cholesterol concentration for the group was 4.2mmol/L (SD=1.0), equal to levels achieved in shared care practices. The mean LDL cholesterol concentration was 2.3mmol/L (SD=0.81) compared to 2.1mmol/L in shared care practices. The mean HDL cholesterol concentration was 1.2mmol/L (SD=0.36) compared to 1.3mmol/L in shared care practices.

Table 39 outlines the percentage of patients in this sample achieving national target for blood pressure, total cholesterol, LDL cholesterol and HDL cholesterol. Using the Pearson chi square test, there were significant associations between gender and achievement of lipid targets (p<0.001). Fifty seven percent of patients from the primary care initiatives in Ireland achieved a NICE target for total cholesterol of <4mmol/l compared to 37.3% of patients in England.

Table 39 Achievement of national targets for blood pressure and lipids among males and females.

	Recommended Target	Primary-Care Initiatives	Males vs. Females (%)	P value
Blood Pressure	≤130/80mmHg	37% (n=1025)	33.6% vs. 34.5%	p=0.35
Total Cholesterol	<4.5mmol/l	64.5%	69.8% vs. 56.6%	p<0.001
LDL	<2.5mmol/l	64.2%	68.2% vs. 58.9%	p<0.001
HDL	>1.0mmol/l	70.9%	62.6% vs. 82.0%	p<0.001

6.3.3.4 *Smoking Status*

Smoking status was recorded in two of the three schemes (n=1995). Just over 1 in 5 people, who had their smoking status documented, were recorded as smokers (22.2%). There was no statistically significant difference between males and females (p=0.364) (males=22.9%, females=20.8%). A similar smoking prevalence of 18.8% was reported in Scotland.

6.3.3.5 *Body Mass Index (BMI)*

The mean BMI of patients was 30.8kg/m^2 (SD= 6.1) which was above the national recommended target of ≤25kg/m^2 (17). There was no statistically significant difference between males and females (30.6kg/m^2 vs. 31.1 kg/m^2, p = 0.082). A similar average BMI was recorded among patients enrolled in the shared care scheme (mean= 30.4kg/m^2). Fifty percent of patients with Type 2 diabetes (n=1060) in this study were in the obese category (>30kg/m^2) compared to 54% of patients with Type 2 diabetes in Scotland (Figure 31).

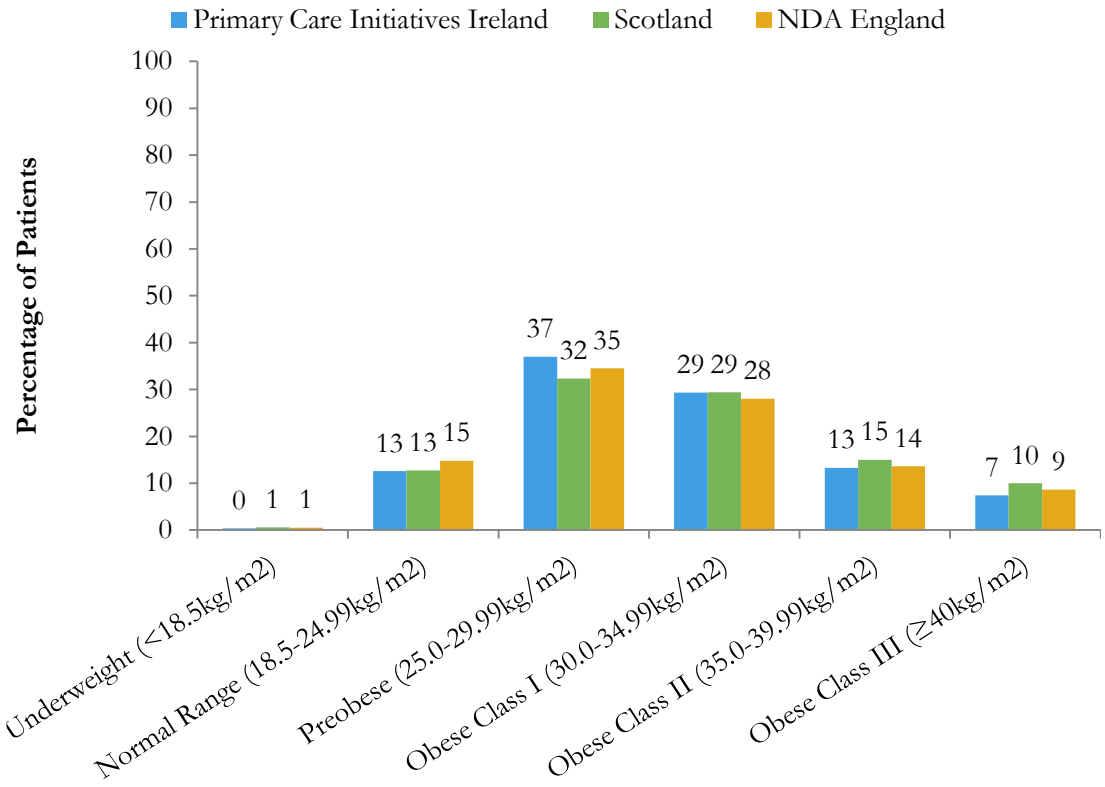


Figure 31 BMI according to the WHO classification

6.3.4 Prescribing medications to reduce cardiovascular risk

Eighty-six percent of patients (n=2381) were prescribed a statin compared to 79% of patients enrolled in the shared care scheme (n=205). Less than 1% of patients were prescribed another cholesterol lowering medication (0.8%, n=23) while 79% of patients were prescribed aspirin (n=2363). Prescribing data were not available from the NDA for England or the Scottish Diabetes Survey for comparison. Prescribing data were stratified by age and gender and the results of this analysis are presented below.

6.3.4.1 *Statin Prescribing*

Overall 87.5% of the patients greater than 65 years old were prescribed a statin (87.8% M, 87.2% F). Statins appeared to be prescribed less often in females below 40 years of age compared to males in the same age group (43.5% vs. 76.3%), and females over 85 years of age compared to males in the same age group (77.8% vs. 85.7%) (Figure 32).

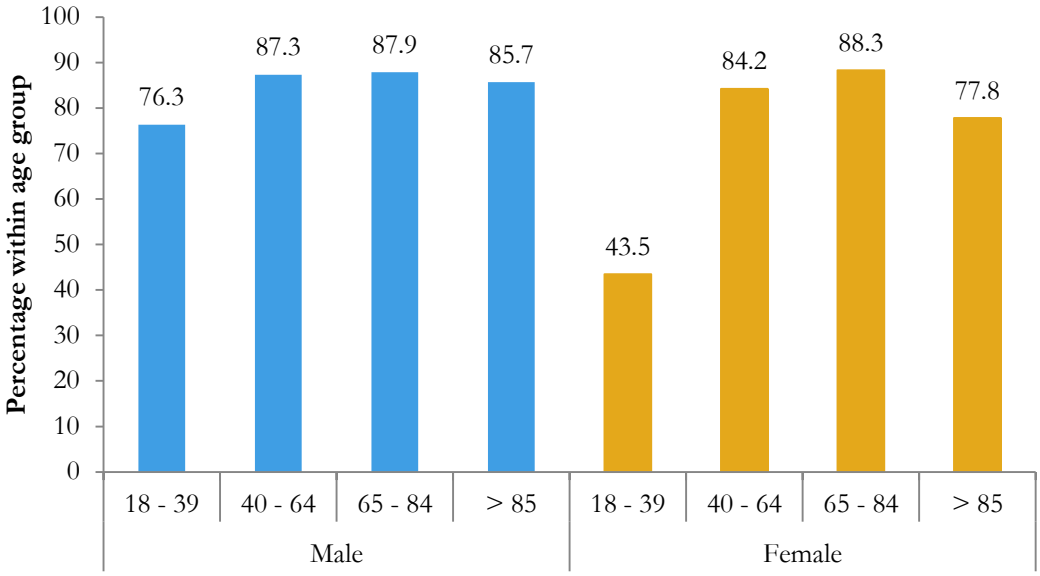


Figure 32 Prescribing of statins by age and gender

6.3.4.2 *Aspirin Prescribing*

Overall 78% of the patients greater than 65 years were prescribed aspirin (78% M and F). Similar to statins, aspirin appeared to be prescribed less often among females under the age of 40 (53.3% vs. 61%). However aspirin appeared to be prescribed less often among males over 85 years compared to females in the same group (61.6% vs. 75.3%) (Figure 33).

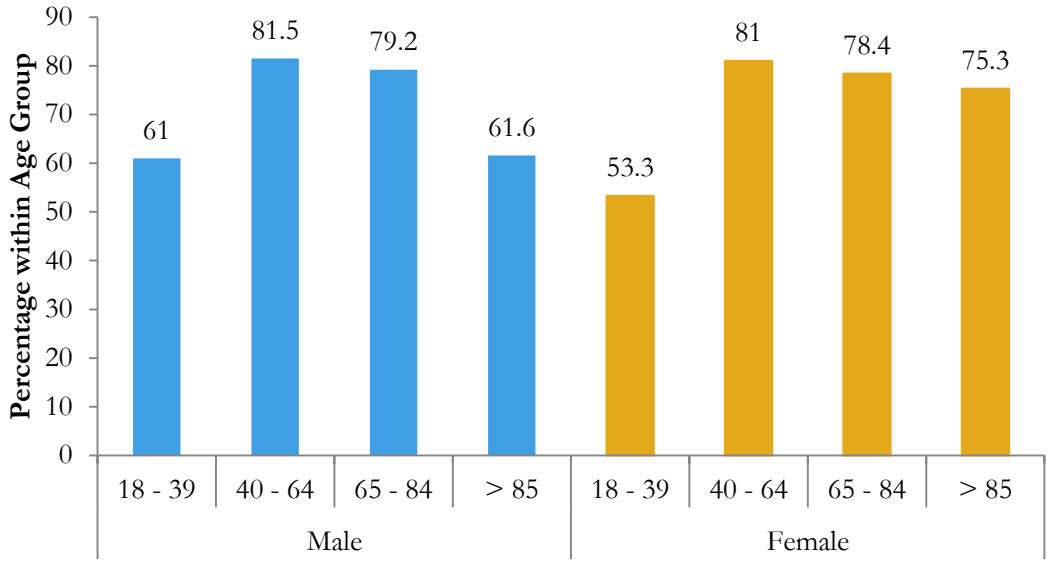


Figure 33 Prescribing of aspirin by age and gender

6.3.5 Relationship between quality of care and financial incentives

There were a number of significant differences between practices receiving a financial incentive for participation (n=2004) and practices which did not receive an incentive (n=1006) (Table 40). Process of care recording was higher among practices in receipt of a financial incentive for all outcomes with the exception of level of retinopathy screening and foot assessment. In both cases a substantial proportion of data were not recorded (NR) by non-incentivised practices (retinopathy screening=35% NR, foot assessment =65% NR).

Table 40 Differences in recording of care processes of care between practices receiving and not receiving financial incentives

	Practices receiving incentives % (n)	Practices not receiving incentives % (n)	% Difference	95% CI	P value
HbA1c	98.6 (1978)	73.4 (738)	25.3	22.6-28.1	p<0.001
Blood Pressure	99.5 (1993)	81.6 (821)	17.8	15.4-20.3	p<0.001
Total Cholesterol	99.0 (1984)	78.7 (792)	20.3	17.7-22.8	p<0.001
LDL Cholesterol	97.1 (1946)	65.4 (658)	31.7	28.7-34.7	p<0.001
HDL Cholesterol	97.1 (1945)	60.5 (609)	36.5	33.4-39.6	p<0.001
Smoking Status	76.9 (761)	50% (502)	27.0	23.0-31.1	p<0.05
BMI	86.7 (1737)	38.0 (382)	48.7	45.4-52.1	p<0.001
Retinopathy screening received	67.3 (1331)	541 (83.1)	-15.8	-19.4- -12.3	p<0.001
Foot assessment	64.1 (1242)	67.7 (239)	-3.7	-8.9-1.7	p<0.05

There were also significant differences between the groups in terms of clinical outcomes (Table 41). There was a significant difference in HbA1c levels with practices receiving a financial incentive having a HbA1c value of 6.9% compared to 7.3% among practices not receiving an incentive ($t=4.785$, $p<0.001$). There was also a significant difference between the groups in terms of systolic blood pressure ($t=2.647$, $p<0.01$), diastolic blood pressure ($t=3.395$, $p<0.01$) and total cholesterol ($t=3.757$, $p<0.000$). There was no significant difference between the groups in terms of LDL cholesterol ($p=0.66$), HDL cholesterol levels ($p=0.7$) and BMI ($p=0.06$). Of those practices receiving an incentive 19% of patients were current smokers (n=146) compared to 26.7% of patients in practices where no financial incentive was received (n=134) ($p<0.05$) however recording of this outcome was below 65% overall.

Table 41 Differences in clinical outcomes between practices receiving and not receiving a financial incentive

	Practices receiving incentives Mean (SD)	Practices not receiving incentives Mean (SD)	p
HbA1c	6.9 (1.25)	7.3 (1.4)	P<0.000
Systolic BP	135.76 (16.3)	137.57 (16.9)	P<0.01
Diastolic BP	76.8 (9.1)	78.1 (9.8)	P<0.01
Total Cholesterol	4.2 (0.99)	4.3 (1.03)	P<0.001
LDL Cholesterol	2.3 (0.81)	2.3 (0.81)	P=0.66
HDL Cholesterol	1.2 (0.37)	1.2 (0.31)	P=0.7
BMI	30.7 (6.0)	31.3 (6.3)	P=0.06

6.4 Discussion

6.4.1 The quality of primary care-led diabetes management

This study has demonstrated what can be achieved by proactive and interested health professionals even in the absence of a national infrastructure to support diabetes management. There was a high level of recording of intermediate clinical outcomes such as HbA1c and blood pressure, comparable to results in the UK. However the recording of lifestyle factors such as BMI and smoking status was markedly lower. Similar proportions of patients in Ireland and the UK were achieving targets for HbA1c, cholesterol and blood pressure. Over one third of patients reached the national target for glycaemic control (HbA1c <6.5%) compared to one quarter of patients in the National Diabetes Audit for England (NDA). The proportion of patients meeting the NICE blood pressure target (≤140/80mmHg) was also similar to results in the National Diabetes Audit. However, less than half of those receiving structured care achieved the national recommended blood pressure target of ≤130/80mmHg. Half of all the patients were categorised as obese (>30kg/m^2), similar to findings in Scotland.

6.4.2 Financial Incentives and Quality Improvement

The existence of the Quality Outcomes Framework (QOF) in the UK goes some way towards explaining the high level of process recording found in the National Diabetes Audit and the Scottish Diabetes Survey. Introduced in 2004, QOF consists of a set of indicators and pre-specified targets established for a number of chronic diseases including diabetes. General practices are financially rewarded for achieving certain levels of process recording and levels of control for HbA1c, blood pressure or cholesterol in patients registered with diabetes. There are also components relating to practice organisation, patient experience, additional services and access to primary care (237). However the proportion of patients in Ireland achieving targets for intermediate outcomes was similar to UK results despite the lack of a comparable national incentive structure to improve the quality of care. This is in keeping with the suggestion that it is easier to improve the recording of care, which is under the control of the health professional, without necessarily making a significant impact on patient outcomes (73, 238).

The merits of a 'pay for performance' system such as QOF are continuously debated. A number of studies have demonstrated the positive impact of QOF on the achievement of targets since its introduction six years ago (239). However these gains appear to be

short-term benefits and have since reached a plateau. In addition a reduction in quality has been highlighted among aspects of care not linked to incentives (186). QOF has also been accused of subtly changing the purpose of data recording among general practitioners (240). However the increased investment, both financially and in terms of interest in primary care diabetes management, since the introduction of QOF has been acknowledged (241). Regardless of the arguments for or against incentivizing care, it is more often than not a feature of changes to models of care. Of the ten European countries reported to have implemented structured care programmes, seven of these are sustained through financial incentives (126).

Although not comparable to the UK where QOF accounts for approximately 25% of a GPs income (186), two out of three initiatives involved in this study financially reimbursed general practices for their involvement. In this study receiving financial incentives was related to higher quality care. Process of care recording was significantly associated with whether or not practices received a financial incentive and there were also significant differences between the groups in terms of clinical outcomes. As highlighted in the qualitative study of barriers and facilitators to diabetes care, the lack of remuneration for chronic disease management is considered one of the main obstacles to optimal care. The lack of remuneration has limited the extent and scope of primary care initiatives in Ireland. While the latter initiative is open to participation by all GPs in Cork and Kerry, at present it only accounts for approximately 10% of practices in the region. While the lack of incentives has not stopped those with a special interest in diabetes in Ireland, it may be a barrier to wider engagement in quality improvement at primary care level in the future.

6.4.3 Role of Special Interest

In the absence of financial and structural incentives, primary care initiatives are ever-more reliant on the interest and enthusiasm of general practice staff. The 'special interest' concept is not unique to Ireland. The role was formalized within the National Health Service (NHS) Plan in 2000 (66), as part of the reconfiguration of services within the NHS to improve accessibility, free up specialist hospital services and reduce waiting times (66, 242). It is also envisaged that GPs with special interests would take referrals from other GPs (243). Evaluation of this policy direction is limited at present however the scheme has been piloted in the field of dermatology whereby a GP with a special interest achieved similar clinical outcomes to the hospital-based service, was more

accessible and preferred by patients (244) although the cost of providing the specialist service in general practice was higher (245). In Ireland formal specialisation is limited to nursing staff at present with calls for increasing numbers of Diabetes Nurse Specialists to facilitate the reorientation and reorganisation of diabetes care (246).

6.4.4 Audit- a special interest activity

Special interest is not only central to comprehensive diabetes management in the three primary care initiatives; it is also a driver in the pursuit of quality improvement in Ireland. Practices in the initiatives participate in ongoing audit and feedback on a voluntary basis and data collection is manual and laborious. There is a growing need for stable and robust IT systems such as those available in Scotland, to facilitate routine data capture at general practice level. In Scotland agreed core data are routinely collected on diabetes registers at practice level. Data entered at practice level are automatically uploaded onto the main repository run by the SCI-DC (Scottish Care Information Diabetes Collaboration) Network (234). Automated data extraction from GP software systems is a feasible and attainable solution in Ireland however this process is restrained in the absence of an agreed core dataset for diabetes care.

6.4.5 Prescribing among patients with Type 2 diabetes

In 2003, a population study using the national primary care prescribing database in Ireland found the under-prescribing of cardiovascular therapies for patients with diabetes in primary care (247). Less than a quarter of males (23%) and females (22%) with diabetes were prescribed statins. However in this study, the majority of patients (85%) enrolled in structured care practices were being prescribed statins. Similarly with aspirin approximately half of males (51%) and less than half of females (45%) with diabetes were prescribed aspirin compared to 79% of patients enrolled in structured care practices. The findings suggest intense management of cardiovascular risk factors using medication among practices involved in structured care. However the use of aspirin as a primary preventative medication for patients with diabetes is subject to ongoing debate (248) (249). As the diagnosis of cardiovascular risk was not recorded in the dataset it is not possible to comment on whether prescribing was for primary or secondary prevention.

With regard to statins, there was substantially less prescribing among women below the age of 40 (44%) compared to other female age groups and also compared to males in the same age category (76%). There was also less statin prescribing among females over

the age of 85 (78%) compared to men in the same category (86%). The national study of cardiovascular therapy prescribing in diabetes demonstrated slight gender differences in prescribing, with less statin prescribing among females compared to males (51% vs. 45%), however age was not taken into account (247). The gender disparity could indicate a missed opportunity to manage the development of complications particularly in the younger female age group.

6.4.6 Comparing Models of Diabetes Care in Ireland

The similarity of the results between the GPs providing structured care and those participating in the shared care scheme suggests a consistent standard of care is being delivered by local diabetes initiatives in Ireland. The findings also reflect the overlap and ambiguity detected in the literature around models of care. More often than not shared care initiatives foster a structured approach to care delivery, incorporating regular review and recall, the use of guidelines and audit and feedback (109). Thus the terms shared and structured are not mutually exclusive. The integrated model of care proposed for Ireland envisages care which is *"integrated, planned, shared and structured"*(1). As illustrated by the findings of the qualitative study with GPs presented in Chapter 4, structured care is associated with the primary care setting while shared care is a joint collaboration between GPs and the hospital-based team. Our results suggest that the underlying and somewhat diminishing distinction does not produce noticeably dissimilar results. The important factor is the structured and regular delivery of care to patients with diabetes.

6.4.7 Isolating the Improvement Factor

It is important to note that the essential ingredient for improving diabetes care has not been isolated. The evidence seems to suggest that a multifaceted approach is most successful. A review of quality improvement interventions by the Agency for Healthcare Research and Quality (AHRQ) in the U.S. did not identify one particular type of quality improvement (QI) strategy for improving glycaemic control or provider adherence to guidelines however, interventions employing more than one strategy had a greater chance of success (8). A more recent review of systematic reviews on diabetes care programmes also failed to find conclusive evidence of the critical components of such programmes or indeed practical guidance on design or implementation or evaluation of diabetes care programmes (120). The search for the single x factor in quality improvement may be futile as strategies are rarely introduced in isolation and improvement may be a result of the synergy between different approaches (114).

Research has now begun to look towards what are the common features of high quality care. One common feature among the three initiatives involved in this study is the involvement of a nurse who is dedicated solely to supporting the delivery of evidence based diabetes care in the community.

6.4.8 Strengths and Limitations

The complexity of evaluating multifaceted quality improvement interventions has been acknowledged. The use of a Randomised Controlled Trial (RCT) to evaluate a complex real-world intervention is not always practical for example where large scale implementation is already underway as is the case in Ireland (123). This study is limited in its comparisons by the dearth of information on the quality of diabetes care across Europe. The absence of an agreed core dataset for diabetes also limited the potential of the study as it was not possible to combine all data collected by the three initiatives. While data on long-term complications were available from two of the three groups, data collection has yet to be standardised and these outcomes are often not recorded consistently by all GPs involved. The overemphasis on intermediate outcomes measured in the short-term may underestimate the true effect of quality improvement interventions which have yet to be realised (118). Data on long-term outcomes will contribute greatly to our understanding of the full extent of the impact of structured care and whether benefits have been sustained.

It should be stressed that this study is not a comparison of 'like with like' but rather a benchmark of the performance of a select group of special interest practices providing structured care in Ireland against the standard of care observed in countries supported by a national diabetes management infrastructure. Furthermore the results of this study are not typical of diabetes care in Ireland. The lack of routine data collection in Ireland prohibited the inclusion of a reference group of 'typical' practices not participating in formal primary care initiatives delivering structured care. It appears that elements of structured care may be scattered throughout Ireland as a recent survey found that half of the GPs reported using guidelines, engaging in routine recall or using a diabetes register (170). However what is absent is a consistent standard of care for all patients with diabetes. While the gap between shared and structured care narrows, another opens up between those involved in proactive quality improvement initiatives and those who are not. The challenge now becomes creating a national infrastructure which supports

local efforts to improve quality, to avoid a situation whereby the quality of care received by patients is determined by geography.

6.4.9 Conclusion

This study which highlights what can be achieved by a group of proactive health care professionals working together to provide evidence based care in the community in a system with minimal incentives. The recording of processes of care was similar to the UK with the exception of recording lifestyle factors, and similar proportions of patients achieved clinical targets. Primary care initiatives are a viable option for health systems trying to tackle the growing burden of diabetes care but we cannot presume or rely on special interest to improve the quality of care for all patients. The challenge facing health systems is to establish quality assurance as a responsibility for all health care professionals, rather than the subject of special interest for a few.

7 Improving Diabetes Care through Policy Formulation: a Case Study of the Expert Advisory Group for Diabetes.

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Prof. Colin Bradley

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Abstract

Aim: Diabetes has struggled to make it onto the national policy agenda in Ireland despite consensus on what needs to be done to improve care. In 2006, the Health Service Executive established an Expert Advisory Group for Diabetes (EAG), to act as its *"primary source of operational policy and strategic advice"(1).* The aim of this study was to examine the EAG process as an instrumental case study of policy formulation in the Irish health system. The study examined the process of and reasons for establishing the group as well as the outcome of their recommendations.

Method: The primary method of data collection was semi-structured qualitative interviews. Fifteen interviews were conducted with a purposive sample of stakeholders and members of the EAG. Interview data were supplemented with secondary data from published and unpublished documents relating to the process e.g. meeting minutes. The topic guide was informed by three theories of policy formulation: Rational Model of Decision Making (250), Multiple Streams Theory (251), Advocacy Coalition Framework (ACF) (252). An 'alternative lens' perspective was adopted during thematic analysis in which the principles of the three theories were applied to the data to compare their usefulness in explaining the findings (36). Analysis was conducted in NVIVO software.

Results: In keeping with the rational model of decision-making**,** the EAG process appeared to follow a logical process: identifying priorities, developing recommendations and putting forward a strategy for approval by the HSE. However this theory became less useful as the process moved from approval towards implementation. There was a lack of clarity around what constituted a decision and who made decisions in the HSE. The ACF assumption that advocacy coalitions share 'policy core beliefs' although members often disagree about secondary beliefs, reflected the decision-making dynamic in the EAG; *"I think we were all there with the same purpose but how we went about it, how the problem is going to be solved might be slightly different."* From this theoretical perspective the economic recession could be considered an external shock which constrained the resources available to the group and pushed implementation down the agenda.

The three streams of the Multiple Streams Theory illuminated the phases of the EAG process. Defining diabetes as a problem was the result of a number of factors including comparison with the standard of care in other countries. The criteria for judging the viability of alternatives distinguished between those policy ideas which obtained HSE approval and those which were put on hold. As well as barriers in the policy stream

there were changes in the political stream including faltering support for change from the HSE, and a shift in jurisdiction following the establishment of the Clinical Care Programme for diabetes.

Conclusions

Different aspects of the policy formulation process were highlighted and hidden by applying an alternative lens perspective. The Multiple Streams perspective appeared to offer the most comprehensive explanation of the dynamic EAG process, in particular illuminating why some recommendations were approved and implemented while others did not survive the process. The case of the Diabetes EAG highlights some of the constraints on the policy process including fleeting support and interest in topics and the instability of the economic environment. External factors such as these accounted for the gap between formulating policy for and implementing changes in diabetes care in Ireland.

This study will be submitted for publication to Health Policy and Planning

7.1 Introduction

A government's priorities are said to be reflected in the policies and frameworks which have been established and acted upon (253). Diabetes has floated in and out of the policy spotlight for a number of years, struggling to make it onto the national decision agenda. There have been a plethora of position statements, recommendations and reports highlighting the same problems and proposing similar solutions with little or no implementation While the Department of Health and Children (DOHC) disseminated a report on diabetes care in 2006 (145) and published a policy framework for chronic disease management in 2008 (11), there remains no government-led national strategy document dedicated solely to the management of diabetes, akin to those for cardiovascular disease (147) and cancer (148).

7.1.1 Diabetes; a health system priority

Diabetes *"exemplifies the complex nature of chronic disease" (p406)* (54). The prevalence of diabetes is growing exponentially with the worldwide prevalence expected to reach over 4% by 2030 (4). Although the treatment of diabetes is well established, the management of this illness is complicated by the multiple systems of the body implicated in the progression of the disease, and consequently the number of health care professionals involved in providing care. As a result of severe and long-term complications diabetes places a huge burden of care and cost on the health system. People with diabetes are more likely to be admitted to hospital that people without diabetes and multiple hospitalisations are common (254). In 2007 Ireland had the second highest rate of hospital admissions for acute diabetic complications, an indicator of the quality of health systems (44 admissions per 100,000 population) (255). This was double the OECD average rate of 21 admissions per 100,000 population.

In 2010 global health expenditure on diabetes was projected to total at least $376 billion USD, rising to $490 billion USD by 2030 (49). There is a lack of up-to-date cost data for Europe to assess the true financial burden of diabetes, however analyses conducted in 1999 across eight countries (CODE-2) estimated the total direct medical cost was €29 billion a year (1999 values) or an average of €2834 per person per year (50). The total cost of managing patients with both micro- and macrovascular complications was up to 250% higher than those without complications (51). In Ireland the most recent study of the cost of diabetes is based on data from 1999/2000, which estimated that €580million

was spent on the management of Type 2 diabetes (256). Most of the cost was due to the treatment of avoidable complications.

7.1.2 Policy as a pillar of effective chronic illness care

In 1989 the St Vincent Declaration called for formal recognition of the problem of diabetes and the deployment of resources to tackle the condition (65). Part of this formal recognition was the need to develop national policies and plans for the long-term management of diabetes. The availability of policies to inform and guide service development is a resource for effective chronic illness care (84). According to the Chronic Care Model, one of the six pillars of high quality care is the presence of community resources and policies. These resources and policies enhance integration and the continuity of care across health system boundaries (81). Policy activities which can support the provision of services to people with chronic illness include legislation, leadership, financing and the allocation of resources (87).

The most recent policy activity in relation to diabetes care in Ireland was the establishment of the Expert Advisory Group for Diabetes (EAG) in 2006. Set up by the HSE, the EAG was intended as the source of *"operational policy, strategy and quality standards"* for the Irish health system (p1) (146). In addition to representing a dedicated plan for diabetes services, the EAG was envisaged to have wider potential as the starting point for the development of chronic disease management programmes in Ireland (11). This study will examine the Expert Advisory Group process as a case study of policy formulation in Ireland. The EAG proposals were approved by the HSE in 2008 however implementation did not follow as expected. This study of policy formulation will explore the outcome of the Expert Advisory Group and its recommendations, including the factors impeding progress from formulation to implementation at the time.

7.1.3 Policy Background

Over the past decade a number of priorities and principles have emerged in the health policy arena which appears to create an environment conducive to the improvement of diabetes care in Ireland. Yet concrete proposals for the development of a national diabetes programme have remained within the pages of recommendations and reports. This section outlines the relevant developments in Irish health policy beginning with the overarching health policy context and moving on to documents pertaining specifically to diabetes. Figure 34 provides a graphical overview of the developments prior to and during the Diabetes EAG process to establish the context in which the group was formed and made its recommendations.

7.1.3.1 *Health Policy in Ireland*

"Quality is one of the guiding principles" of the national health strategy, 'Quality and Fairness; a Health System for You' (p128) (257). In 2001, the strategy prioritized 'high performance' as one of the four goals of health policy in Ireland. To achieve this goal, the strategy proposed the establishment of standardised quality systems and the introduction of regular monitoring of care to *"encourage a culture of continuous improvement"* (p86). Part of this objective included the development of chronic disease management protocols, the promotion of integrated care planning between health care providers and enhanced support for self management. Emphasis was placed on planned regular interaction between the patient and health care provider, and primary care was deemed the appropriate setting for continuous coordinated chronic illness care.

Chronic disease management in the community was part of a wider focus on primary care in the national health strategy. The Department of Health and Children dedicated an entire policy document to the reform of primary care in the same year, 'Primary Care; A New Direction' (182). The main proposal in this document was the establishment of primary care teams across the country to provide multidisciplinary integrated care. Teams would comprise of GPs, nurses and other professionals within a wider primary care network of professionals such as dieticians and community pharmacists. A major selling point of this proposal was the expected improvement in integration between primary and secondary settings, particularly relevant for the management of diabetes. Integration would be facilitated by investment in communication and information technology as well as the development of local referral protocols, discharge plans and shared care arrangements for chronic conditions such as diabetes.

The role of primary care in chronic disease management and the need to strengthen this care setting were reiterated in the National Chronic Disease Management Framework disseminated by the Department of Health and Children in 2008 (11). The framework highlighted a number of challenges to effective chronic illness care including the lack of integration between settings and the reliance on acute reactive care as opposed to planned structured care. The principles promoted within the framework document were congruent with the Chronic Care Model; enhanced self management support, information systems and patient registers to support monitoring and communication, a model of shared care to integrate settings and the need for multidisciplinary care teams.

The framework document also recommended the development of evidence-based multidisciplinary disease management programmes, putting forward the Expert Advisory Group process as the start of this work. Reflecting the focus on quality in the health system, there was a pledge to assure the quality of such programmes through performance indicators including disease incidence, hospital utilisation, and clinical and patient outcomes. As illustrated by Figure 34, this policy framework was published in the same year as the EAG Report on diabetes care, reiterating the call to develop diabetes care and the deployment of resources. The most recent policy document "Changing Cardiovascular Health" published in 2010, also promotes planned integrated care for diabetes as part of the primary care prevention management of cardiovascular disease. This represents some progress from the previous cardiovascular strategy in 1999 which devoted little attention to this high risk patient group. Diabetes was described as 'the Cinderella' of the strategy (258) reflecting the insufficient attention given to diabetes in broader health policy over the last decade.

As indicated at the outset of this section Figure 34 presents an overview the policy and practice developments relating to diabetes in decade leading up to the publication of the EAG recommendations in 2008, as well as the consequences of that process in the years to follow. The figure illustrates the accumulation of related activities by interest groups such as the National Obesity Taskforce and the Institute of Public Health (IPH) as well as publication of the aforementioned policy documents by the DOHC. However, primarily the timeline illustrates the frequency with which different working groups were established with scarcely a two-year gap between recommendations and reports on how to improve diabetes services in Ireland.

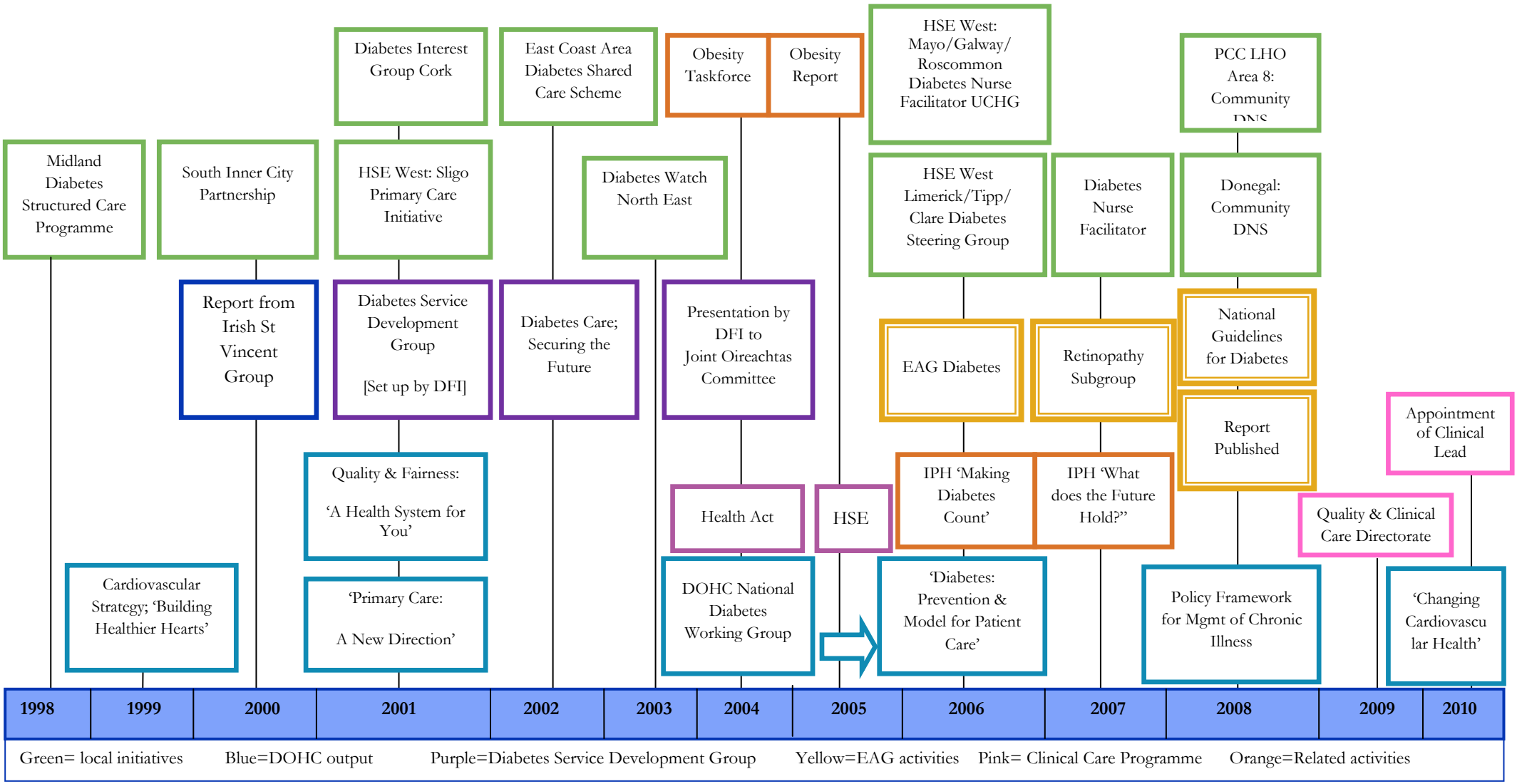


Figure 34 Overview of policy & practice developments from 1998-2010

7.1.3.2 *Diabetes Policy Context in Ireland*

In 2000, the government was urged to form a policy planning group dedicated to identifying objectives and strategies for the development of a national diabetes care programme (143). This call was taken on by a number of multidisciplinary groups including the Diabetes Services Development Group (DSDG), the DOHC Working Group and most recently the Expert Advisory Group. The priorities and proposal of each group are outlined below to illustrate the consensus on the need for improvement.

Addressing the St Vincent Declaration in Ireland

The Irish St Vincent group, which issued the call for a national diabetes programme in 2000, was established as a result of the St Vincent Declaration. The St Vincent Declaration of 1989 was an international endeavour to improve the quality of diabetes care. Health departments from all European countries including Ireland, came together with patient organisations and diabetes experts, to set standards and goals for better diabetes care and outcomes (65). The onus was on each country to develop services and strategies to meet these targets. In Ireland the St Vincent Group, comprising of health care professionals and patient representatives from around the country, highlighted the disorganised nature of diabetes care outside the major cities and lack of service planning (143). The areas in need of attention, including retinopathy screening, paediatric care and integration between providers, were to re-emerge in several reports over the course of the next decade.

In 2002, in the absence of a government-level response, the Diabetes Service Development Group (DSDG) was formed to plan the development of diabetes services over 4 years (144). The multidisciplinary group, initiated by the Diabetes Federation of Ireland (DFI), reiterated the priorities of retinopathy screening, paediatric services and structured shared care across settings. As part of the proposed model of care, the group recommended the establishment of local DSDGs to monitor and advise on services. The report was presented to the Minister for Health and the group advocated for a national strategy before the Joint Oireachtas Committee on Health and Children however implementation did not materialise (258).

Department of Health Response to Diabetes

The report by the DSDG was followed in 2004 by another multidisciplinary working group set up by the Department of Health and Children to examine the burden of

disease and make recommendations on care provision (145). Similar priorities were raised including; retinopathy screening, podiatry services, the need for a diabetes register and an integrated model of diabetes care. Again local Diabetes Service Development Groups were recommended to assess needs and plan services at local level. Unlike the previous strategy put forward by the DSDG, this report was commissioned by the Department of Health. The document is often referred to as *"a national policy on diabetes"* in response to Dáil questions (259) and related policy documents (147). However the work of the group was hampered by industrial action involving the Irish Hospital Consultants Association (ICHA) at that time, which prevented the participation of a number of the consultants/endocrinologists, thus limiting the impact and weight of the subsequent proposals (145).

The lack of progress towards a clear national diabetes strategy has been noted at European level. A 2005 report from the International Diabetes Federation European Region and the Federation of European Nurses in Diabetes documented the absence of a national diabetes plan in Ireland although one was expected that year according to the DOHC (253). This may be a reference to the aforementioned DOHC working group report published in 2006 however it was not made explicit in the report. At the time eleven of twenty-five countries in the Europe Union (44%) had a national framework or plan for diabetes. By 2008, thirteen out of twenty-seven member states (48%) had a national plan in place for the management of diabetes including countries such as Romania, Poland and Lithuania (38). Ireland, along with Germany and Luxembourg, was one of the countries reiterating the promise of a national diabetes framework. The DOHC working group document was now referred to as a report rather than a policy and reference was made to the Expert Advisory Group for Diabetes as a *"strategic review of the provision of diabetes treatment and services"* (p46).

HSE Response to Diabetes: establishing the Expert Advisory Group

The report by the Expert Advisory Group (EAG) in 2008 was diabetes' most recent foray into the policy spotlight. Established by the HSE in 2006, under the administration of the CEO Brendan Drumm, Expert Advisory Groups were assigned to mental health, care of the elderly, care of children and diabetes. The multidisciplinary EAG for Diabetes comprised of health care professionals, senior HSE management, patient representatives and representation from the Department of Health and Children (DOHC) (1). The group held meetings from 2006 until 2010 in an effort to produce and

implement a national coordinated system of diabetes care. The EAG report was described as the *"blueprint for the development of first class services for people with diabetes"* in Ireland (Brendan Drumm, Chief Executive of the HSE, 2008) (260) (1). To date the majority of recommendations from the EAG have not been implemented. Some of the priorities and proposals have been adopted by the Clinical Care Programme for Diabetes (CCP), the newly established structure within the HSE, under the auspices of the Quality and Clinical Care Directorate, to improve access to and quality of services in a number of areas.

7.1.4 An alternate perspective of quality improvement in diabetes care

This study analyses the Expert Advisory Group process as an example of a national-level initiative to improve the quality of diabetes care through policy formulation. It is suggested that diabetes provides a *"lens through which to view the performance of a health system"* in terms of its ability to manage chronic diseases (p406) (54). As mentioned previously policy is one of the resources necessary for the effective management of chronic illnesses (81). This study builds on results previously presented in this thesis including the analysis of primary care initiatives seeking to improve the quality of diabetes care in the practice (Chapter 6). While these initiatives are in line with emergent policy from the Department of Health and Children to enhance the involvement of primary care in chronic disease management (11), local developments were not the product of an overarching strategy for diabetes, nor were they the result of concerted implementation of a national diabetes programme. The bottom-up piecemeal approach to improving diabetes care in Ireland was captured by the following quote from a GP involved in the qualitative study of experiences providing diabetes care in general practice presented in Chapters 3:

> *"People are cobbling together these local things when it should be a national system."*
>
> *(GP participant in qualitative study)*

7.1.5 Analysis of the formulation of "operational policy"

The Diabetes EAG signalled the first time a group had been given the responsibility by the Health Service Executive, to address the inconsistent standard of care and formulate operational policy for the development of a national service for people with diabetes (146). Hence the EAG process will be used as an instrumental case study to examine policy formulation in the Irish health system. As part of the formulation stage the study

examines the HSE approval process for the recommendations and efforts to advance the recommendations towards implementation. This is in keeping with the definition of health policy as *"courses of action and inaction that affect the set of institutions, organisations, services and funding arrangements of the health system"* (p 6), which incorporates a wide range of policy participants (37).

Gilson & Raphaely (2008) suggest that the main focus in policy analysis is often 'what happened' with less consideration given to the question 'what explains why that happened' (261). Applying theories to the policy process allows for *"a more thoughtful conceptualization of the process that goes beyond telling a story"* (p311) (29). This study provides not only a description of the EAG process but also identifies the influential factors behind decision and non-decision making by applying three theories which seek to explain the policy process: Rational Model of Decision Making, Multiple Streams theory (251) and the Advocacy Coalition Framework (ACF) (262). The former stage theory proposes an ideal logical decision making process while the latter two theories, Multiple Streams Theory and the Advocacy Coalitions Framework, take into account the multiple actors involved in policy making. Each theory provides an alternative "theoretical lens" through which to view and explain the policy process presented in the case study. According to Hill, adopting an 'alternative lens' perspective illuminates and obscures different aspects of the decision making process (36). One of the earliest examples of this approach is the study of the Cuban Missile Crisis by Alison (1971)(263). The methodological approach of applying alternative theories has previously been used in health policy analysis to assess priority setting (264). The following section outlines the main principles of each theory followed by specific propositions derived from each theoretical perspective.

7.1.6 Theories of the policy process

7.1.6.1 *Rational Model of Decision Making*

According to the rational model of the policy process, decision-making is guided by an individual's assessment of alternatives and consequences. A rational decision is *"…one that pursues a logic of consequences"* as a rational actor tries to maximise the achievement of goals/values by analysing all alternative courses of action (p192) (265). Based on this analysis the best option is chosen; that is the option with the highest net benefit and highest probability of occurrence. This approach is not concerned with the source or substance of personal goals and values (266). The model proposes a deliberate process following a logical sequence of steps which lead to a rational choice (37, 250).

1. Identify the problem.
2. Clarification of decision makers' goals and objectives.
3. Identification of all alternatives for achieving those goals.
4. Comprehensive analysis of these alternatives and their consequences.
5. Choice of the strategy most conducive to reaching the goals.

There are a number of constraints which limit actors' choices including the scarcity of resources, institutional norms and information. Information plays a central role in the analysis of alternatives and their consequences. All available information, which is assumed to be reliable and precise, is collected from a variety of sources so decision makers are completely informed before choosing between alternatives (267). While the rational perspective acknowledges these circumstances they are not of primary concern (266).

This approach to decision-making draws on economic theory which proposes a rational or "economic decision maker" who weighs up the costs and benefits of alternatives before making a decision (268). Originally rational choice theorists were concerned with individuals as the unit of analysis. However more recently this approach has been applied to social and political processes (266), including policy making in the health arena (264). Herbert Simon, who examined rational choice in the decision making process of administrative organisations (250), sought to address the tension between an

individual's and organisations' values. A decision was personally rational if it was orientated towards individual's goals as opposed to organisationally rational (269).

There are several variations of the rational choice perspective with no universally accepted version of the theory (270). However there are a number of assumptions underlying all variations which have been outlined above. This study will apply the broad principles of the rational model of decision making to the EAG process.

7.1.6.2 *Multiple Streams Theory*

Multiple Streams Theory focuses on agenda setting, defining the agenda as *"the list of subjects to which government or those around them are paying serious attention at a given time"* (p3) (251). The theory is based on the study of policy making in the US Federal Government. Kingdon and colleagues conducted over 200 in-depth interviews with decision makers, government officials and active participants involved in health and transportation policy in the US. The theory was informed by the Garbage Can Model (251) which considered organisations to be 'organised anarchies' which are constantly evolving. The outcome of the decision-making process depends on the mix of problems, solutions, participants and resources and how this mix is processed(271).

The Multiple Streams Theory also considers policy formulation to be a dynamic process According to the theory three largely separate streams run through the policy system: problem, policies and politics. At a critical point known as the policy window these three streams are coupled or connected by policy entrepreneurs, moving the issue onto the agenda. The process is not automatic or passive; policy entrepreneurs look for opportunities to join policies to problems. The theory is also concerned with the drivers behind the policy process i.e. how and why policy issues rise and fall from the agenda known as the *"pre-decision policy process"* (p2).

The first stream, *the problem* (which can be a disease for example) is brought to attention by indicators (e.g. disease incidence), a focusing event (e.g. crisis, personal experience for example with the health system, or an outbreak) or feedback on the success of current policy programs. An issue such as diabetes care is only recognised as a 'problem' when it is decided to do something about it. Problem definition can be the result of people imposing their values on the situation as it does not meet their perception of the ideal, through comparison within or between countries, or through classifying a

condition in a certain category. The recognition of a problem alone is often not sufficient to get an issue onto the policy agenda.

The 2nd stream, *the policy stream*, involves the formation and refinement of policy ideas generated in narrow policy communities. Policy communities consist of 'specialists' such as health care professionals, academics, bureaucrats and government agencies. Communities can vary in their degree of fragmentation. Policy advocates in fragmented communities often have different outlooks on the problems and solutions leading to a lack of consensus, an unstable agenda and as a result a disjointed policy proposal. In the policy stream, termed the *"primeval soup",* ideas float around, confront each other and fade in and out of consideration (p116) (251). Ideas tend to be a recombination of existing or familiar proposals that have been discussed, debated and revised over time. This process is referred to as *"softening up"* which builds acceptance for a proposal in anticipation of a policy window. Hence the emphasis in the Multiple Streams theory is on the survival as well as the origin of policy ideas. To survive an idea must meet certain criteria:

1. Technical feasibility: how the proposal will actually work i.e. the feasibility of implementation.
2. Value acceptability: are proposals compatible with values of the policy community, usually the community of specialists in that field. Health in particular is subject to ideologies about equity and fairness which can help or hinder proposals.
3. Anticipation of future constraints: As well as considering the acceptability of the costs attached to a policy idea, the proposal should also have a reasonable chance of being politically and publically acceptable.

Through this process the list of policy ideas is reduced to a small number of alternatives for serious consideration. Reaching consensus involves diffusion or the spread of ideas which have endured the 'softening up' process, as well as the acceptance of proposals which have satisfied the criteria for survival. This progression reflects how ideas gradually take hold in a policy community, reaching a tipping point when they become common place. The presence of viable policy ideas ready and waiting to attach to a problem increases the chances of a proposal making it to the decision agenda.

The 3rd stream, the *politics stream* refers to the broader political context within which policy is made including public mood, pressure group campaigns and changes within government including changes in government agencies. In the latter case the agenda may be influenced by turnover (people change) or jurisdiction (boundaries of responsibility change). Consensus building in this stream is different to that in the policy stream as it involves more bargaining than persuasion.

Change occurs when the problem is recognised, the solution is available, the political climate is conducive to change and the constraints do not hinder action. The policy window is an opportunity for action. Windows are opened by a change in the political stream (political window) or when a pressing problem captures attention (problem window). Windows are closed for a number of reasons; administrations feel they have addressed the problem with a decision, actors fail to get action and give up, a focusing event which opened the window passes and the opportunity is missed, a change in personnel alters the agenda or there is no viable alternative to attach to the problem. Policy windows are fleeting opportunities and require quick action on the part of policy entrepreneurs, advocates of particular proposals who are active in coupling streams. For example policy entrepreneurs keep their proposals ready for an opportunity to couple an idea with a recognised problem. The chances of an issue making it onto the decision agenda are greatly increased by the coupling of all three streams.

7.1.6.3 *Advocacy Coalition Framework*

The Advocacy Coalition Framework (ACF) considers policy formulation to be a product of competing coalitions of actors with different beliefs which they want to translate into policy (272). The framework was originally developed in the 1980s by Sabatier and Jenkins-Smith and has undergone several revisions (262, 272, 273). Originating in the US through the analysis of energy policy, its application has widened to Europe across other sectors including health (274). There are five main principles underlying the framework concerning the policy subsystem, policy actors, their belief systems, timeframe and the role of technical information.

Subsystems and Coalitions

According to the ACF, policy-making takes place in a subsystem between specialized *"actors from a variety of public and private organisations who are actively concerned with a policy problem or issues and who regularly seek to influence public policy in that domain"(p99)* (275). The

subsystem is defined according to a substantive dimension (e.g. diabetes) and a territorial dimension (e.g. Ireland) which shapes the interaction between participants. ACF broadens the scope of policy analysis to incorporate all actors who share expertise in a particular domain, including interest groups and governmental agencies but also journalists and researchers, as scientific and technical information play an important role in policy making (273). Policy actors cluster into advocacy coalitions composed of people with similar beliefs who often coordinate their activities to achieve common objectives; that is to translate their beliefs into policy (272).

Belief System

Drawing on social psychology, ACF relates public policy to an individual's belief system with its own values, relationships and preferences. The belief system is divided into three tiers; deep core beliefs, core policy beliefs and secondary beliefs.

- *Deep core beliefs* are stable fundamental beliefs which span the entire policy system e.g. beliefs about importance of human rights.
- *Policy core beliefs* cover the policy subsystem and relate to basic policy choices e.g. relative seriousness and causes of the problem in the subsystem. These beliefs reflect how actors think the subsystem *should* be and therefore guide a coalition's strategic behaviour in policy making. Policy core beliefs are considered 'the glue' holding coalitions together (p195) and are therefore difficult to change (272). These beliefs are also what divide coalitions and the unmovable debates between groups sometimes centre on divergent policy core beliefs (273).
- *Secondary beliefs* are narrower in scope, relating to the details of policy. Secondary beliefs are amenable to change in the light of evidence or in line with strategy and require fewer agreements among actors (272).

Paths to Belief and Policy Change

Changes in a subsystem or policy are triggered by a number of conditions: policy oriented learning, shocks to the subsystem (internal or external) and negotiated agreement. Policy oriented learning refers to changes of thought or behavioural intentions resulting from *"experience and/or new information and which are concerned with attainment or revision of policy objectives"* (p104) (275). Policy oriented learning includes increased knowledge of the problem and the factors affecting it, feedback on the effectiveness of policy strategies and perception of the impact of various policy

alternatives. This learning is influenced by actors' perceptual filters as they may resist or avoid information at odds with their deep core or policy core beliefs. Hence policy oriented learning tends to alter secondary beliefs leading to minor changes in policy.

Events or 'shocks' to the subsystem can also influence policy change. As Figure 35 illustrates, external factors can be stable (e.g. attributes of problem) or dynamic (e.g. economic changes). Stable factors rarely trigger change within a policy subsystem. A recent modification to the ACF was the introduction of coalition opportunity structures which mediate between the stable parameters and the policy subsystem (272). The structures include the degree of consensus needed for policy change and the openness of the policy system; that is the number of decision-making venues a proposal must go through and the accessibility of each venue. Changes in dynamic external factors are considered necessary for major policy change (272) and can include a change in government or in the economic conditions of a country. Such changes or 'perturbations' can shift the agenda or the focus of attention, leading to changes in the resources available to a coalition (e.g. public support).

Originally the ACF only emphasised the influence of external events on subsystems however in 2007, the concept of perturbations was revised to include internal shocks as another potential condition for policy change. Internal shocks can confirm policy core beliefs in the minority and increase doubt in the dominant coalition (272). Recent revisions of the ACF have also taken into account policy change which occurs in the absence of shocks. The idea of a negotiated agreement, which draws on policy oriented learning, focuses on agreement crafted by competing coalitions after long periods of dispute (272). According to the Advocacy Coalition Framework a decade or more is required to understand and analyse the full policy process including the impact of policy change and revision of beliefs. However as there has yet to be a concerted effort to implement a national diabetes programme, this study considers diabetes policy to be in the policy formulation stage with the Diabetes Expert Advisory Group as the most recent example of this phase.

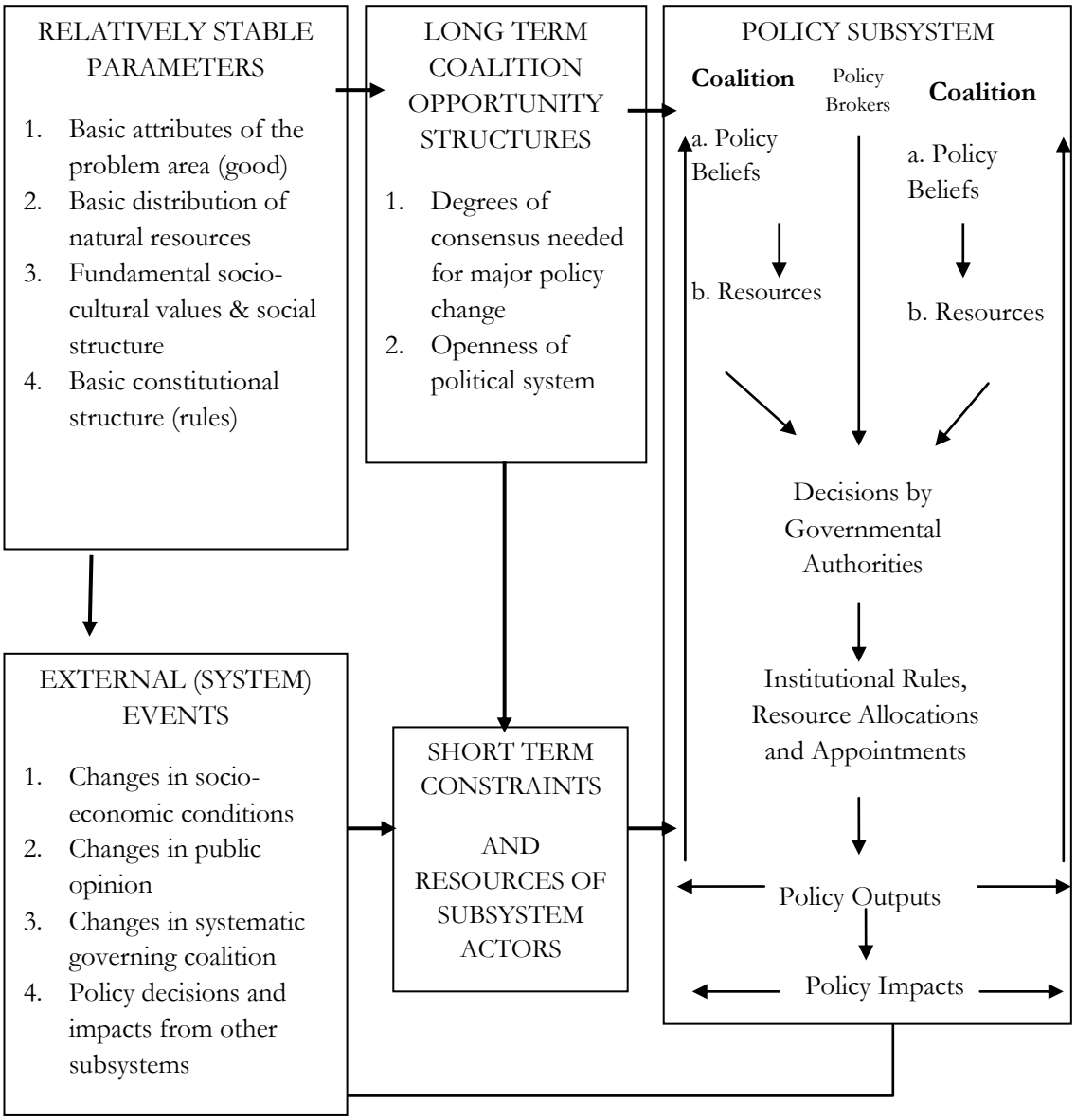


Figure 35 Advocacy coalition framework (2007) (272)

7.1.7 Aims & Objectives

This study addresses one of the overarching aims of this thesis, which was to examine efforts to bridge the quality gap in Ireland from practice to policy. The specific objective of this study was;

1. To analyse the formulation of the recommendations from Expert Advisory Group for Diabetes, a top-down approach to improve the quality of care in Ireland.

Case study research is commonly driven by how and why questions (276). The following questions focus on the process and outcome of the Expert Advisory Group to address the study's objectives;

- How and why were the Expert Advisory Group established (process)?
- How did the recommendations evolve and why did it happen in that way (outcome)?

Theoretical propositions were established as possible explanations of the policy process based on the principles of the theories previously outlined. Theoretical propositions link theory with data collection and analysis, directing attention to sources of evidence and issues which should be examined in the data (276).

7.1.7.1 *Theoretical Propositions*

1) Rational Choice Perspective

The proposition to be explored was that a logical sequence of steps was followed by the EAG which led to the formulation of the EAG recommendations. Firstly the nature of the problem was identified and defined; that is the variability and deficiencies in diabetes care. Secondly, the goals and objectives of the EAG members were clear and explicit from the outset. Alternative strategies and their consequences were analysed using multiple sources of reliable information to minimise uncertainty and ensure informed decision-making. Based on this analysis the best option was chosen, that is the alternative with the highest chance of occurrence and most conducive to the goals and objectives of those involved.

2) Multiple Streams Framework

The second proposition was that there were three largely independent streams operating in the policy context; problem stream (the problem of diabetes and suboptimal standard of care in Ireland), policy stream (the development of proposals by the EAG) and politics stream (changes in the HSE). Ideally these streams would come together at a critical point to open a policy window which would provide an opportunity to get diabetes management onto the decision agenda. However the policy window did not open during the EAG process due to economic constraints and changes within the structure of HSE.

3) Advocacy Coalition Framework

The third proposition to be examined in the data was that policy formulation was a function of three sets of factors. Firstly competing advocacy coalitions (health care professionals and health system management) interacted within the policy subsystem of diabetes. The coalition shared core policy beliefs about the importance of diabetes and the standard of care. There were subdivisions within the coalition regarding the merits of various proposals particularly the ideal model of care. Changes external to subsystem (i.e. economic recession) influenced the resources of the actors within the system which limited the policy output of the group.

7.2 Methodology

7.2.1 Design

This study involved a retrospective analysis of policy formulation using a case study design. The case was the development of the recommendations by the Expert Advisory Group for Diabetes to improve diabetes services in Ireland.

A case study investigates a contemporary phenomenon within its real-life context (277). There are two ways to distinguish a case study; by the size of the case (single/multiple) and by the intent of the case analysis (intrinsic/instrumental) (153). In terms of size, this was a single case study design involving the selection of one bounded case, the EAG process. In terms of the intent of analysis, this was an instrumental case study as the case was analysed to illustrate the policy formulation process. Conversely an intrinsic case study focuses on the case itself because the case presents unusual or unique situation (276). Hence case study design was appropriate for this study as there was a clearly identifiable case with boundaries (278). The EAG process has identifiable boundaries in terms of timescale and participants. The focus of analysis was on the lifecycle of the EAG from establishment in 2006 until the final EAG meeting in July 2010.

7.2.2 Data Sources

A detailed case description was built through in-depth data collection using multiple sources. The primary method of data collection was qualitative using in-depth semi-structured interviews with various stakeholders. Secondary data included published and unpublished documents relating to the EAG process (Table 42). The interviews with stakeholders provided an opportunity to access additional documents including meeting agendas and minutes.

Table 42 Secondary sources of information

TYPE	SOURCE
National-level Policy	
National Health Strategy 2001: *"Quality & Fairness; a Healthy System for you "* **(279)**.	DOHC 2001
Primary Care Strategy 2001: *"Primary Care: A New Direction"* **(182)**	DOHC 2001
"Tackling Chronic Disease: A policy framework for the management of Chronic Disease." (2008) **(11)**	DOHC 2008
Position Statements	
"Diabetes: Prevention & Model for Patient Care" (2006).	Diabetes Working Group established by DOHC in 2004
"Diabetes Care; Securing the Future" (2002)	Diabetes Service Development Group linked to DFI
"DFI: The Way Forward 2006-2010"	DFI Strategy Paper 2010
EAG Process Documentation	
Meeting Agendas	Participants
Meeting Minutes	Participants
Evaluation questionnaires of the process	Participants
Copy of some presentations to the group	Participants
Official press release from HSE	Online
Media	
HSE Press Releases	Online
Coverage in national newspapers, online health forums	Online
Other	
Dáil Questions	Online
Oireachtas Reports	Online

7.2.3 Participants

Purposive sampling was employed in this study as the population of interest was the 22 core members of the Diabetes Expert Advisory Group (EAG). The EAG was multidisciplinary group including GPs, consultant endocrinologists, diabetes nurse specialists, pharmacist, dieticians, biochemist, public health specialist, diabetes patient association representative, representatives from the department of health and various sectors of the HSE including Primary Community and Continuing Care (HSE Directorate) and the National Hospitals Office which have now merged into the Integrated Services Directorate.

7.2.4 Recruitment

Potential participants were invited to take part via an email with the participant information sheet and the consent form attached (Appendix XVI). If otherwise requested or if no email address was available the cover letter, participant information sheet, two consent forms (personal copy and copy for researcher) and a pre-paid self-addressed envelope were posted to the participant. Participants were given the option of

returning the consent form via post or email and following this an interview date was arranged. A snowball sampling technique was also used to identify other relevant stakeholders who could be contacted.

7.2.5 Sample

Fourteen of the twenty-two group members agreed to be interviewed for the study (2/3 of group). Another stakeholder was interviewed as a result of recommendations from within the EAG. Reasons for non-participation included retirement and workload while other members did not respond to the invitation or to follow-up correspondence. The sample was mixed in terms of gender, profession and location reflecting the constitution of the group as a whole. Upon dissemination of the transcripts, one participant withdrew from the study leaving a final sample size of 14 participants.

7.2.6 Topic Guide

The topic guide was informed by the policy analysis triangle (280), developed specifically for health which identifies the factors affecting the policy process; content, context, actors and process (Appendix XVII). The topic guide is loosely organised around the pathway for developing evidence-informed policy proposed by Bowen & Zwi (2005)(281). The assumptions underpinning the three analytical theories were also used to inform the content of the topic guide for the interview.

7.2.7 Interview Protocol

Data collection took place between November 2010 and January 2011. Interviews were usually conducted in the workplace of participants. While the expected interview duration was approximately 30-45 minutes, the average interview length was 52 minutes. Informed written consent was obtained and participants were provided with an information sheet and a copy of the consent form for their records. Audio-recording and note-taking during the interviews was discussed prior to commencement and participants were reminded that only anonymous extracts or quotes would be reported. All interviews were digitally recorded and subsequently transcribed by the researcher.

7.2.8 Analysis

Data were managed and analysed in NVIVO 8 software. Thematic content analysis was applied to the data which is considered useful for informing policy development (282). Initially open-coding was applied to transcripts to allow themes to emerge from the data rather than imposing a structure on participant accounts. During the second wave of

analysis the three theories of the policy process were applied to the data as analytic tools. The theoretical propositions were used to orientate and guide the analysis (276). Hence codes were inspired by the assumptions and central tenets of each theory (274). For example the theory of rational policy making suggests that policy formulation is characterised by deliberate and discrete steps, therefore one of the first steps in coding for this theory was to ascertain whether there were obvious stages in the formulation of the EAG recommendations.

7.2.9 Ethical Approval

Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Appendix XVIII). Participant quotes utilised in the results section were fully anonymised including the removal of information on position or profession in the health system as some participants were the only member of a professional group within the EAG.

7.3 Results

This section presents the findings of the analysis of the formulation of recommendations by the Expert Advisory Group for Diabetes to improve the quality of diabetes care in Ireland. The results are presented in three sections. The first section corresponds to the first research question; how and why the EAG for Diabetes was established. The second research question, how the recommendations to improve care evolved and why it happened that way, is dealt with over two sections. This reflects the disproportionate attention paid by participants to the approval process involving the HSE, and the incomplete transfer of the EAG report from the formulation phase to the implementation phase. The three theoretical perspectives are referred to throughout the findings with an overall appraisal of their applicability at the end of the results section.

7.3.1 How and why the EAG for Diabetes was established?

Summary

The Expert Advisory Group (EAG) was an assembly of health care professionals, stakeholders, and representatives from the health service, who volunteered to act as the *"primary source of operational policy"* for the HSE and *"to ensure policies are implemented appropriately"* (HSE document, 'Expert Advisory Group; An Introduction'). The CEO of the HSE was credited with the idea for setting up the EAG primarily as a way to involve health care professionals in policy making and planning. Members of the group were volunteering in a personal capacity and were not representing colleagues or local areas. Diabetes was gradually recognised as a priority by the health service given the cost and scale of the problem. Equally there was an accumulation of efforts highlighting the problem (evidence) and the solution (local groundwork). In the beginning the EAG was perceived to be different from previous efforts as it was internally driven by the HSE and came with a "promise of implementation", the reason many health care professionals volunteered to the group.

'An idea of the CEO to involve clinicians in management'

The former CEO of the HSE, Prof. Brendan Drumm, was seen as instrumental in devising the shape and purpose of EAGs with one participant describing it as *"the CEOs pet subject"*. A clinician in the role of CEO was seen as an important and unique factor driving the development of the EAGs.

"I would imagine it was Brendan Drumm's interest in having clinicians involved at the core of health service delivery. It was to do with bringing clinicians central to management, service, planning and delivery. Because Brendan Drumm became the CEO and he was a clinician and it was a question of bringing a unified HSE in a different direction."

The group was set up one year into the life of the Health Service Executive and transformation had become a buzzword in the health system. *"The EAG was started at a time when there was plenty of money around, when the HSE was new, there was going to be action, things were going to change.* In keeping with this mood the CEO was *"quite keen to do things differently"*, that is establishing a multidisciplinary group as opposed to the tradition of commissioning a report from one interest group reflecting one perspective which had the potential for bias.

The most commonly cited hypotheses as to why EAGs were established, was the desire to involve clinicians in service planning and policy development. Table 43 outlines respondents' views as to why the HSE established the EAG compared to the purpose of the EAG put forward in the official introductory document on Expert Advisory Groups developed by the HSE (*Expert Advisory Group; An Introduction*).

Table 43 Participant views on the reasons for the establishment of the EAG compared to purpose put forward by the HSE.

Reasons given by Participants	Purpose of the EAG in the HSE Introduction
Opportunity to involve clinicians (Referred to by 7 respondents)	▪ Platform for wider involvement ▪ Opportunity for health professionals to influence operational policy ▪ Enable application of expertise including international perspective
Expected increased demand on services & the need for planning (Referred to by 4 respondents)	▪ Drive integration between 3 service delivery units in the HSE.
Seeking improvement (Referred to by 1 respondent)	▪ Ensure international standards and best practice are part of planning

7.3.1.1 Why diabetes?

Diabetes was one of four areas assigned an EAG. The cost of diabetes alone made it an obvious priority for the HSE: *"well diabetes is 15% of our total health-spend, a major epidemic coming at us, and if that can't hit a policy agenda what can?!"* Deficiencies in the standard of care in Ireland were also emphasised and in the EAG report the chairman of the group noted that *"most people knew services in Ireland were behind that available to their counterparts elsewhere in the developed world"* (p2)(1). This quote illustrates how comparison between countries can be used to define an issue as a problem, an approach to problem definition outlined in the Multiple Streams Theory. The reasons given by participants as to why diabetes was singled out as a priority for the health service, appear to fit with Kingdon's 3 streams; it was a costly epidemic (problem), there was existing evidence and groundwork to improve care (policy), people were advocating for change (support in the political stream) (Table 44).

Table 44 Why was diabetes assigned an expert advisory group?

Why Diabetes?
Cost & Complications
"It permeates many other medical illnesses. It has a very big impact on cardiac disease and a very big impact on costs and complications of diabetes"
Complexity & Quality of Management
"It's a real challenge to manage it well. I've heard it said that at any 1 time up to 10% of in-patients in a hospital have diabetes… these patients tend to come in more and stay for longer and even straightforward things when you have diabetes can be problematic. So I think the health service has identified it as an area to target in terms of improvement in care delivery."
"Archetypical" chronic illness
"I suppose if you look at the wider context and you were to take an example condition where you felt that you could try and pioneer how we could revolutionize, maybe how health care is delivered in this country, diabetes is a perfect example."
Epidemic of growing importance
"We keep talking about this ticking time bomb but it's just getting more and more of an issue. And as our population ages it's becoming more of an issue."
Existing Groundwork
"...there were some things that were happening on the ground, I mean regardless of whether it was being driven by the HSE, health care professionals were lobbying and doing it anyway."
Interested groups and individuals advocating for change
"I think as well there were a lot of soldiers' voices in diabetes and a lot of influence in media at that time so that's why it was seen as the one most in shape or most ripe for movement on."
Accumulation of Evidence
"You had the IPH data coming in [at that time]. So a lot of stuff came in at the same time...and you had the obesity taskforce so people were beginning to realise that there was going to be this burden of care into the future and the HSE very gradually began to realise that they couldn't possibly cope with it in the traditional way that they had been"
"A glaring omission"
"It's well known that in Ireland we have a very poorly organised diabetic care system so I think lots of people in senior positions both in the Dept. of Health and the HSE know that, so it was a glaring omission. We have a cardiovascular strategy and a cancer strategy…"

Finally being "accepted as a priority

Although a number of participants felt the reasons for choosing diabetes were obvious, the recognition of this condition as a priority by the HSE was gradual. With the exception of financial cost, none of the factors were seen as sufficient on their own:

> *"We've been nipping away for a long time but given the current explosion in diabetes and the evident costs that going into it, plus 15% of people in hospital beds have diabetes and being there for longer than other people, it obviously was an area that had at some stage to come to the forefront of HSE thinking."*

Figure 34, contained in the literature review, outlined the main policies, publications and events preceding the setting up of an EAG for diabetes. This timeline illustrates the accumulation of efforts which preceded the EAG for Diabetes including local initiatives, drive from interest groups and stakeholders and evidence of cost, prevalence and associated risk factors. Together these factors contributed to the perception of diabetes as *"most ripe for movement"*.

7.3.1.2 Recruiting Members: "handpicked" volunteers & assigned representatives

The EAG compromised of volunteers and selected representatives from within the HSE and DOHC. Volunteers were recruited through a call for expressions of interest in February 2006 which required interested individuals to outline why they wanted to be involved. In reference to their application letters, participants spoke about their *"experience on the ground"* in diabetes, interest in quality and chronic disease management, experience working in different health systems, involvement in service development at a local level *"that was...similar to what the EAG was trying to accomplish nationally"*, previous experience in developing policy and finally personal experience of the impact of diabetes. Members of the EAG, including the chairperson, were then *"handpicked"* by the CEO. The members themselves acknowledged the importance of the leadership in the group:

> *"The chairperson of the EAG needed to be a strong person and need to be closely aligned to the CEO which he was. A lot of the chairpersons I understood were deliberately picked by the CEO, many for personal relationships and knowledge."*

Concerns were raised during the EAG process about the lack of patient representation in the group although representatives were invited to attend and some of the subgroups invited people with diabetes to be part of discussions.

Functional Representation

The EAG also included people assigned from within the HSE, to represent the three service delivery units in the organisation: the National Hospitals Office (NHO), Primary Community and Continuing Care (PCCC) and Population Health. The rationale was that this would:

> *"enable the group to meet their data requirements, seek formal input from front line providers and examine existing practices and innovations within the health service."*
>
> 'Expert Advisory Group: An Introduction'(146)

However this function, as set out in HSE introductory document, did not emerge from participant accounts. One participant suggested these representatives should have been central in connecting the recommendation phase to the implementation phase although no one else referred to their responsibility in this area:

> *"I think the key missing point that I see from the group was the people who were representing the key service delivery areas, them being able to sort of say well this what needs to be done, set up a process to do it and that wasn't do there. I think they were unable to do it or I perceived it as they were unable to do it because nobody gave them permission."*

7.3.1.3 *Reasons for Volunteering – Expectation of Implementation*

The desire for change was the most commonly cited reason among health care professionals for joining the EAG, which is described within the Multiple Streams Theory as an incentive for policy entrepreneurs (251). Other incentives, according to the theory, include personal interest. While few participants in this study referred to specific personal goals for joining the EAG there was personal interest in the desire to learn from the experience (Table 45). Appointed representatives of the HSE did not refer to any reasons for joining. Some participants' spoke about their expectation of implementation while others referred to the EAG as a chance *"to get things moving"*. This expectation was a powerful motivation given participants' previous experience of developing reports which had never transferred into action.

"What he promised which made it attractive from my point of view I suppose was that there would be an implementation arm to this. [That was the expectation?]That was the expectation from the beginning and that was what was novel about it from previous things…"

The EAG was going to be different to "what happened before"

As the last quote suggested, the expectation of implementation differentiated the EAG from previous reports which were *"lost in the wilderness"*. Another unique feature was that this group was *"internally drive";* requested and established by the HSE.

"This was the 1st time the HSE had wanted to roll something out. And this was being led by the HSE as opposed to the diabetes health care professionals who had really been shouting about this for a long time...Previous ones were being led a lot of times by consultant endocrinologists or the Diabetes Federation and they were banging on the door of the HSE but I suppose this was the 1st time it came from the other direction."

Previous experience of policy arena – a "talking shop"

There was a clear contrast between optimism joining the group and scepticism given the track record of previous efforts. One participant spoke about struggling with whether or not to submit the letter of interest having heard from colleagues that *"being involved in things nationally can bring more frustration than reward."* The term *"talking shop"* was used on a number of occasions to describe previous efforts in the policy arena and from the outset *"quite a lot of eminent people around the table said 'look I'm prepared to give this a year and if it doesn't start having sort of tangible effects at the end of that I'm quitting it. I'm not sitting around here as a talking shop.' "* The perception of past efforts as 'talk without action' was not limited to those who were involved in earlier working groups; it seemed to have permeated the health system.

"There was a lot of anxieties going into the EAG because a lot of people who were in that group had been involved in writing documents before that were gathering dust on the shelf. Here was another report and more paper work. And you got that from a lot of your colleagues who weren't even on the EAG as well."

Table 45 Reasons for joining the EAG

Reason	Quote
Stakeholder involvement	"I was taken by the idea of assembling a group of people who are involved in delivering and/or received or organising diabetes care and getting them in the one room." (HCP)
Opportunity to "shape policy"	"And just generally it was both a learning opportunity, networking yes but also ultimately to see in terms of having something in place like a policy for diabetes in Ireland." (HCP)
To make progress	"Really to get things moving. I mean, there was a lot of interest in diabetes and yet people seemed to be helpless about how to move forward and I felt that I could definitely contribute something to that."
Learning Opportunity	"To influence the policy, to be…to ensure that wherever I could bring my own knowledge and experience could be brought to bear on a process but also I could learn as part of that process." (Other)
Understand the workings of the HSE	"I still believe that to get things done you need to understand the workings of the organisation...You can't come in like John the Baptist with your declaration of what's going to happen, you have to work with the people who are running the organisation. And so my reason in the end for signing up to actually sit on the EAG was not so much that I was going to change the world but it was to understand the HSE better. And I definitely did." (HCP)
Standard of diabetes care	I would have tried to impress on them that this wasn't a passing interest it was a passion in terms of really I think...that we have the wherewithal to do a much better job than we do at delivering effective diabetes care. We don't really maximise I think, the talent that we have. (HCP)
Representation: regions, patients and professions	"I would have my own bias in terms of how I think diabetes care should be delivered but I don't know that I had clarified in my mind things I wanted to get out of the EAG...I would not have had specific objectives that I wanted to get out. I was keen to represent my region and have it do well out of it, if there were any resources or if there was any opportunity to pilot or to develop things" (HCP)

Impartiality: Representation vs. Personal Capacity

Although a number of participants referred to representation among their reasons for volunteering, it was not an official part of the EAG process. As explained in the HSE document 'Expert Advisory Groups: An Introduction' members were not there to represent colleagues or professional bodies but rather on a personal basis (146). This point was emphasised in the terms of reference for the various Expert Advisory Groups circulated at the first meeting. It was envisaged that the personal capacity of membership would:

> *"…remove any obligation members may feel to put forward the views of peer groups and interest groups with specific local and regional agendas. It also enables members to retain their impartiality and apply a national perspective"*
>
> Expert Advisory Group-An Introduction(146)

Most participants recalled this caveat during the interview however some equally felt it was not possible to separate oneself from ones profession and *"by its very nature you're always very conscious of the group you are involved in and how this would best suit them and how you can best represent a group of them."* One participant questioned the rationale behind the notion of membership based on a personal rather than professional capacity, as the final selection of multidisciplinary members from different parts of the country suggested people were there *"on the basis of their profession"*. Furthermore meetings were held during work-time which had substantial cost implications for GPs, who had to employ locums to cover their practice. Other members attended as part of their work day and thus *"were paid to be there"* which did not fit with everyone's definition of volunteering. Hence despite the prerequisite that people were joining as individuals, to some extent it was an unrealistic expectation as members acknowledged the difficulty separating themselves from their profession or their local area.

7.3.1.4 *Remit of the EAG - Source of Operational Policy & Involvement in Implementation*

According to the HSE the EAG was to act *"as the HSE's primary source of operational policy and strategic advice in the service area of diabetes" (*HSE Introduction). This broad remit was echoed by participants' descriptions of an open brief which was not *"terribly specific"* to give the group *"some discretion"*. Table 46 illustrates the key aspects of the brief as outlined in the EAG blueprint document compared to participants' accounts.

According to the CEO's foreword to the EAG report, involvement in implementation was also part of the remit as the group was established to review the issues of diabetes management and to *"make recommendations to and be involved with HSE management in implementing them" (p2)*(1). Participants' expectations of implementation were based on concrete plans, set out in the HSE's modus operandi, to put the recommendations into practice under the governance of a cross-directorate Implementation Group. This group would be chaired by the Assistant National Director or the Hospital Network Manager from within the relevant service delivery unit in the HSE. In hindsight one participant suggested this was a rational but naïve expectation;

> *"The issue was the naivety around the connection from policy to implementation…that expectation that we were going to set up an expert advisory board, [thinking] 'they're not going to keep putting their sweetness onto the desert air and not find root somewhere'…." (Non-health care professional)*

Table 46 Remit of the Expert Advisory Group in HSE introduction document compared to participants' accounts

HSE	PARTICIPANT
Advise on Policy	
Primary source of operational policy and strategic advice.	"The main remit was to advise the CEO in matters relating to policy, that was my recollection of the broad brush"
Provide baseline knowledge of diabetes	
Needs assessment, analysis of current service provision, explore alternative models	"I think the powers that be wanted some baseline knowledge or how diabetes was or was not managed. And how we could implement things for the future"
Plan development of diabetes services	
Explore alternative models of service delivery, consultation process, evaluation of best practice, standards, option appraisal	"I knew it was an advisory group that would formulate recommendations that would hopefully lead towards how diabetes care would be, how services would be directed, how policy might change in the future."
Implementation	
Verifying and assuring adopted policies and strategies are implemented and legislation, national policies, standards and best practice are complied with.	"He promised that there would be an implementation to this"
Following adoption of an EAG's reports and recommendations, a cross-directorate Implementation Group is established to ensure they are put into practice	"That was the impression we got; this would form the roll out of diabetes services nationally"

7.3.2 How did the recommendations evolve?

Having outlined the background to the establishment of the EAG and the purpose of the group, this section outlines how the recommendations were formulated and the outcome of the EAG report.

Summary

In keeping with the rational model of decision making (250), the EAG followed a deliberate sequence of steps from priority setting to analysis of alternatives in subgroups to choosing the recommendations to put forward to the HSE for approval. However the analysis of alternatives was strongly determined by previous proposals and local capacity. The formulation of proposals within the group was facilitated by an underlying common goal and agreement on the main priorities which were termed a *"no-brainer"*. Participants reported that the group focused on issues with the highest chance of success such as retinopathy screening. Other proposals were subject to the influence of personal preferences and places. There were divisions within the group regarding the details of some of the proposals. Discussions around the model of care caused divisions both between and within professions however there was a gradual sense of acceptance around a model of integrated care. According to participants the group employed a number of tactics to increase the chances of their proposals being accepted including aligning recommendations with previous policy and the future direction of the EAG as well as making plans for implementation.

7.3.2.1 Priority Setting – "Commonalities"

Identifying priorities was one of the primary agenda items at the first meeting of the EAG in early December 2006. In advance of this meeting, members were instructed to prepare a list of the priorities to bring to the wider group. The main concerns to emerge were; retinopathy, podiatry, diabetic register, education, uniformity and adequacy of care, obesity, dietary issues, sharing of knowledge, develop model of care/national agreed guidelines, cost effective prevention. A number of participants commented on the similarity of priorities raised. The following quote summarizes the factors which facilitated agreement;

Standards set internationally

Another factor which facilitated agreement in the group was the international consensus on the main priorities in diabetes care. The similarity of opinion among experts working

in the Irish health system was reinforced by reports from other countries such as New Zealand, Scotland and the UK and *"in essence 80-90% of all of these things were saying the same thing. So it was a no-brainer."* Some members of the group had first-hand experience of diabetes policy and care delivery in other health systems, particularly the NHS in the UK. The National Service Framework in Scotland was especially *"impressive"*. This country of similar population and geographical spread was considered *"light years ahead"* of Ireland in terms of their organisation. This appears to fit with the Multiple Streams assumption mentioned previously, that international comparisons inform the definition of an issue as a problem (251). There was an element of international aspiration and policy transfer, which was seen as a pragmatic approach given the global consensus on diabetes care;

> *"…Several times people used the old phrase 'there's no point in reinventing the wheel'. Things that are important in Scotland or Denmark are likely to be the things that are important in Ireland so our set of priorities and indeed our standards for diabetes care would have been modelled on the UK equivalent. Probably dressed up a little bit in the Irish context and that but its eyes, kidneys, feet, education of patients and health care professionals and support structured, that's probably it."*

7.3.2.2 Prioritising Priorities

The group adopted a pragmatic approach to priority setting, categorising the priorities into immediate, medium term and long term issues with the expectation that all topics would be dealt with in turn. The decision about which priorities to tackle first appeared to be largely drive by the realistic chances of success, congruent with the rational perspective of choosing the alternative with the highest chance of occurrence.

> *"We said 'look there's obviously about 7 different priorities that we should start with first to see if we can make any progress'. Because there was that sense of scepticism as well, 'let's try a few of these things to see can we get any kind of throughput on this' or are we wasting our time."*

Subgroups were assigned to formulate detailed recommendations in each priority area that would then be fed back to the whole group at the main meetings. Members self-selected themselves to join a particular sub-group based on their interest or area of expertise; *"It was very much a 'hands up who wants to be involved in what groupings'"*. There were efforts to have some professions represented on all sub-groups again suggesting the representation was an implicit part of the process.

Rise & Fall of Priorities

The priorities of the EAG shifted over time. According to minutes from the first meeting the top four issues were; Retinopathy, Podiatry, Diabetes Register and Care Delivery Models. However at the second meeting the following four topics were assigned a subgroup to be dealt with first;

- Retinopathy Screening
- Education/Podiatry
- Paediatric Diabetes Care
- Standards of Care

The development of a register dropped off the EAG agenda over the course of 2007 as a research project was funded by the Health Research Board to look specifically at the feasibility of a register. This group involved some members of the EAG who were invited to give a presentation to the EAG reflecting the coordination of activities with the wider advocacy coalition. Analysis of meeting minutes revealed the rise and fall of particular issues on the group's agenda. Table 42 outlines the issues discussed by the group over the life of the EAG. While some topics were addressed consistently throughout the EAG process others, such as the development of a diabetes strategy, did not survive on the agenda. The table also illustrates how the process moved from developing proposals to gaining approval, from the content to process.

Table 47 Rise & Fall of Issues from the EAG Agenda

ISSUE	12.06	01.07	02.07	04.07	05.07	07.07	08.07	09.07	03.08	04.08	05.08	10.08	11.08	12.08	03.09	05.09	09.09	12.09	01.10
Retinopathy																			
Podiatry																			
Register																			
Model																			
Standards																			
Paediatrics																			
Education																			
DM Strategy																			
Estimates																			
DSIG																			
ICT																			
Future of EAG																			

National Director																		
HbA1c change																		
Insulin Pump																		

7.3.2.3 *Retinopathy Screening – a "quick win" situation*

Retinopathy screening was one of the issues to the forefront of the agenda and maintained its position throughout the EAG process (see Table 47 above). The sub-group was established in February 2007 to prepare a national strategy for the development, implementation and monitoring of a National Retinopathy Screening Programme. Retinopathy screening wasn't *"the number one priority, it was the number 1 chance of success."* The probability of occurrence is one of the influences on the selection of alternatives according to the rational model of policy making (266). The main reasons, as to why retinopathy *"made complete sense"* as a priority, are outlined below (Table 48).

Table 48 Factors underpinning retinopathy as a "quick win" situation

Facilitator	Quote
Regional Groundwork	"That [retinopathy] came out because there was already movement towards it and because it was something that could be delivered upon. There was already a mobile clinic up and running in the West and was showing great results and great compliance. So it was already on the agenda. And as I said we were practical enough to hitch our wagon to something."
International Evidence	"...the fact that the eye screening service had been developed in the North West, that it was based on international evidence and it was very much they had looked to their colleagues and their counterparts in the UK and in Scotland. So it was very much looking beyond Ireland at was is the best way of delivering the screening programme. So there was no real question about that really I suppose."
Financial commitment	"There was some money for retinopathy" to extend screening, so it was "obviously picked because it was already in progress".

7.3.2.4 The Power of People and Places – Different forms of interest

There were different types of interest shaping the agenda and proposals of the EAG including personal interest, local interest and financial interest.

- **Personal Interest.**

While personal interest did not emerge among participants reasons for joining the group, preferences were reflected in some of the proposals of the group. Retinopathy was not everyone's number one priority and some items on the agenda were perceived to be *"someone's baby"*. IT for example, was described as something that got *"grafted on"* to the agenda:

> *"In terms of projects and money coming out of it, for some reason everything went to one place, I don't know why. One place gets this IT money. Whoever said that IT was (a priority), that a new IT package was needed? I don't believe it's the case."*

The three theories applied in this study emphasize the influence of personal interest: personal goals driving selection of alternatives (rational model), personal interest as an incentive in the Multiple Streams theory and the aim of translating beliefs into policy which drives coalitions according to the Advocacy Coalitions Framework. However in this study local interest was also a strong feature on the agenda.

- **Local Interest**

Local loyalty could hold more sway than research, as illustrated by the experience of patient education subgroup. Patient education was the subject of local allegiance and an inconsistent evidence base and therefore did not enjoy the same clarity and confidence of the retinopathy screening recommendations.

At the time of the EAG, patient education embodied the variation of diabetes care in Ireland with several different patient education programmes in various parts of the country *"funded through varying methodologies"* and location as a key determinant of access. This inconsistency was a result of *"the absence of a national policy and dedicated funding*" (p51 EAG report). There were different opinions within and outside the education subgroup about how best to provide a national direction in the face of such diversity. The issue was complicated by the financial and personal investment in local programmes. One option was to use existing evidence to decide on *"a national patient education"* programme from the various alternatives;

> *"...I mean the <u>obvious</u> thing would have been to examine the various programmes, get some evidence base and decide on a national patient education programme. That would have been the obvious (thing) but that couldn't be achieved because there was great loyalties to the existing programmes and they couldn't get agreement on scrapping any of them."*

However while this may have been deemed *"the obvious"* option by one participant, it was never an achievable option as illustrated by the following conflicting perspective:

> *"One of the things is the variety of structured education programmes so we were never going to promote one over the other. I think that was something people would have agreed with at the start."*

The evidence base for patient education was also ambiguous. Internationally education programmes had been evaluated with varying degrees of rigor and there was no

published evidence of effectiveness in Ireland. NICE guidelines in the UK did not provide "direction as to the effectiveness of any specific programme" (EAG report, p51). A review of existing programmes in Ireland was carried out in 2009, the outcome of which was that *"key criteria for structured diabetes education in Ireland were agreed by multidisciplinary group of diabetes experts and HSE personnel"* (Education report, p4). It was suggested that the criteria for approval, and therefore funding from the HSE, should be based on the NICE guidelines for structured patient education however one programme did not *"effectively meet the NICE criteria"* thus further compromise was required:

> "*…you're within the group, not challenging their program but saying in order to be recognised and if the HSE are going to give you money to roll this out you should be meeting certain standards. And that's where then you'd kind of get a rap on the knuckles a little. So it was almost like there was something else going on in the background"*

Ultimately, having examined all the programmes *"they concluded that all the programmes achieved the objectives. So all they could say was all the future programmes need to pick from these effective programmes but they couldn't say we need to standardize on one programme"*. There was little compromise but rather accommodation of powerful preferences and local loyalty.

- **Business Interest**

There was only one clear example of a business perspective being brought to bear on the EAG process. This was the case of the Optometrists who were *"keen to keep their members in the loop (of the EAG)"* with regard to development in retinopathy screening *"maybe because private practice; probably a big part of their business is diabetes."* Unlike Ophthalmologists, Optometrists "*would be seen as private workers and not HSE employees"* giving rise to a potential conflict of interest. The EAG had a clear vision for a high quality screening service which created tension among the groups;

> *"Opticians wanted to do it in a relatively ad hoc way and we were very keen to quality assure a programme that would be a standard like they have in England and Scotland."*

The *"controversial"* issue went right to the top of the administration. There were *"meetings with Mary Harney and all kinds of stuff"* such is the power of business interests. In the end a

compromise was reached by allowing optometrist involvement on the condition of certain standards being met:

> *"So the compromise in the end really was that they would be part of the process if they were certified as graders and that kind of thing."*

7.3.2.5 *Commitment to Quality*

The development of standards for diabetes care highlighted one of the challenges of making recommendations; striking a balance between aspirational and achievable goals. The difference between aspiration and achievement in the context of the EAG appeared to be the level of commitment given by the HSE to the recommendations. Participants reflected on the gap during discussions about "*whether the standards should say 'a person with diabetes should get such and such' or 'will get such and such'. Is there a commitment behind it? …there's a hell of a lot of things we already knew people should be getting and they weren't."* In the end the EAG report outlined what standards the person with diabetes 'should' expect, *"something the person with diabetes could aspire to"*. While the group could propose standards of care, the responsibility for meeting these standards was placed at the door of the HSE in terms of putting in place systems to facilitate and promote quality assurance, depending on their 'commitment to the concept of the EAG improving care' (report p26). In contrast, one participant felt that the vagueness of the standards served to *"placate the powers that be"*.

The final EAG report made reference to quality assuring care as part of the future work of the EAG which would include incorporating *"measurable outputs into the standards to facilitate audit"*. This was in keeping with a key responsibility of EAGs specified by the HSE; to verify and assure that "legislation, national policies, standards and best practice protocols are complied with" (HSE Blueprint). However as one participant reflected *"we never got to that space"* and quality assurance did not emerge on the EAG agenda (Table 42). The EAG could only *highlight* the need for commitment; it could not make that commitment on behalf of the HSE, an early indication of its limited power.

7.3.2.6 *Model of Care: "Tug of war" between settings & division within professions*

Developing recommendations on the model of diabetes care was considered *"the poison chalice"* given the difficulty devising a model which would be accepted by all professionals and applicable in different areas. Some participants felt there was a

reluctance to broach the issue even though it was considered one of the immediate priorities.

According to one participant *"the idea that a large proportion of diabetes care was going to take place in general practice was too contentious to talk about"*. The contention reflected the different perspectives in primary and secondary care on the ideal model of care and the extent of involvement from each setting, giving rise to "a tug of war" between settings.

> *"There's the whole ownership battle that's kind of going on, because a lot of the endocrinologists, and even on the EAG, were very keen that they don't give diabetes back to primary care completely. They were very keen that in reality people with diabetes need to be going in once a year into hospital for their annual review"*

Participants suggested these *"entrenched positions"* were shaped by past experience, misinformation in some cases and the tension created by settings *"losing out"* to each other in the competition for limited resources. For example some specialists were perceived as being *"absolutely opposed any kind of involvement from primary care"* perhaps due to previous bad experience; *"some of the consultants got badly burned trying to run diabetic clinics and GPs pulling out and all this kind of craic"*. Another participant felt opinions were based on an inaccurate understanding of the nature and contribution of primary care, leading to a lack of faith in the capacity of that setting:

> *"...there was and still is a huge dearth of information at secondary care about how it operates in primary care and that's the problem…Tensions arose because of their basically lack of awareness, lack of awareness of our capacity, they have no concept of how well trained people are and the resources and capacity that is there."*

As well as different health setting perspectives, there were subdivisions *within* professions as participants stressed that *"it wasn't GPs against hospitals*" when it came to the detail of how care would be managed between settings. There were *"slightly different perspectives"* within professions depending on the local circumstances in which they worked.

> *"There would be different viewpoints…I know Dr X would have had a different philosophy to Dr Y, but there would be different ways that their services were organised, completely different ways their services were organised"*

Hence the discussions around the ideal model of care revealed subtle divisions in the traditional professional groupings, in keeping with the Advocacy Coalition Framework's proposition that subdivisions can emerge within coalitions around the secondary policy beliefs (272). The example of developing recommendations for the model of care also suggested that professional beliefs interacted with local experience and circumstance to shape participants' positions on the model of care.

'Fudging' to allow for local circumstances

Given the *"completely different ways services were organised"*, the model of care subgroup had to strike the right balance between outlining a comprehensive model of care and *"not being to prescriptive"*. As one participant attested *"there was this kind of fudge that we needed to organise"* so that the model could take account of local capacity and acceptability:

> *"…it would really depend on the local circumstances; if there was very good GPs and very good primary care centres who were doing very good work we weren't going to stifle them and insist that they send every micky mouse patient with type 2 diabetes up to the consultants and stuff like that. And the consultants, some of them thought that they should see every patient y'know that kind of way."*

"Horse-trading" around the details

In an effort to accommodate the local nuances and professional preferences, there was much discussion and debate about the details of a model of care; *"about the number of times people should be seen and who… Absolutely (it was negotiated), right up to the last, the wording of the actual report."* The wording of the model of care evolved over time. Originally the group were using the term 'shared care' to describe the desired model however it was perceived to have a number of different meanings depending on the context. Eventually the term "integrated care" was chosen to reflect a *"more unified approach by all of the stakeholders going forward in how care could be delivered"*.

There were two features which smoothed the way to agreement. Firstly the group resisted assigning responsibility to one particular profession; *"integrated care"* encompassed *"joint management of the diabetes patient...nobody kind of owned the patient, nobody had the priority, people were to be working off a joined protocol"*. Secondly, much like the patient education criteria, the description of 'integrated care' accommodated existing local care arrangements bringing *"all those definitions under one umbrella"*.

Key change component:

Redesigned model of care which embraces a population health focus and offers a practical national model in linking primary, secondary and tertiary care services within an integrated clinical network (structured, shared and planned).

(EAG Report pg10)(1)

Gradual acceptance of the idea

The evolution of the recommendations for a national model of integrated care illustrated the emergence of consensus rather than complete agreement during decision-making. According to one participant there was a gradual acceptance within the group *"that they [endocrinologists] don't have the capacity to cope because they what their numbers are and some of they have 2 year waiting lists…I mean they just know"*. The Multiple Streams Theory of policy making also refers to the gradual emergence of consensus while acknowledging that all participants may not be in absolute agreement about a proposal (251). Similarly in this study some participants expressed doubts about the feasibility of the model of care. One participant used the same rationale, the epidemic of diabetes, to question the feasibility of the model, reflecting different interpretations of evidence being used to argue positions:

> *"The reality is that it's not achievable into the future because there are too many numbers [of patients]."*

In particular the proposal to review patients annually in the hospital, preferred by some members of the EAG, was considered unsustainable by members of different professional groups, nurses, GPs and consultants, further demonstrating the different perspectives within professions. One participant anticipated "*doing nothing but review visits forever! And you'd get nothing else done as a hospital team"*. Despite striving for flexibility, some participants still felt the model was too prescriptive:

> *"This is not a model I would subscribe to, which almost mandates a certain number of visits per year with the GP and then with the consultant. To me that's not looking at things properly, you need to look at it from the patient's side of things and meet their needs. And often times their needs can be met entirely in the community, sometimes their needs can only be met in the hospital and frequently they can dip in and out."*

7.3.2.7 *System-level Barriers to Implementation*

Barriers to implementing an integrated model of care in Ireland related to the financing and organisation of the health system according to participants (Table 49). The main barrier that prompted discussion was the challenge of engaging all GPs in the diabetes care and the role of financial remuneration including the wider policy issue of the renegotiation of the GP contract. The GP contract was an issue that *"kept coming up over and over again… [because] there is no recompense for looking after chronic disease in the present GP contract"* and this was seen as *"the fundamental piece that's missing"*. There were efforts by the group to address this barrier through meetings with senior advisors in the HSE and members of SPRI however it was an issue beyond the scope of the EAG.

> *"The message at the end of the day would have been that the GP contract isn't about diabetes, it's about many other things of which diabetes would be an important element of it and it's still on the agenda, it hasn't gone away..."*

Participants were being asked about implementation in light of a well-established economic recession which was only emerging at the time of the EAG (2006). This may have led to the reassessment of the model of care and its feasibility.

Table 49 Barriers to implementing 'integrated care'

BARRIER
"Consultant control"
"I think a lot of GPs are prepared to take it on board, and even better if they got paid for it, but even so I think GPs would be more inclined to take these things on board. Where I think the problem may lie in the future is the so-called consultant relinquishing some of their control."
GP Interest
"I would be a bit anxious that the view would be taken that all GPs are as enthusiastic about delivering diabetes services as the ones representing [in the EAG], that's not the case. Not every GP is as experienced in diabetes. And it mightn't be their area of interest..."
Resource allocation
"How do you decide, if you're going to employ podiatrists or put mobile cameras out there, where are you going to put them? If in theory 90% of care is going to be in general practice, shouldn't it all go into primary care? But that's not what's happening. He's going to stick them in hospitals to boost the setting and we'll have to drag them out again when we shift care."
Financial restrictions
"There is no way there is going to be money to set up what they want; diabetes day centres all over the country, it's not going to happen.

7.3.2.8 *Improving Diabetes Care: general agreement despite debate over detail*

A theme which united all the subgroups and priorities was the overarching agreement among members on the problems facing diabetes care although opinions differed on how best to solve the problems. There were two factors which facilitated agreement. Firstly the group had a common goal, whether they were health care professionals or senior management. As one member described the group dynamic; *"we were pretty much to be honest on a common path most of the time"*. The second catalyst was the clear problems facing diabetes care and the "obvious" solutions.

> *"It stands out a mile what needs to be done. Anyone that's involved in diabetes care could see what was missing."*

The issues were considered a *"no-brainer",* term used to describe priority-setting and echoed across the various subgroups (Table 50). While highlighting the consensus among members, participants also acknowledged the difference of opinion over the finer detail of proposals echoing the Advocacy Coalition Framework assumption that subdivisions emerge in coalitions around the finer details of specific aspects of a policy however these opinions are amenable to change. The consensus among members was seen as one of the reasons the EAG were so efficient in coming up with their report (<2 years).

Table 50 Quotes reflecting overall agreement with "smaller arguments around the fine tuning"

Theme: Overall Agreement with "smaller arguments around the fine tuning"
Common goals with difference of opinions in how to reach them
"I think we were all there with the same purpose but how we went about it, how the problem is going to be solved might be slightly different..." "There might be smaller arguments around the fine tuning but there's fairly unanimous agreement around how abysmal services are."
Shared desire for implementation
"I'm trying to remember were there any kind of big flaming issues that people couldn't agree on. I don't really think so because there was a common purpose: everybody at the end of the day wanted to actually implement a good diabetes programme. How you make that happen and the resources being made available etc, I mean yes there would be discussion about that"
Standards of Care- "a given"
"I don't think [there's] anything that you would argue with. People with diabetes in Ireland should be able to access high quality services to treat and delay the progression of complications (reading report): how do you do that is the thing, where do you do that, how do you fund it?
Paediatrics- "fairly obvious"
"In the paediatric diabetes one [subgroup] there was not much discussion. It became fairly obvious that it couldn't all be done from Dublin basically…therefore it was a critical mass that was needed so you had to have a regionalization...but you couldn't have too small of centres, so there was that kind of discussion. While we agree it's regional…how many do you need, what is the critical mass, what is the composition of the team you need?"

7.3.2.9 Policy tactics: increasing the chances of uptake

A number of strategies to increase the chances of the EAG proposals being adopted and implemented emerged from participant accounts (Figure 36). As mentioned previously, the probability of occurrence is a criterion for judging alternative proposals according to the rational model of policy making. In addition to international evidence and local experience, the EAG were cognisant of previous policy reports relating to diabetes and the expected future direction of the HSE. The group also adopted the idea of establishing local implementation groups from previous reports, in anticipation of action.

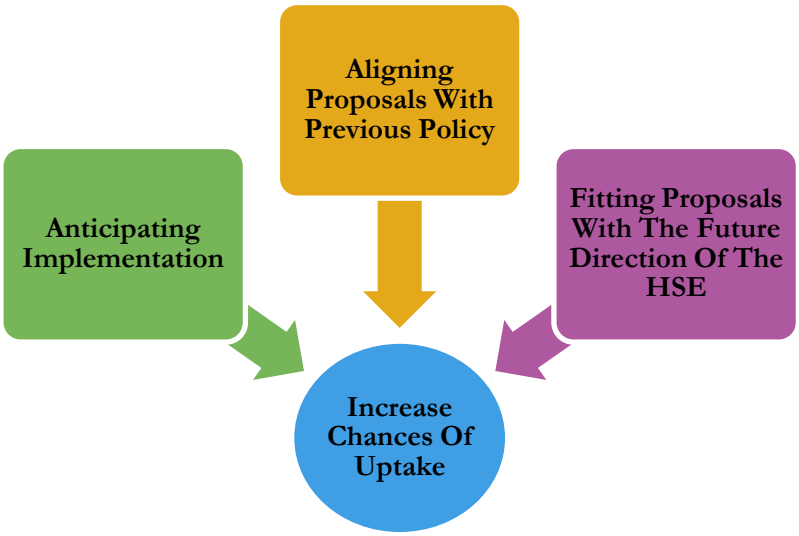


Figure 36 Strategies to increase the chances of recommendations being adopted

Aligning proposals with past reports

In terms of priorities, the EAG was *"building on other strategic documents in the department"* and outside the Department of Health and Children including the national health strategy, the DOHC working group report "Diabetes: Prevention and Model for Patient Care", 'Securing the Future' from the Diabetes Services Development Group and the St Vincent Declaration. There was significant overlap of membership between previous reports and the EAG and substantial similarity in the issues raised.

> *"...It's the same issues all of the time so there isn't a need to reinvent the wheel because several groups have got together. There has been overlap in who's been involved in the groups to some extent but all of the stakeholders are represented and they all perceive the same."*

In particular senior management in the group highlighted the strategic efforts of the EAG "*to make sure we keep aligned with policy and not wander off message so that it had the*

maximum opportunity to be picked up." This awareness of strategy to increase uptake of ideas reflected the experience of some the group in formulating policy.

Fitting proposals with the future direction

As well as trying to stay on message, the group was keen to contextualize proposals and pitch ideas at a level that could be achieved by the HSE. Trying to fit with where the HSE was *"moving to"* was reflected in one participant's recollection of preparing submissions for the estimates process. Quite early in the life of the EAG the group was instructed, at short notice, to prepare submissions to put forward to the HSE which would then inform the Statement of Revenue Requirements prepared by the HSE and submitted to the Department of Health and Children. This statement is used to inform the Department of Finance who decide the budget allocations for each department in its Estimates of Receipts and Expenditure. The group prioritised community diabetes nurse specialists who could form the link between primary and secondary care;

> *"…we agreed that if there was one thing we could change or get to happen it would be community diabetes nurses and my recollection of the submission to the estimates was prioritizing that link to primary care teams and primary care networks which our GP colleagues kept, well I don't know if it was our GP colleagues or our HSE admin colleagues but that was clearly the direction of travel at the HSE at that time. The whole transformation agenda was very much to the fore and things were going to be moved out to primary care and the vehicles were primary care teams and primary care networks. So we came up with a proposal for the estimates to have a community diabetes nurse linked to each network"*

Another example of the efforts to align the EAG proposals with the direction of the HSE was the matching of each priority area with the various components of the HSE Transformation Programme, illustrated in the EAG report (p8-9). For example it was hoped that the model of care, which incorporated the standards and guidelines, could form a pilot for the Transformation Programme to implement a model for chronic disease management. Integration was a *"big theme"* in the HSE at the time, *"it was very much one of Brendan Drumm's big ideas for transformation"*. One of the main challenges for the model of care subgroup was *"contextualising"* the model of care within the changing structures of the HSE: *"we had to sort of say 'ok this is what where we see integrated care how does this relate to the changes that's going on in the HSE as regards networks and ISAs'"*. The group stressed the challenges of planning in an ever-changing structure.

Anticipating Implementation: Diabetes Services Implementation Groups (DSIG)

The final proposal of the EAG, the establishment of regional Diabetes Services Implementation Groups, reflected the ultimate goal and strategy of the EAG; implementation. The DSIG was seen as *"a way of getting things to happen locally"*. Members of the EAG who were part of groups *"could feedback what the national recommendations were and get things moving on the ground"*. It was envisaged that *"...theses implementation groups would prepare a process, a plan for implementation and identify what they're existing resources are, what they wanted the shape of this integrated care model to be in the particular region and say 'right this is the resources we have how do we actually crystallise that in the provision'*.

The Diabetes Services Implementation Group proposal received support from senior management during the process of negotiating the approval of the recommendations. The structure was described as one of *"the biggest outputs of the EAG"* and many participants hope *"it will be a legacy"* of the process. The function is now directly linked into the Clinical Care Programme for Diabetes with the Chair of the DSIG in each area liaising with the Clinical Lead as the *"voice of the region which speaks to the clinical lead"*. With this plan for local implementation, the EAG were actively trying to increase the feasibility of the recommendations. The technical feasibility of proposals is one of the hurdles which proposals must overcome to survive the policy stream according to the Multiple Streams perspective. The lack of cost implications is another criterion which facilitated the success of the DSIG idea over others which were proposed by the group.

7.3.3 Moving from Formulation through Approval to Implementation

Having presented the development of the EAG's proposals and the factors which influenced that process, the third section will outline the approval process undertaken by the group and the barriers to the implementation phase. The recommendations were finalised by the Expert Advisory Group in September 2007, less than 1 year after the formation of the group. The next phase involved obtaining final approval from the HSE and ultimately working towards implementing the recommendations. Figure 37 outlines the timeline of the approval process.

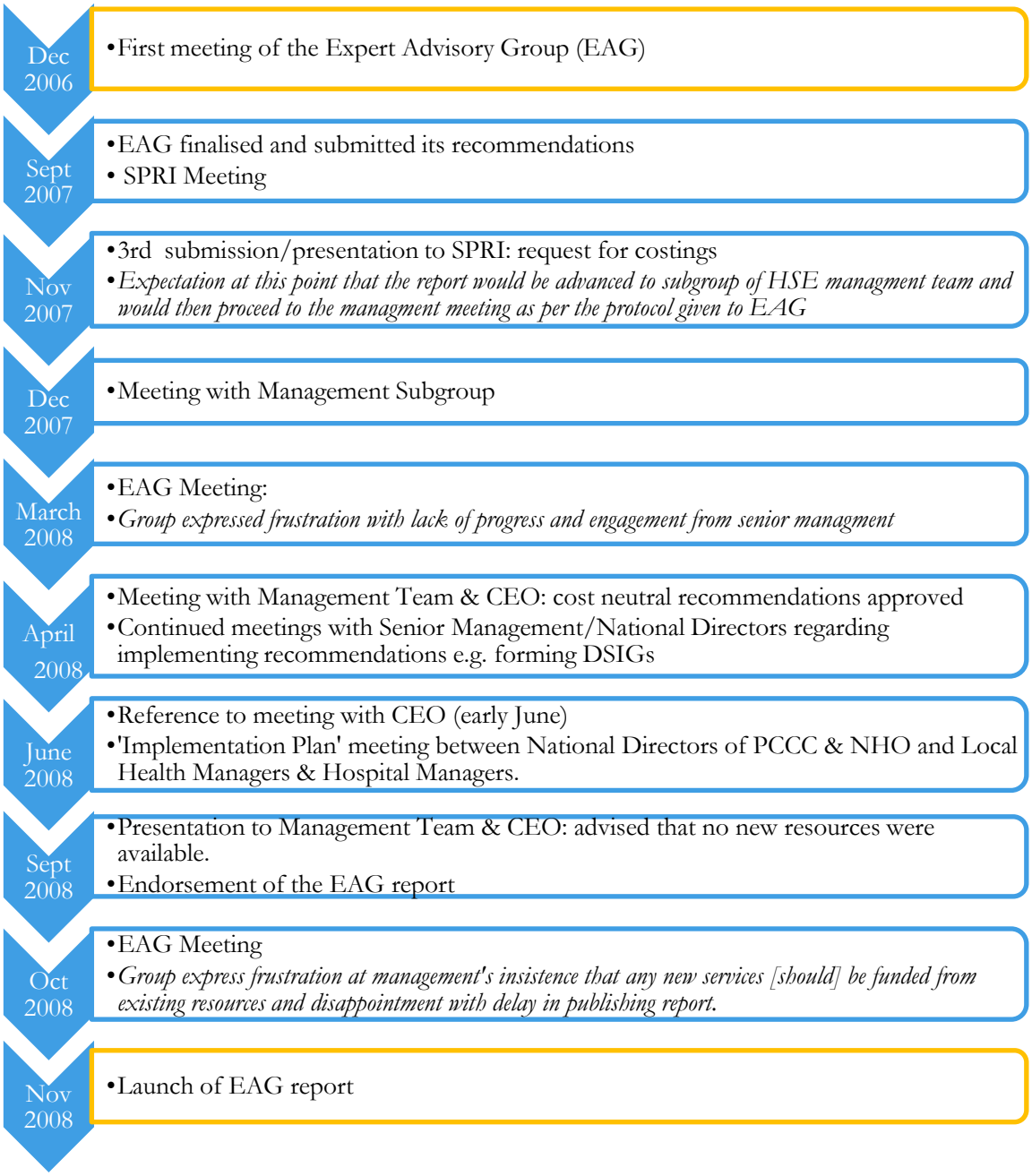


Figure 37 Timeline of the approval process

Table 51 outlines the approval process as set out in the HSE document 'Expert Advisory Groups: An Introduction'. This process appeared logical with the groups ultimately working toward the HSE management meeting for final approval. Similarly during the interviews participants delineated steps in the approval process which appeared to fall neatly into stages. However the road to obtaining approval was convoluted according to participants. Decision-making within the immediate EAG was contrasted to decision-making within the HSE, which was ambiguous in terms of how decisions are made and who makes them. The weaknesses of the EAG process emerged at the juncture of moving from approval to implementation including the lack of power within the group and the lack of impetus for implementation outside the group.

"The issue was not in setting the policy; the issue was setting the action."

Table 51 The Approval Process.

Steps taken from HSE Introduction on EAG (146)		Stage	Participants' Account
1	Report and recommendations presented to the HSE's Strategic Planning and Reform Implementation (SPRI) Group	**SPRI Consultations**	"SPRI was at that point in time the group that was trying to provide a national focus...They would see if they could provide, with what we were doing with the diabetes subgroups, integration with other strategic directives or strategic plans that the HSE had so we went through that."
	Address issues raised by SPRI	***Requested costing and timeframe for model of care***	
2	Report & recommendations presented to the CEO and Management Team for consideration	**Meeting with Management Team Subgroup**	"At the time the process for it to be published, for the HSE to adopt it as such, was it had to go through those stages and through the senior management team…"
		Requested gap analysis	
		Management Meeting	"We went to the board, we did our presentation. And a huge big group, the CEO and the director of finance and population health and all these people...So we got about 10 or 15 minutes and they had lots of questions, good questions... Then we kind of thought 'well we'll withdraw now, thank you very much' and they'll think about it or talk about it. And we were walking out the door; they were on about something else (they had moved on). And I kind of said to myself 'what does that mean'."
3		***Prioritising formal agenda***	"Once that work gets done, it gets put into…I'll call it an management structure within the HSE, where the various priorities and the report itself is discussed and issues are discussed and out of that the HSE determines how it's going to prioritise this work and what it's going to do and the resources to be made available and so on."

1. SPRI- "a vetting system"

One of the steps or "hurdles" in the approval process was a series of meetings between representatives of the EAG and SPRI, the Strategic Planning and Reform Implementation Group in the HSE (Nov 2007). Officially SPRI dealt with "strategic planning, reform and implementation aspects of national initiatives" and "recommend action plans for consideration by the CEO and senior management team" (p44, Introduction to the HSE). The purpose of the meetings between the EAG and SPRI were to look more closely at the implications of the EAG recommendations. The rationale and merit behind this stage was questioned by some participants beyond creating a delay.

2. Senior Management Team

Following consultations with SPRI, the next step was a number of meetings with the senior management team. The following quote suggests the EAG report had still not reached the top of the agenda within the HSE;

> *"Having gone through the SPRI organisation we thought we were about to get to the actual board meeting and then…one of Brendan's kitchen cabinet people met us with a couple of other people. Again it was very slow; it just took a lot of time."*

A subgroup of the management team indicated that they would recommend the acceptance of the report following a gap analysis to outline the cost for the Model of Care, Paediatric care, Podiatry and Retinopathy. The service units of the HSE would assist with developing this cost framework. The recommendations would subsequently be sent to the Management Team for further consultation.

3. Gap Analysis – "creating need" & scaring off interest

The SPRI group and the subgroup of the management team requested a costing framework and gap analysis. This process highlighted two features of the policy process; the lack of adequate information available to policy makers and the *"fear of creating need"* by making recommendations for improvement. Firstly some participants questioned whether the gap analysis would have been more comprehensive if completed by the implementation group in each region and it was not envisaged as part of the EAG remit originally. The rational approach to policy making assumes complete information is available to actors to make decisions however but this was not the experience of the EAG when conducting the gap analysis. The exercise highlighted discrepancies between

the information available on the ground by contacting hospitals and the figures *"coming out of HSE land"*.

Secondly according to one participant the final gap analysis *"frightened the bejaysus out of them"*. It became apparent that the recommendations would "create a large need" that the health system could not meet. There was continuing insistence from senior management that recommendations needed to be cost neutral and any new projects would need to come from existing resources. One participant suggested that at this stage the enthusiasm and commitment waned from within the HSE, the EAG became *"a headache"*. It should be noted that the recommendations emerged during changes in the economic circumstances of the country and the health system thereby changing the scope for implementation, which will be discussed later. One participant reflected on the inevitability of creating need given the lack of investment in diabetes hence the outcome should have been anticipated and expected:

> *"I can only speculate but very early on it was clear that this is going to cost money and more importantly it is going to cost new posts because I mean the fact of life is that diabetes is very poorly served in Ireland certainly on the community side and from ambulatory care and general practice…So our first report sketched out the sort of investment it might need and mm I think that just frightened them off."*

What was unexpected perhaps was the scale of the economic downturn which accelerated over the course of the EAG process *"and that frightened off how we were to do this"*.

4. Getting to the "formal agenda"

The final "endorsement" for the EAG came in September 2008, a year after the recommendations were completed by the group, at a meeting of the senior management and CEO. This meeting would get diabetes on the *"formal agenda of the executive team of the HSE"* and was seen as the final hurdle on the road to implementation. There is a sense of achievement and also hope probably built up through the frustration of the earlier process:

> *"...we had a [moment of] 'god this is it, we're here now! We're in the door and we're going to get this thing implemented'. And then I came out of it not sure and we had to assume that what they had said in there meant that they were [in agreement]."*

Getting to the management table was not the final step to implementation. Diabetes *"is just one piece of all the work of the HSE so that discussion has to take place in a broader environment in terms of how are we going to implement other disease policies, how are we going to implement contracts"*. Thus it joined a list with other conditions and issues for prioritisation by the senior management of the HSE. The process, although sequential was not clear and while implementation seemed like the obvious and expected next step, this was not the case.

> *"It's one thing signing of the policy document and there are a lot of policy documents, it's another thing to see it into action."*

7.3.3.1 *Decision-Making at the Health System Level: "It wasn't clear".*

Recounting their experience of the approval process, participants highlighted the ambiguity around decision making within the health system. Having presented the recommendations to the senior management of the HSE the representatives of the EAG were none the wiser as to the fate of their report. There is a contrast between the expectation of the decision making process and the reality which was less definitive;

> *"We got about 10 or 15 minutes and they had lots of good questions... Then we thought 'well we'll withdraw now, thank you very much' and they'll think about it or talk about it. And we were walking out the door [and] they were on about something else [they had moved on]. And I kind of said to myself 'what does that mean'. And then we were suddenly faced with; 'well was that an endorsement or was that not an endorsement; was that policy or not policy'. It wasn't clear..."*

The participant went on to suggest that perhaps the ambiguity is part of decision making process, "maybe that was approval with all the questions and all the interest" and we hold unconfirmed expectations of what we think it should be; "a report saying we approve this".

The lack of clarity extended to which person or persons made decisions in the health system. Health care professionals in particular were frustrated by the ambiguity and the pace of the "the civil service way of doing things" which was in stark contrast to decision-making in frontline service provision;

> *"You will never get the name of the person who is making the decision, never! And if they do they'll have made a decision and he'll have changed to another department*

or division… [It] is very odd to our brains as clinicians because every single day, all day every day, we're making finite life-changing decisions."

Not only was the difference in the decision-making process between health care delivery and health care management but between the old and new structure of the health system. Under the Health Board structure health care professionals referred to meeting *"people who would make decisions, who had access to funding, who could swing things"* but in the HSE one participant doubted whether even the CEO *"could do it"*.

The final point of frustration was the speed at which things happened in the EAG process. For one participant the lack of progress was related to the absence of a champion, *"a programme person",* to push the recommendations inside the HSE, which again reflects the lack of clarity around who was responsible. What should have been a rational next step i.e. implementation, was being ignored;

"…where people got exercised about it was in lack of progress of implementation and lack of engagement with senior management in that we felt we were writing good reports which had evidence behind them which recommended things that needed to be done in diabetes and nobody was listening."

"No clear implementation road put out"

The benefit of hindsight has imposed a sequence on the approval process however at the time the path beyond developing a set of recommendations was not set out. Participants questioned whether this step had even been considered;

"Unfortunately really they never looked…I could even accuse Brendan Drumm of this, they looked as far as this is a good way to make this kind of policy direction, to give it some kind of a shape and put priorities in place. And then had never thought about how that would be put into practice."

The drawn out series of meetings and consultations involved in gaining approval gave some *"the impression that it was just delaying, just holding the thing back a bit"*. It was as if *"each step was almost being made up as we went along"*. The rational next step, implementation, was not in place to allow the recommendations to progress. On the contrary according to the HSE Introduction Pamphlet there was a pathway to implementing the recommendations including the establishment of a cross-directorate Implementation

Group chaired by an Assistant National Director or Hospital Network Manager from within the relevant delivery unit of the HSE (146).

This gap between approval and action was one of the most commonly cited disappointments of the EAG experience expressed by both health care professionals and senior management involved;

> *"We started asking ourselves questions towards the end of the process about 'how is this going to go? What's going to happen after this' and you could just see we were coming to a point where the cliff edge was there, there was no road ahead and sure enough we just walked off the edge of it basically. It was incredibly disappointing seeing that happen but…And to be honest even the mangers involved had to come to that realization the same way I did. They didn't know any better than we did at the start, how it was going to work out. But the kind of idea that you should have this effort to make a plan and then just, it would be dumped."*

The layers of management involved in the approval process and ambiguity of decision-making were reflective of the openness of the policy system, described by Sabatier & Weible as a coalition opportunity structure in modifications to the Advocacy Coalition Framework (272). The openness of the policy system is one of the enduring features of the government system, determined by the number of decision-making venues policy proposals must go through and the accessibility of these avenues. There were multiple avenues and stages to the approval process for the EAG. Decision-making was centralised to a large extent among the CEO's "kitchen cabinet" and therefore was not transparent to members of the EAG. Participation in the approval process was restricted to the Chairman and senior management representative in the EAG and a number of participants commented on difficulties securing meetings between the CEO and the wider EAG.

Public Spotlight

The pace of progress following the formulation of the EAG report was raised in a number of circles to put pressure on the HSE. One of the resources of a policy coalition is its ability to garner public support according to the Advocacy Coalition Framework (272). Over the course of 2007 and 2008 several Dáil questions focused on the progress of the EAG and a national strategy for diabetes. In June 2008 the lack of progress was raised in a presentation by members of the Irish Endocrine Society and DFI to the Joint

Oireachtas Committee on Health and Children. During the presentation representatives highlighted the lack of political will and lack of resources as barriers (283). At the same time the issue was highlighted on the online forum irishhealth.com (284) and in August 2008 the lack of progress was highlighted in the national media (285). Despite the attention, implementation remained at a standstill. According to Kingdon's research on the policy process in the U.S, media have a less than expected impact on agenda-setting however they have other functions (251). In the case of the EAG, the media were used to communicate a sense of frustration felt inside the group to the wider community.

7.3.3.2 *Implementation Standstill- Weaknesses in the EAG Process*

Reflecting on the frustration and disappointment of the group, a number of participants put forward reasons for the gap which emerged between formulation and implementation of the recommendations. The previous phase mentioned above, standing on a cliff edge waiting, suggests one reason was *"they (HSE) hadn't thought it through"*. Other reasons for this standstill raised by members of the group clustered around 3 weaknesses illustrated in Figure 38:

1) Lack of power conferred to the EAG to implement the recommendations

2) "No solid backing" from the centre/senior management to implement the recommendations

3) A weak link between the EAG and the Executive

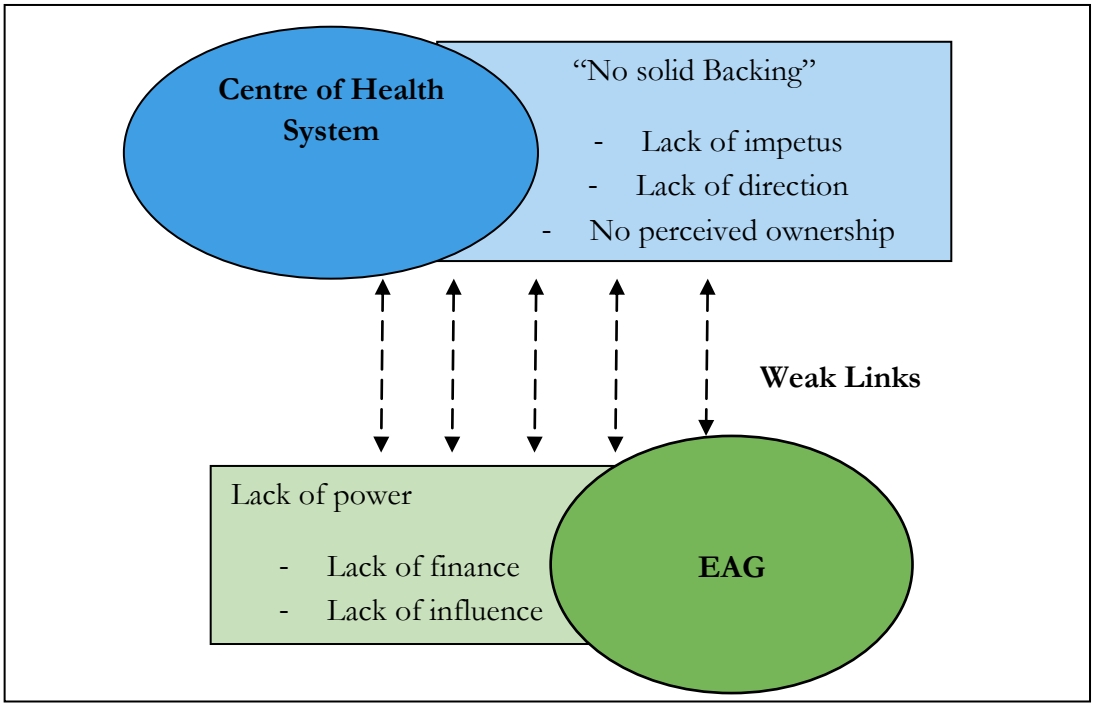


Figure 38 Barriers moving from Approval to Implementation Phase

Lack of power: "The authority and the mandate to go off and make things happen"

One of the most commonly cited reason for the gap between making the recommendations and implementation was the lack of power within the group to *"go off and make things happen"*. This mandate lay with senior management in the HSE according to one participant who was very experienced in the policy making process. As it transpired the remit of the group did not involve advancing the recommendations to implementation;

> *"...well it was given a brief but it wasn't given all the powers. It was purely advisory and it wasn't very clear how the advisory function would be translated to implementation."*

As mentioned previously a number of participants were attracted to volunteer for the EAG on the basis of expected implementation. Involvement in implementation was initially envisaged as part of the EAG remit as according to the HSE's Introduction pamphlet.

> *'Each EAG is also responsible for verifying and assuring that within its area of responsibility;*
>
> *- Adopted policies and strategies are implemented; and*
>
> *-Legislation, national policies, standards & best practice protocols are complied with.'*
>
> -Expert Advisory Group; An Introduction (p2)

A core element of power missing in the group was the absence of a specific budget to make changes or allocate resources. Any new projects would have to come from existing resources. Another absent source of power according to one participant was representation within the EAG that could drive change from inside the HSE and "fight their case in terms of the overall HSE budget";

> *"It didn't have money behind it therefore it was a talk shop. It didn't have strong personalities representing the HSE there who could move this forward. They didn't have a mandate to actually implement anything."*

The lack of strong links between management, service delivery and the EAG function was emphasised by another participant with the suggestion that senior representatives in

the HSE did not perceive their role to involve driving implementation. The mandate to drive implementation had to come from the CEO and this was never clarified;

> *"I think the representatives from the particular areas of the HSE, for instance the acute, the primary community and continuing care (PCCC), possibly didn't see their role as providing that link (between the recommendations and service delivery). And I think that fell down...if that had been ironed out very early on by the CEOs division and the objectives put down by his office to say these people were given the control that would have done it, that would have been a lot stronger."*

Given the relatively new division of labour between policy making in DOHC and commissioning and delivery in the HSE, the EAG was left in an *"invidious position"* as it did not *"have the power to make policy which the department does or the power to implement it"*. Having the formal authority to make policy decisions is one of the key resources that coalitions can use to influence policy according to the Advocacy Coalition Framework (272). This includes having participants in the coalition in positions of power and influence however according to participants some members of senior management did not perceived themselves to be in that position.

Soft centre- 'non-movement, non-commitment and non-support'

As well as a lack of power within the group, there was a lack of force behind the EAG, described by one participant as "no solid backing". Implementation *"needed to be a priority not only from the CEO's office and senior management team but also local management and local delivery"*. However instead there was a perceived lack of direction from the centre that implementation needed to happen. The group was frustrated by the lack of urgency around the recommendations;

> *"It (the EAG) needed the implementation side to be more aware of the work of the group and where this should go. And I think the linkage there wasn't as great. And I think in fairness that needed to come from the CEOs office, it needed to come from the national director's office to actually ensure that what direction was given was actually and discussed and implemented by service delivery."*

There was also a perceived lack of interest or commitment from the executive as the EAG process moved on, suggesting support within the political stream had flowed on from a Multiple Stream's perspective. The two key elements to implementation according to one participant were that *"the executive want it to be done and feel required to*

implement what is proposed". The commitment at the outset when members volunteered was no longer evident. It was embodied for many participants when the launch of the report was not attended by the CEO:

> *"...that was for me the most stark confirmation that nothing was going to happen. And even the language that was used which was really frighteningly badly informed…But it certainly, just the fact that it was (that person) who appeared, you just knew there was no power behind this person, no sign of any influence and no motivation to do anything."*

The failure to link the formulation aspect of the EAG with implementation created a situation whereby:

> *"The recommendations aren't owned by those that might be able to implement them. So certainly because of the difficulty of getting things done in Ireland I would think it would better actually to have the executive wanting to get it done and call in the experts to help them as opposed to the experts telling them this needs to be done."*

This is a paradox given that the HSE established the EAG to develop the recommendations. And the perception among members of the EAG was that the executive did call in the experts to help them.

Weak links to the centre

A number of the quotes cited above illustrate the weak links between the EAG and the HSE. Originally it was envisaged that the group would have quite a strong connection with the executive. The HSE Blueprint states that the Chairperson and Assistant National Director of each EAG would meet with the CEO on a quarterly basis. However as time went on it became increasingly difficult to meet with the CEO. The lack of engagement from the executive did not bode well for fate the EAG recommendations.

> *"…coming towards the end of the work, the frustration was certainly higher that now 'ok we've done the work now where is the next element'. 'Why is the HSE management now not coming back in and discussing this with us?'"*

7.3.3.3 *Bad Timing- "It's a pity that all this happened at the time it did"*

A final barrier to the advancing the EAG recommendations was timing reflecting the fleeting nature of the open policy window proposed by the Multiple Stream's Theory

(251). Over the course of the EAG process a number of changes took place within and outside the health system which influenced the fate of the group and the recommendations. The two major changes were structural and financial; the establishment of the Quality and Clinical Care Directorate and the economic recession.

> *"It's a pity it didn't happen 8 or 10 years ago because we were probably a little bit more financially secure. It probably was more likely that more of it could have been implemented a few years ago."*

7.3.4 Changes in Financial Capacity

As mentioned earlier the cost implication of the recommendations was seen to frighten off the interest of senior management affecting the level of support for policies within the political stream. The original impression of participants was that *"there would be money behind this and that things would change"*. In light of the economic recession this became less likely and participants were quick to acknowledge the new reality; contracting budgets and a recruitment embargo. The lack of engagement from senior management and clarification about what was feasible meant that expectations were allowed to remain unrealistic unbeknownst to the entire group;

> *"They didn't engage with us, which was disappointing because, ok some of the recommendations may have been rather large but the professionals were citing normal staffing ratios from abroad and so on for this and for that. And if management didn't agree with them then they should have come back and say 'well look you're looking for 90 podiatrists and that's just not on guys, can ye come back to us with a more modest proposal'. But that didn't happen, so we just didn't get any further."*

This theme was reinforced by another participant who felt they *"were working on what we felt was achievable"* but the lack of engagement from senior management meant *"we didn't have access to what was <u>really</u> achievable from a financial perspective",* which was of detriment to the group. The financial constraints which hinder many ideas in the policy stream were a major barrier for the EAG proposals.

7.3.5 Changes in the HSE Structure: The Clinical Care Programme.

The future of EAG was *"taken over"* by the establishment of the Quality and Clinical Care Directorate in the HSE which was described as one of the most *"dramatic"* organisational changes in the system. At their first meeting in 2008, the future role of the EAG was raised. Meeting minutes suggest three possible roles were discussed:

- National Clinical Directorate
- Underwriting quality and professional training
- Monitoring and Evaluation

However this desire for involvement in implementation was superseded by the new structure within the HSE, the Clinical Care and Quality Improvement;

> *"All the people like ourselves at the EAG board meeting, all were kind of keen to be involved in the actual development and implementation...but Barry White wanted it to be his baby so it so we had to dissolve."*

Some members of the EAG wanted to meet again at a later stage to evaluate and discuss the progress of the Clinical Care Programme but *"he (Clinical Director) wasn't having any of that, he wanted a completely separate prorgamme and a lead and they would do it their way."* The group has no choice *"except to trust him"* as the improvement of diabetes services was one of their *"big priorities"*. Kingdon encompasses the creation of new positions of authority and governance within the politics stream (251) as a change which can promote, or in the case of the EAG, inhibit proposals moving onto the decision agenda.

The new structure was launched officially by the CEO in 2009 to enhance clinical leadership in the HSE. Under this directorate a number of clinical care programmes were to be established including one for diabetes. Indeed the EAG had a central role in bringing about a Clinical Care Programme for diabetes. One of the key proposals of the EAG was the need for leadership in diabetes care at a national level. The Clinical Care Programme (CCP) was put forward as a way to realise that proposal. Participants outlined a number of factors which determine the success of this policy idea including support (acceptability), lack of cost implications and feasibility all of which are key criteria for the survival of proposals according to the Multiple Streams Theory (251).

Bringing a recommendation to the top

A central success factor in obtaining national leadership for diabetes was that it caught the attention of those at the top, namely the Minister for Health. As one participant recalled the group *"didn't really get an impetus for the national lead until we actually got Mary Harney on board"*. The path to the Minister of Health was facilitated by the Diabetes Federation of Ireland, who had meetings with the minister "now and again". The idea of a national lead had become attractive in the Irish Health system as the role had been

successfully established for cancer care and had led to significant changes in how cancer services were organised in Ireland. Hence the proposal was in concordance with the values held in the health system at that time. It was felt the minister agreed with the core value inherent in the proposal, the need for leadership:

> *"Mary Harney latched onto this notion of a lead…I supposed being that kind of personality, her phrase at the time was 'you can never get anything done around here unless you give the job to 1 person'. So she called a meeting...".*

The meeting would involve the minister, the CEO and members of the CEO's advisory team. While the idea was favoured by the minister the proposal required the approval of the CEO as *"you could never say anything until you'd see how Brendan would react to it"*. This may reflect the devolution of decision making powers about service delivery from the DOHC to the HSE. The *"solution that was offered before we got to meet"* was the possibility of including diabetes as a programme under the emerging Clinical Care Directorate. This solution was clarified at the meeting with the minister and the CEO and a meeting was set up with the Director of the CCP, Dr Barry White.

Diabetes as a CCP: "a quick win"

Establishing a Clinical Care Programme for diabetes was mutually beneficial and feasible solution to the lack of leadership in the area of diabetes. It kept diabetes on the national agenda, introduced national leadership but it was also a potential *"quick win"* for the CCP:

> *"If your Barry (thinking) '2 years to do this, what am I going to do, which things am I going to pick'. And if I were him I'd be thinking 'what can I get delivery on quickly, what were those fellas doing over in diabetes'…so a) diabetes is the big one and b) oh here's one we prepared earlier."*

Because of the groundwork of the EAG on how care should be delivered the Directorate *"didn't have to start from scratch"*. Hence the critical success factors were the intervention of the Minster for Health and support from senior management and the CEO for a topical and current recommendation fitting with changes already afoot in the HSE structure hence there were no additional cost implications which had stymied other proposals.

Moving from the EAG to the CCP

There was some ambiguity and scepticism about how the fate of the recommendations in light of the organisational changes in the health system. While there is some overlap in membership between the groups which would allow the learning and experience to be carried forward, this was seen by some as a "coincidence". One participant suggested that the group were *"almost be going back to the very beginning reinventing the whole bloody thing again."* On the whole most participants felt there was commitment to the recommendations *"in a general way",* leaving room for discretion.

> *"They don't have to follow policy and it's [the report] probably being, if you like, usurped a bit by the programmes so they can legitimately pick and choose from it…"*

The new group *"couldn't but commit"* to some priority areas, reflecting the consensus around priority setting early in the EAG process. Other proposals such as integrated care would be revised while some priorities such as paediatrics did not *"survive"*. There were subtle differences in participants' attitudes towards the new structure with the language used around this issue reflects both a sense of disappointment or optimism (Figure 39).



Figure 39 Transition from the EAG structure to the Clinical Care Programme

7.3.6 Better Chance of Success

Despite the expressed concerns and perceived changes from the EAG proposal, there was a perception that the Clinical Care Programme had *"more of chance"* of success and so it may represent another policy window to get diabetes proposals onto the decision agenda. According to participants the CCP had been afforded more of an opportunity to bridge the implementation gap:

> *"I think the director will get senior management to push it as a commitment to implement as much as possible. I think that they've probably gone a greater distance bridging that gap between clinical priority setting and implementation than the EAGs were given the chance to or were afforded (the opportunity)"*

Three main differences between the Clinical Care Programme and the EAG according to participants are outlined in Table 52.

Table 52 Differences between the Clinical Care Programme and the EAG according to the participants

Difference	Quote
National leadership for diabetes	"The big difference I would see is that the National Working Group, at the moment you have a strong HSE person leading it with a mandate to get action."
Part of the HSE structure	"The implementation piece was never tied in…Its changing now with the care groups being set up and we now have leads for diabetes and chronic care and its tied into the executive and that's where the EAG was weak"
Representation	"It's very evident in the National Working group that if there is a representation they are representing the (profession)…like nurses, it is their responsibility to bring all of the nurses on board. That has never been so implicit in any group before. Before you were brought onto a group to represent your discipline but you were never asked to bring that discipline in behind you when change was warranted...there is a much bigger responsibility"

7.3.7 Is it Policy?

Given the lack of implementation around the priorities of the EAG, participants were divided about the achievements of the EAG and whether the proposals represented policy, strategy or merely advice (Table 53).

Table 53 Does the EAG report represent a policy for diabetes

Definition	Explanation
Policy is set by the DOHC	**Traditional sense of an over-arching document**
"This isn't a policy document because the department set policy. The HSE does not set policy the EAG does not set policy. The department sets policy."	
"Plan of Implementation	**Building on previous reports**
"What we were setting is an action plan as to how to implement policy. We were taking the policy document and trying to develop it into how to give life to it in a structured way."	
Potential for Policy	**An expected goal of the EAG**
"Certainly my expectation and I voiced at one point was that as well as picking off specific priorities which we would work up we'd have an overarching strategy or framework but that's actually never happened... There's no proper document you can consider as the National Diabetes Strategy."	
"Operational Policy"	**HSE strategy**
"You had a couple of reports that were done through the department as a different wing but this was policy now, and this is a moot point, this was now policy internal to the HSE. Because as you know in the past the 'department', are the policy developmental wing of our system.	
"Paper Exercise	**A report ≠ policy**
"I don't think it does because it's not a policy. It was just recommendations. It was a group that was formed, they made recommendations, there was no money behind it.../I think the very fact, it's not a strategy; it's not a policy change…that's why I kind of say it was kind of like a paper exercise."	

Disconnect between policy & action

The last definition of the EAG recommendations as *"just a report"* is related to the lack of action which followed. This suggests that 'policy' is seen as something which brings about implementation or change. One participant felt the detachment between policy and implementation was reflective of the Irish health context rather than policy making in general, having experienced the implementation and evaluation of the National Service Framework in the UK;

> *"The NSF in the UK really resonated with people on the ground…I knew it was coming, I knew when it was published and I really set about locally trying to meet or to make sure we were auditing and meeting the targets so it really did come right down to the grassroots level. I don't get the same impression with this document here. And that's not a criticism or an indictment of the EAG its just we don't have that…connection between the top-end and the delivery end of the HSE. It's like policy is over there and yet we're continuing to deliver here and they're not really connected."*

As a consequence of the disconnection between policy and action, local activity is often detached from the "top-end" of the HSE. Participants suggested it was easier to make changes at local level rather than waiting for national implementation. The disconnect between paper policy and action was not a unique feature of the Expert Advisory Group but rather a feature of the wider diabetes policy process;

> *"That documentation (DOHC report 2006) was never signed off as policy. And this is what you kind of learn because I was involved with that group as well, that you actually learn that it isn't enough to produce a report, you must make sure that that report becomes signed off as policy."*

7.3.8 Application of theories to the EAG Process

The underlying principles of each theory of the policy process have been applied throughout the results section. A summary of the 'fit' between these principles and the EAG process will be now presented.

7.3.8.1 *Rational Model Explanation of the EAG Process*

A logical sequence of steps were followed which led to the formulation of recommendations. Firstly the nature of the problem was identified and defined, that is the variability and deficiencies in care. The goals and objectives of the rational actors involved were clear and explicit. Alternative strategies and their consequences were analysed. Multiple sources of information were consulted to minimise uncertainty around the various alternatives. Based on this analysis the choice was made regarding recommendations which were deemed most conducive to the goals and objectives of those involved.

In keeping with the rational model of policy process, decision-making *within* the EAG appeared to follow a logical sequence of steps (269). Participants recounted the EAG process in stages from priority setting to examining alternatives and making a decision on the proposals to put forward for approval by the HSE. While the rational model suggests that objectives and goals are explicit at the outset it does not consider the personal reasons for participating in a collective decision making process such as the EAG (286). Few participants referred to *apriori* personal goals when joining the group but rather personal motivations such as representing a local service (loyalty) and the opportunity to be involved in shaping policy.

Considering alternatives

The rational model of decision-making assumes that all alternatives and their consequences are considered however the solutions considered by the EAG were determined by number factors including previous policies, local loyalty and existing models of care. The EAG reiterated the problems and proposals identified in the past hence in many cases the solution was *"obvious"*. While EAG members considered alternative models of care such as the Dutch and Scottish model, the choice was limited by local context and capacity:

> *"The Dutch model of care is very different to our own. It is predominantly primary-care-led but their whole structures are very different and…I suppose we looked at elements*

that would work and others which wouldn't be possible. And at the end of the day we have to try and look at what we were dealing with."

Some alternatives, such as proposals for a unified approach to the patient education, were never up for serious consideration. The subgroup was *"never going to promote one (programme) over the other"* given the investment and loyalty of participants towards local programmes:

"Both personally and from their own unit perspective where they worked, a lot of time and effort and money into different kinds of education".

A common criticism of the rational model of decision making is its failure to account for the influence of past experience, available information and the preferences and power of the various actors which constrain the list of alternatives considered (268). March (1994) suggests the first alternative considered is usually close to the status quo and requires marginal change (265), fitting with the early prioritisation of retinopathy screening which was already established in certain areas.

Selecting the 'best option'

According to participants retinopathy screening was to the forefront of the agenda as it was deemed to have the highest chance of success, it *"was something that could be delivered on"*. This fits with the rational perspective of the best choice as the option with the highest net benefit and the highest chance of occurrence. In the case of the model of care discussions, the alternative most conducive to reaching the goal, which was agreement on the model of care, was to abandon the existing terms and move towards a new "unifying" approach of integrated care. However according to some, this alternative does not have a high chance of occurrence in the current economic climate:

"There is no way there is going to be money to set up what they want, diabetes day centres all over the country, it's not going to happen"

Unlike the Multiple Streams Theory (251) and Advocacy Coalition Framework (272), the rational model of decision making does not account for the prolonged negotiation (268), which characterised the model of care discussions. In this instance individual "entrenched positions" on the ideal model of care were considered to be the result of past experience, misinformation and competition for limited resources however the

rational model fails to explain the way in which such factors constrain the analysis of alternatives (266).

The role of information in decision-making

Decision-making within the EAG was particularly limited by information. Within the rational model information is essential to fully evaluate alternatives and reduce uncertainty (267) however information is not always available or reliable as participants in this study acknowledged. While anecdotal experience was widely cited, reliable research evidence of the quality of care in Ireland was scarce:

> *"There's very little evidence gathered in the hospital sector in terms of outcomes and process of care... I mean they look at different things but they don't actually look at the types of patients that are going in, the numbers of them and their outcomes...So the dearth of data is a problem because then you're getting anecdotal stuff being brought to the table...without decent research behind it."*

The group had imperfect information on the availability of resources required to implement recommendations. As a result many of the chosen alternatives did not in reality, have a high chance of occurrence:

> *"As a group we were working on what we felt was achievable but really we didn't have access to what was really achievable from a financial perspective going forward."*

Even when research evidence was available is was of varying quality and inconclusive as was the case when making recommendations on patient education. Local capacity and participant experience was often given more weight in consideration than research evidence or international experience. The influence of context went a step further as ideas and innovations from different regions of Ireland could not be transferred from one part of the country to another, such was the variation in the organisation of care:

> *"...(if) you just get a recommendation 'shared care is the way to go', I think that people down here; consultants work a bit differently, the orientation of services is a bit different, those areas are a bit closer together… So I think it needs to be worked nearly at a local level almost to see what would work best..."*

Influence of contextual factors

A number of constraints, beyond resources and information, were identified in the analysis including the lack of power within the EAG and the lack of impetus outside the EAG to implement the proposals. Political will and power in policy making are not addressed by the rational choice perspective. While again the approval process through the HSE was discussed by participants in a series of steps, moving the recommendations from advice to action was ill-defined. The following quote reflects the distinction between rationality of process and rationality of outcome (268):

> *"If you're going to create an advisory function…what were they advising and what was going to happen with that advice? That was missing".*

This rational model of policy making is based on a central decision making group however as the EAG process progressed from formulating recommendations to seeking approval and advancing implementation, the network of actors and influences extended. The rational model became less applicable as the process became more dynamic and open to contextual factors which constrained decision-making such as the economic recession and changes in the structure of the HSE. While going through the stages of the approval process from SPRI meetings to the management table, participants responded to crises and opportunities such as meeting with the Minister of Health to advance the recommended clinical lead for diabetes. Such has been described by some authors as the politics inherent in policy making which goes against the need order of the rational model of decision making (286).

The approval process was ambiguous and the stages were not as well-defined as the rational model would suggest. Indeed the process of moving the recommendations from advice into action is still ongoing at odds with the discrete stages proposed by the rational model of decision making. A number of the recommendations have continued to evolve while others have been deferred. The Multiple Streams Theory dealt with next proposes a more dynamic policy process which highlights the role of policy entrepreneurs in identifying and maximizing opportunities.

7.3.8.2 *Multiple Streams Theory Explanation of the EAG Process*

There were three largely independent streams operating in the policy context; problem stream (diabetes), policy stream (EAG proposals) and politics stream (changes in the HSE structure and governance). Ideally these streams would come together at a critical point to open a policy window. This would be an opportunity to get diabetes management onto the agenda. However the policy window did not open during the EAG process due the lack of feasibility of policy proposals (policy stream), economic constraints and changes within the HSE (politics stream).

Close Knit Policy Community

The EAG process formalised the interaction of an already interconnected diabetes policy community. As Kingdon (2003) has suggested health policy is more tightly knit than other policy arenas (251), reflected in the EAG whose members had a history of interacting and collaborating with each other as well as knowledge of each other's policy preferences. The close connections between the EAG members was reflected in the group consensus on the main priorities, participants references to the shared goal of the group and the stability of issues raised both within the EAG and between the EAG and previous reports.

Problem Recognition

According to the Multiple Streams (MS) perspective an issue becomes a problem when it is perceived and decided that something needs to be done (251). The factors identified by participants in defining diabetes as a problem included the prevalence and cost of the disease as well as the comparison of care in Ireland with other countries. A number of participants had firsthand experience of the achievements of the UK for example and considered the standard of care in Ireland to be below par in comparison. In terms of categorising the problem, diabetes was defined as *"an archetypical chronic illness"* placing it within the wider problem of chronic disease management.

According to Kingdon an issue does not necessarily have to get worse to be recognised as a problem (251). Diabetes was a prevalent condition before 2006 and the burden of disease continues to grow today. Participants referred to prevalence as one of many reasons for assigning an EAG to diabetes which was considered of *growing* importance in the light of the aging population in Ireland. The CEO's own experience as a clinician in the health service was highlighted as a particularly influential factor. Participants did not

refer to the feedback from existing programs as influential in the decision to assign an EAG to diabetes, although it existed in the form of audit reports on the quality of care from local initiatives. Neither did respondents refer to any major crisis drawing attention to the quality of diabetes care. Problem definition in the case of diabetes was seen to be a gradual process resulting from the accumulation of issues which made this chronic condition *"most ripe to move on"*.

Policy Stream

The predetermined choice of priorities and proposals was in keeping with the process of narrowing down ideas proposed within the policy stream of the Multiple Streams Theory, rather than analysis of all alternatives proposed by the rational model of policy making. The reiteration of previous policy proposals in the EAG report and the similarity between it and other reports is in keeping with is the "softening up" process of the Multiple Streams Theory in which ideas are floated and acceptance is built up over time (251). A number of the EAG proposals such as retinopathy were 'floated' in previous reports and recommendations as part of this process. By 2008 there were "3 different processes saying the same thing"; the DSDG report, the DOHC report and the EAG. Furthermore groundwork had already been done on developing retinopathy screening in some regions and funding was available. Hence this policy idea was ripe when the problem of diabetes care in Ireland was recognised and the EAG opportunity arose.

Repackaging policy ideas

The MS theory also suggests that policy ideas are recombined and repackaged over time. Some policy ideas survive (e.g. retinopathy screening) while others fade away (e.g. diabetes register). The model of care proposal illustrates how the established ideas of shared and structured care were repackaged as 'integrated care'. The example of 'integrated care' also illustrates the process of diffusion and acceptance with participants referring to the gradual realization that *"it really was impossible for either service to look after Type 2 diabetes alone"*. One issue in the EAG process identified as "someone's baby" was IT, reflected the MS theory about 'pet proposals' which are often coupled to a problem by policy entrepreneurs when an opportunity arises to get the alternative onto the agenda. Indeed the IT proposals endured during discussions and were put forward for consideration during the estimates process. The other proposals deemed worthy of

serious consideration in the HSE estimates process were retinopathy, model of care and paediatrics.

From participants' retrospective evaluation of the recommendations, it appears not all of the proposals meet the criteria for ultimate survival identified in the MS theory: technical feasibility, aligned with community values and acceptable in light of future constraints. Firstly in terms of technical feasibility, in hindsight some participants questioned the feasibility of implementing the integrated model of care. In contrast the technicalities and feasibility of implementing a national retinopathy screening programme were considered in great detail in the dedicated framework document on the development of a national screening programme which outlined the structure of the service, the manpower requirements, the programme governance and procurement and this proposal is still evolving today. Value acceptability was not a crucial criterion in determining the fate of the EAG proposals as most of the members acknowledged the common purpose and shared goal in the group. As Kingdon suggested health is subject to a number of specialised ideologies which also ran through the EAG process (251). In particular a number of respondents referred to inequity and inconsistency in service provision across Ireland and stressed the need for services outside of major cities.

The main hurdle to the survival of the EAG proposals was the anticipated constraints in the future, in particular the budgetary constraints which MS places significant emphasis in the policy stream. Participants noted that the cost of the EAG proposal *"frightened off"* interest. Kingdon encountered a similar case during his interviews in which a respondent referred to the fear of tackling long-term care given the cost implications and suggested that early optimism and awareness is replaced by the realisation of the costs of action (251). This echoes the latter stages of the EAG process. The initial interest of senior management waned as the *"fear of creating need"* became more prominent. Some EAG members felt they were destined to fail this test as none of the proposals to improve deficient care were going to emerge as cost neutral in a field which was under-resourced and under-developed. The stark change in economic circumstances reflects the dynamic and unpredictable nature of the policy process which was not reflected in the rational model of decision making (286). Notably some participants did suggest that more could have been done to increase acceptance of the EAG proposals among the specialist community. Although the DSIG idea was

promoted around the country to increase local buy-in it did not run smoothly in all locations.

> *"In some other areas of the country no matter how many times we asked that these groups be set up they were never set up."*

Political Stream

The results of this study suggest overlap between the streams proposed by Kingdon as budgetary constraints in the policy stream was related to changes in the support for the EAG's task and its recommendations. The lack of impetus from within the HSE, a deficiency in the political stream, corresponds to Kingdon's observation that sometimes a cause has no supporters leading to government inertia (251). Drawing on theories of attention cycles, he suggested that problems fade as initial optimism and awareness is replaced by the realisation of the costs of action echoing the latter stages of the EAG process.

Opposition from pressure groups was not a challenge to the EAG proposals however health care professionals were not representing their colleagues in an official capacity and GP interest was raised as a future barrier to the implementation of an integrated model of care. Another change which could be linked to the political stream of the Multiple Streams Theory was the creation of a new structure in the HSE, the Directorate for Quality and Clinical Care, which brought with it a new position of authority with it new priorities and alternatives.

> *"…all the people like ourselves at the EAG board meeting, all were kind of keen to be involved in the actual development and implementation…but (the Director) wanted it to be his baby so we had to dissolve."*

According to Kingdon jurisdiction can alter positions of influence and power as well as the position of priorities on the agenda (251), both of which were evident in the case of the EAG. Firstly as the above quote illustrates, most members of the EAG expected to be involved in the implementation of the EAG recommendations, "implementation as regards providing direction, not actually in the implementation, that had to be the service delivery arm (HSE)". However after the approval of the recommendations the baton for implementing any change in diabetes care was passed to the newly established Clinical Care Programme. Only one participant did not see implementation within the

EAG's jurisdiction suggesting that *"implementation is the role of management with the HSE…an expert advisory group has a different remit entirely…it is a developmental role".* Secondly there was uncertainty at the time of interview about which priorities would be maintained by the Clinical Care Programme:

> *"We have no say now whether it [the EAG recommendations] becomes involved or not. The slight disappointment is the paediatric programme, we put a lot into try and make sure that clinical lead knew the priorities; podiatry, retinopathy, integrated care and paediatrics were the big ones and we were assured that they were going to be the ones but it looks like paediatrics has been dropped from the diabetes programme…"*

Closing Policy Window

As mentioned previously policy formulation occurs in a dynamic and unstable environment. The sharp decline in the economic stability of Ireland offered a stark example of this. As a result of changing circumstances and fleeting interest, the policy window is a temporary opportunity. The EAG was seen as an *"overdue opportunity to bring services for all people with Diabetes in Ireland into the 21st Century"* (p2) and *"invest in the necessary infrastructure"* for an integrated model of diabetes care (1). However by the time the recommendations were formulated the window of opportunity for financial investment had closed. A number of participants in this study reflected on the bad timing of the EAG proposals suggesting *"it was a pity it didn't happen 8 or 10 years ago"*. There was a perception among some participants that there was an opportunity for action during the economic boom in Ireland. The EAG was established *"at a very different time in terms of funding and finance so there was an expectation that the recommendations of the group would be implemented"*. By the time the recommendations emerged *"it was clear we were into meltdown"* and the policy window for action was closed. A number of participants referred to the waning enthusiasm of some members of the EAG: *"people got very disillusioned then because it wasn't moving on…they weren't getting action out of their recommendations"*. The initial interest of senior management waned as the "fear of creating need" became more prominent. The EAG process illustrates how fleeting opportunities for action are in the policy process continue to flow and diverge.

There was however a small window of opportunity recognised and seized by the EAG; the opportunity to establish clinical leadership for diabetes at a national level. This policy idea had the support of the HSE and the Minister for Health. The importance of

leadership was recognised in the health policy community at that time (acceptability). Equally the idea was technically feasible as it fit with the emerging Clinical Care Directorate and so did not have additional cost implications, the final and biggest constraint facing the EAG recommendations. This opportunity was brokered by a number of policy entrepreneurs with one participant referring to the instrumental role of the DFI, which had 'claim to a hearing' as Kingdon would describe it, with the Minister for Health. Given that participants highlighted the better chance of success with the Clinical Care Programme for diabetes, there may be another policy window on the horizon for the diabetes community.

The Multiple Streams Theory makes an important distinction between the governmental agenda, the list of subjects getting attention and the decision agenda, the list of subjects "up for active an active decision" (p4) (251). Diabetes was on the HSE's agenda when it was assigned an EAG however it struggled to graduate to the decision agenda for the reasons outlined above.

7.3.8.3 *Advocacy Coalition Framework Explanation of the EAG Process*

Policy formulation was a function of three sets of factors. Firstly competing advocacy coalitions (health care professionals and health system management) interacted within the policy subsystem of diabetes. The coalition shared core policy beliefs about the importance of diabetes and the standard of care. There were subdivisions within the coalition regarding the merits of various proposals particularly the ideal model of care. Changes external to subsystem (i.e. economic recession) influenced the resources of the actors within the system which limited the policy output of the group.

Diabetes as a subsystem

The advocacy Coalition Framework was informative as a network theory which considers the wider policy community and the multiple actors involved in policy formulation (272). From the ACF perspective diabetes care is a nested policy subsystem within the wider chronic disease subsystem which is itself situated in the health policy sub-system. This positioning was recognised by participants who highlighted that diabetes was assigned an EAG as an *"archetypical chronic illness"* whose model of care could act as a framework for other chronic conditions. The diabetes subsystem also overlapped with other subsystems as issues such as the GP contract, which emerged during the EAG process as a constraint in the diabetes subsystem, spanned the wider primary care and health subsystem.

Advocacy Coalition for Diabetes

Taking the activities of health care professionals and patient representatives over the last decade into account (see Figure 34 in the Introduction Section), there appeared to be an advocacy coalition concerned with improving diabetes care in Ireland, *some* of the members of which were involved in the Expert Advisory Group. Other members of the coalition may have been involved informally in the EAG, for example some were invited in to give presentations, or were active in previous reports. From this perspective the EAG process could be considered a coordinated activity among actors within the Advocacy Coalition Framework. Interviewees referred to the EAG as an opportunity *"to shape policy"* and *"really get things moving"*, thereby acting 'in concert' according to the ACF perspective to translate their beliefs into policy (272). The EAG was only one coordinating activity in the lifecycle of diabetes policy. Other coordinating activities occurring at the same time included the introduction of a new way to report

HbA1c results and the formulation of national guidelines, both of which were connected the EAG process.

The EAG compromised of members of the diabetes coalition but also members who were appointed to represent service delivery units in the HSE and DOHC. The positions and roles of these members placed them within the diabetes subsystem, and at times within the coalition. However it was not complete membership suggested within the ACF (273). Certain core policy beliefs united all members of the EAG. For example the group agreed on the seriousness of the problem; *"there was unanimous agreement around how abysmal the services were"*. The group were also united in terms of the 'orientation of priorities'; *"everybody at the end of the day wanted to actually implement a good diabetes programme"*. However subdivisions emerged in relation to policy preferences and secondary beliefs. For example one government agency participant expressed ambiguous views about the expectation of implementation attached to the EAG, which was felt so strongly by health care professionals in the group.

An initial assumption was that the official agencies involved in health care in Ireland would form an opposing coalition. However the fact that the EAG was established by the HSE with the support of the DOHC suggests agreement on the core policy beliefs surrounding the problem of diabetes care in Ireland and the need for change. Rather than an opposing coalition, the results suggest appointed representatives moved in and out of the diabetes advocacy coalition and nominated members were more moderate in their positions regarding the importance of improving diabetes care.

Differences in Policy Preferences

According to the ACF model of the policy process subdivisions emerge within coalitions around the details of policy proposals relating to the secondary beliefs of individual actors (272). In line with this assumption the majority of the discussion and negotiation in the EAG process related to the details of policy proposals and divisions did emerge between coalition members around these details:

> *"I think we were all there with the same purpose but how we went about it, how the problem is going to be solved might be slightly different"*.

The difference in policy preferences was most evident during the development of recommendations for a model of diabetes care. The divisions were *between* settings (primary and secondary care) regarding the extent of primary care involvement in

diabetes management but also *within* professions regarding the feasibility of annual hospital review for all patients. However in keeping the ACF definition of secondary beliefs (272), these positions were amenable to change in line with strategy which facilitated consensus around the model of care.

> *"When we started off I certainly saw that there was a big difference between primary and secondary care but I think as the work of the EAG went on they moved a lot closer together and were willing and wanting to work together as one for the provision of services."*

In recent revisions the authors of the ACF outline a number of characteristics which facilitate 'negotiated agreements' including the agreement that the status quo is unacceptable and there are limited alternative avenues to pursue proposals (272). In terms of reaching consensus on the model of care, participants referred the realisation that *"specialists don't have the capacity to cope because they know what their numbers are"* and the gradual acceptance that *"it was impossible for either service to look after diabetes completely"*. This gradual acceptance reflects the 'policy stalemate' described by the ACF which facilitates agreement. However the experiences of the EAG in negotiating change would also suggest other factors are important in facilitating agreement including shared values and feasibility of proposals. In this way the Multiple Streams Theory offers a better fit to explain the negotiated agreement which led to the establishment of national leadership within diabetes under the Clinical Care Programme for Diabetes discussed previously.

Path to Policy Change

As the ACF seeks to explain the wider policy process both formulation and the implementation of policy are encompassed in the theory (287). Hence the ACF offered a more comprehensive account of the barriers to implementation. The path to diabetes policy change was blocked by a number of shocks or 'perturbations'. The economic recession and the policy decision to freeze recruitment in the health system, both external events, had a significant impact on the viability of the EAG proposals which were *"going to cost money and more importantly…going to cost new posts"*. The financial implications were also a determinant of the lack of impetus from senior management in the HSE which impeded progress from formulation to implementation.

> *"...our first report sketched out the sort of investment it [diabetes] might need and I think that that frightened them off".*

A related internal event which limited the resources of the EAG was the redistribution of the power to implement change to the newly established Clinical Care Programme, which has a *"HSE person leading it with a mandate to get action"*. This internal event is similar to the idea of a change in jurisdiction proposed within the politics stream of the Multiple Streams Theory (251). However participants in this study suggested the EAG was established without power to implement change from the outset, a reflection of the lack of foresight within the health system rather than the unexpected outcome of events.

While the ACF illuminates the events which can impede policy change, examples from the EAG process outlined above were more illustrative of the mechanisms by which such internal and external events constrained resources and obstructed change. The Advocacy Coalition Framework proposes examining the policy process over the course of ten years (272), however this case study of the Expert Advisory Group for Diabetes illustrates the rapid changes which can occur in the policy environment over a short period of time (2-3 years) and immediate impact events have on decisions and action.

7.4 Discussion

7.4.1 Summary of findings

This study examined the establishment of the Expert Advisory Group for Diabetes and the formulation of its recommendations as a good example of the policy process. At the outset the EAG was promoted as the HSE's primary source of 'operational policy', the first *internal* drive to develop policy specifically for diabetes in Ireland. This chronic condition was seen as *"ripe for movement"*, given its rising prevalence, unsustainable health care costs and the existing groundwork to improve care at local level. Indeed the foundation of previous efforts facilitated the formulation of recommendations by the group. Participants noted the overarching agreement within the group regarding the "obvious" priorities while the details of how to address the priorities was influenced by personal preferences and local loyalties. The group tactically tried to increase the chances of translating their recommendations into action by aligning proposals with past policy and future direction. There were also concrete plans for implementation which was a palpable expectation within the group.

This study offered an unexpected opportunity to explore issues around engagement with senior management and decision-making within the HSE. The relative ease with which the recommendations were developed by the group was in stark contrast to the decision-making process within the HSE, which was protracted and surrounded by ambiguity. According to participants the original interest and impetus behind the EAG process was "*frightened off"* by the financial implications of the recommendations. Another contributory factor to the implementation standstill was the lack of power conferred on the EAG to make change happen. The EAG, which was established by the HSE, found itself outside the organisation with no connection to the decision-making centre. These factors amounted to a perception among stakeholders of *"bad timing"* for diabetes care improvement. Despite the frustration of participants with another *"paper exercise",* the EAG led to developments which changed the face of diabetes care at a national level, namely the establishment of a Clinical Care Programme for Diabetes and the appointment of a national clinical lead, to advance recommendations to the implementation phase.

7.4.2 Indecision equating to inaction

This study applied three theories to the case of the Expert Advisory Group for Diabetes as an explanation of the policy formulation process: the Rational Model of Decision

Making (267, 269), Multiple Streams Theory (251) and the Advocacy Coalition Framework (272). Policy formulation as an activity has a number of consequences some of which are action while others are inaction (288) and the EAG process had a mixture of both consequences as illustrated by this analysis. It has been suggested that a definition of the policy process should not exclude all reference to implementation, as policy formulation is not merely a decision but a decision to act (289). Therefore it unsurprising the analysis in this study strayed into implementation territory, as decisions by the HSE were considered decisions to invest and implement change in diabetes. The lack of implementation which accompanied the EAG process led many participants to conclude that the recommendations did not represent a policy for diabetes care, as policy was synonymous with action. The theories chosen for this study focus on decision making rather than implementation with the exception of the Advocacy Coalition Framework. However given the blurred lines between decision and action many of the issues which explained indecision by default also accounted for inaction in this study.

7.4.3 Applying an Alternative Lens Approach

By adopting an 'alternative lens' approach to policy analysis some features of the EAG process were illuminated while other aspects were obscured depending on the theory being applied (36). The process was best described by Kingdon's Multiple Streams Theory (251) which accounted for both the pre-decision process of how and why the EAG was established and the decision-making and non-decision making which characterised the approval process. This theory offered an explanation for the survival of some recommendations such as the appointment of a clinical lead which was in keeping with emphasis on leadership in the health system and had the support of the Minister for Health at the time. In contrast decisions around the implementation of the model of care were deferred as this policy idea was subject to cost constraints and questions about its feasibility. The Multiple Streams Theory captures the dynamic unstable nature of the policy process in which streams diverge and opportunities are lost. In the case of the EAG, the feasibility of proposals and budgetary constraints (policy stream) coupled with changes in the structure and support of the HSE (politics stream) closed the policy window. The group as it found themselves without resources or the authority to advance from advice to action, two factors which have been emphasised as barriers to implementation (290).

Despite the complex and unpredictable reality of policy formulation, the rational or stages heuristic model of policy formulation has maintained its use in both in the study and practice of policy making (288). This was a practice followed by EAG which followed a logical sequence of steps in keeping with the rational model of decision making. However the group examined a limited number of alternative proposals heavily influenced by previous reports and existing groundwork to improve care, more in keeping with the Multiple Streams theory that policy ideas are typically revisions of previous proposals rather than completely new ideas (251). Considering a select number of proposals was not an illogical step on the part of the EAG but rather a strategic approach to increase the chances of success. Hence what is defined as rational should be considered within the constraints of time, interest and money in the policy community. This idea fits with later revisions to the concept of rational decision making. In the theory of bounded rationality proposed by Simon (1957) decision makers are deliberately rational however they face real world constraints on time, attention and resources which impact their ability to make perfectly rational choices (37). The proposed "the administrative" decision-maker aims to 'satisfice' rather than choose the best solution from alternatives, that is choose the strategy that meets satisfactory standards (291).

The rational model offered little insight into the fate of recommendations beyond choosing the 'best options' to put forward for approval by the HSE. The stages of the EAG process beyond the approval process did not appear logical or discrete. A distinction has been made between rationality of process and rationality of outcome, as the former does not always lead to the latter (268). In the case of the EAG the process appeared rational with priority setting, formulation of recommendations and submission of the best alternatives for approval. However participants questioned the rationality of the outcome; putting together a group to develop operational policy in the area of diabetes and not employing this advice to improve services.

The Advocacy Coalitions Framework (ACF) was selected as an analytical tool in this study as it focuses on the network of actors involved in policy and the group dynamics of the process (272). This theory illuminated the interaction and familiarity among actors in the EAG process and accounted for the mixture of perspectives which united and divided the group. In particular the ACF principle of unifying core policy beliefs and divisive secondary beliefs within coalitions appeared to fit the EAG dynamic

between health care professionals in particular. However the membership of the diabetes coalition was not as clear-cut as the ACF would suggest as some EAG members were assigned to the group and therefore assigned to the coalition in some respects. Diabetes was just of one the priorities for senior management in the health system and they may have occupied several coalitions at the time depending on their role. Equally there were health care professionals dedicated to improving the quality of diabetes care who were not formally part of the EAG but would be considered members of the diabetes advocacy coalition. Hence membership of the diabetes coalition may change over time depending on the coordinating activity. The permeable boundaries of an advocacy coalition were previously described by Larsen et al (2006) as *"a solid core with fuzzy edges"* (274). Furthermore, their study of pharmacy policy in Denmark identified strategic manoeuvring as a core part of policy formulation. This concept is similar to the policy tactics identified during this study were employed by the EAG to increase the chances of their recommendations being accepted including anticipating implementation and fitting proposals from with the direction of the HSE.

7.4.4 Use of Information and Evidence in the EAG

Previous studies have highlighted the use of 'soft evidence' by decision-makers when formulating policy. 'Soft evidence' includes personal and professional experience, the rationale of what worked in other areas, local research, understanding patient preferences and financial information (292, 293). The rationale of what worked in other areas had a strong influence on the EAG discussions particularly around the model of care and retinopathy screening. While international priorities and proposals were influential in priority setting, policy transfer from other countries or other regions of Ireland was not taken as a panacea, guidelines and initiatives had to contextualised and adapted to fit with regional variation. Personal and professional experience also shaped the formulation of recommendations reflecting the power of expert knowledge of health care professionals during the early stages of the EAG process. However the power, conferred by access to information, was then transferred to senior management during the approval phase. Participants commented on the lack of clarity around decision-making within the health system and the lack of feedback on the progress or viability of the recommendations. Information in policy formulation is not always reliable, available or unbiased (270) an observation at odds with the assumptions of the rational choice model of decision (266).

7.4.5 Covert Power in Decision-Making

The power processes involved in obtaining approval and translating the recommendations to action were largely outside the Expert Advisory Group. The perceived centre of power in the health system appeared to be 'the kitchen cabinet' as one participant described senior management in the HSE. This term was used by Hill (2005) to reflect as the covert nature of power in policy making (36). Ambiguity surrounded what constituted a decision and who was responsible for making it. Participants in this study suggested this ambiguity was rooted in the changed structure of the health system from decentralized decision making at the Health Board level to the centralized system of the HSE. As the system became more centralized, the decision making process became more opaque leaving health care professionals in particular unsure of how to make change happen.

7.4.6 Disconnection between policy and practice

Two disconnections in the policy process emerged from the findings of this study. The first is the well-established gap between policy and implementation which exposed the weaknesses within the EAG structure and the lack of support for implementation outside the group. The second disconnection highlighted by participants was the gap between paper policy and practice in the health system. There are no clear targets for diabetes as those set out in the UK's National Service Framework (66). The EAG tried to bridge this gap by proposing Diabetes Services Implementation Groups (DSIG) to link national direction with local decisions. There is a danger of policy fatigue among health care professionals, some of whom are frustrated and despondent by the lack of return on their investment. Similar low expectations regarding quality improvement emerged from the qualitative study with GPs in Chapter 5.

7.4.7 Strengths and Limitations

This study has contributed to both the theoretical principles but also practical principles of policy formulation. For example theories such as the Advocacy Coalition Framework have been accused of listing variables which potentially influence policy change without analysing the mechanism by which such influence is conferred (288). The results of this study illustrated how external events, such as an economic crisis, suppressed internal support from senior management leaving the EAG powerless to implement change. In terms of practice, this case study has identified a number of policy tactics within the Irish health context which could increase the chances of acceptance and approval of

policy proposals within the health system. Retrospective analysis of success and failure in policy-making creates a learning environment for those involved in the policy process(294).

There are numerous challenges when conducting health policy analysis not least the 'temporal challenge' of the long-term nature of the policy process from development to implementation versus the short-term nature of research funding and the demand for results (295). This is why policy analyses almost always focus on retrospective case studies (296). Also problems such as recall bias arise when studying a series of processes and decisions covering a long period of time (29). This study concentrated on the policy formulation process which incorporated early indications of implementation. However implementation is ongoing in some priority areas under the auspices of the Clinical Care Programme and this stage deserves dedicated and rigorous evaluation. The short-term perspective of this study may have limited the applicability of the ACF which is ideally applied over the entire policy process spanning at least a decade according to its authors (272). Some aspects of the framework such as policy oriented learning were not strong features during the EAG process although there were indications that learning occurred *as a result of* the EAG process. For example the group moved from holding several viewpoints on the ideal model of care to adopting a more united stance in favour of integrated care. Other theorists have criticised the ACF for its long range view given the radical changes which can occur in a policy field (297). The economic crisis nationally and internationally exemplified radical change in this study.

7.4.8 Conclusion

Contrary to the discrete phases of decision-making under the rational model, a number of stages of the EAG process, such as the evaluation of alternatives, are also ongoing as part of the Clinical Care Programme for Diabetes. The MS Theory proposes a more fluid iterative approach to policy making which reflects the dynamic nature of the diabetes policy process in Ireland. This perspective could also be applied in a follow-up study to explore whether the new Clinical Care Programme presents another window of opportunity for action. Participants in this study emphasised its greater chances of success and facilitating factors in the political stream such as change in administration within the Department of Health could prize open another policy window for diabetes. This study is one of the first policy analysis studies of its kind in health services in

Ireland. This approach, which is grounded in theory, could have utility in studying and analysing other important health policy issues and processes.

8 CONCLUSION

8.1 Summary of Main Findings

This thesis has examined the organisation and coordination of diabetes care in the community and explored the challenges to and opportunities for improving care. The findings illustrate a scale of service and involvement in diabetes quality improvement initiatives in Ireland. At the upper end of the scale there are *"pockets of interest"* where local 'champions' have developed a structured systematic approach to diabetes care within general practice or in collaboration with the hospital-based team. Such initiatives are quality assuring care as part of provision through routine audit and feedback. However there is no comparative information on the quality of care being delivered in the remainder of the continuum, where most patients with diabetes receive care.

The findings of this thesis highlight the 'quality chasm' of organisation and coordination surrounding diabetes care. A substantial proportion of care in general practice is unstructured with approximately half of the GPs surveyed using a diabetes register, guidelines or routine recall. Almost equal proportions of practices utilised all three strategies as employed none of these, illustrative of the extreme ends of the scale. The delivery of diabetes care is further compounded by the deficient access to services and the lack of formal integration between settings. The qualitative follow-up study of diabetes care provision explored these issues in more detail. Care delivery was characterized by a number of continua; the extent of structure in the practice, the balance of care between settings, the extent of sharing between providers and division between informal and formal initiatives to improve care. Participants wanted greater 'sharing' between providers rather than either/or care. This 'sharing' should be reflected in both attitude and behaviour, with a sense of shared responsibility for patients and shared protocols to clarify the realms of responsibility. However they did not prescribe the exact workings of such 'sharing', which depended on local interest and capacity to manage diabetes care in the general practice setting.

This qualitative study also highlighted the everyday consequences for providers and patients of deficiencies in the health system. In particular, the lack of coordination between settings led to waiting times, overburdened hospitals and the uncertainty for patients and providers of *"in the meantime"* care. The lack of adequate remuneration for diabetes care had a similar ripple effect creating costs for patients and apathy among GPs. There was also a sense of inertia around quality improvement activities, particularly at a national level. This attitude was strongly influenced by previous

experiences of change in the health system. In contrast GPs spoke positively about their experience of change within the practice which was enabled by a practice *"ethos"* supportive of improvement, special interest and leadership. The quality of local-level bottom-up improvement was illustrated in the cross-sectional study of three primary care diabetes initiatives led by local champions. The standard of care was comparable to the UK in terms of the recording of clinical processes of care and achievement of clinical targets.

With regard to policy efforts to improve diabetes care, this chronic disease has struggled to make it onto the national decision agenda. Several reports have proposed solutions to address the substandard service, however little tangible change has emerged. The Expert Advisory Group process was an instrumental case study of this cycle. The evolving process of action and inaction was best described by the Multiple Streams Theory. There was a sense of reserved optimism that a new window of opportunity is being prized open by the Clinical Care Programme for Diabetes which is perceived to have the leadership, power and mandate to implement change that was not granted to the Expert Advisory Group. However the development of infrastructure to deliver organised coordinated diabetes services will require investment of both money and minds.

8.2 Interaction between evidence and context

Quality in healthcare is not the product of one single effective strategy, nor is it entirely the result of the circumstances of implementation, but the interaction between the two (28). This idea of a 'fit' between evidence and context proposed by Donabedian and borne out in evidence from systematic reviews of multifaceted quality improvement interventions (8), is reflected the findings of this thesis. Firstly the study of the primary care-led diabetes initiatives demonstrated the quality of care delivered by local champions implementing evidence based care in response to a need in their area. Results from the qualitative study of attitudes to quality improvement suggested GPs were sceptical, and in some cases affronted, by change imposed from above which carried an implicit assumption that policy makers and planners knew what was needed to improve care. Similarly local circumstances were two of the primary considerations of the EAG in making their recommendations to improve diabetes services in Ireland. Taking into account research and international experience, policy ideas were *"contextualized"* to *"irishise"* recommendations.

Recent research has shown how local circumstances can be used as opportunities for improvement. Lemmens et al (2011) have used 'bottlenecks' in service as focal points for improvement in COPD care in the Netherlands with encouraging results (298). Bottom-up disease management programmes were developed comprising of interventions targeted at the bottlenecks identified in three different regions. The problem areas were originally identified and ranked by stakeholders in each area which were then used to guide the selection of appropriate strategies. For example one area ranked the division between primary and secondary care as a major bottleneck which led to the implementation of regional arrangements for referral and greater task delegation within and between settings. The tailored approach had a positive impact on processes of care, quality of life and patient experience as well as patient outcomes.

This best fit approach to quality improvement corresponds to the classification of barriers as 'would-be facilitators' by participants in the qualitative study of care provision. Indeed the model of barriers and facilitators outlined in this thesis illustrates the correspondence between problems and opportunities. Participants identified the coordination between settings as barrier to diabetes care, proposing shared protocols as a mechanism for clarifying roles of responsibility. The overburdened hospital clinics could be addressed by enhancing the capacity of general practice to manage a greater majority of diabetes care in the community, in keeping with policy proposals. Within the practice, the delegation of tasks between GPs and nurses emerged as a facilitator of structured care provision.

Given the apathy towards national level quality improvement, a bottom-up tailored approach such as this, may be appropriate in the Irish context. The findings of the qualitative study of barriers and facilitators to improvement, revealed a distinction between GPs' positive experiences of change at a local level and their apathy towards national level change. The wariness of national level endeavours was echoed in the policy analysis as *"being involved in things nationally can bring more frustration than reward."* A bottom-up approach, such as that employed in the Dutch study, could create a sense of ownership over improvement by acknowledging the challenges of diabetes management and utilising the experience of those delivering care. This approach would address the physical barriers but also the attitudinal barriers to QI as something that is imposed or threatening. The opportunity exists for regional Diabetes Services Implementation

Groups to assess the needs of patients and health care professionals in their jurisdiction and act accordingly.

This is not to suggest that quality improvement should be a pick and mix of strategies without consideration of the evidence. The development of quality improvement initiatives should be underpinned by a theoretical framework, a notable absence in many studies (120). This would make explicit the mechanisms by which strategies are expected to improve outcomes. It would also guide the selection of appropriate indicators to evaluate the expected changes (217) (120, 298). As mentioned previously in this thesis, flexibility to address the needs and capacity of an area is not at odds with a national standard of diabetes care which all regions must meet. Local adaptation is one of the prevailing properties of successful dissemination of innovation (299).

8.2.1 Culture of Quality Improvement

Culture encompasses underlying assumptions, values, physical and behaviour manifestations (208). This thesis has explored the culture of quality surrounding diabetes care in the Irish health system. The qualitative study of GPs' attitudes to quality improvement in diabetes care gives some indication of the subculture among this professional group, which was characterised by a sense of wariness and apathy towards change in the health system compounded by previous experience. Participants did not prioritise improvement strategies at a population level when weighed against the deficiencies in the current level of service for individual patients. According to Coiera (2011) engaging people in change will always be a struggle when the health system is over-constrained, regardless of the merits of the innovation. This is an important observation in the context of the current economic recession with increasing pressure on the Irish health system to deliver more for less (207).

According to Donabedian "*the pursuit of quality depends ultimately on human will*" (p138) (28). In the case of diabetes care in Ireland the pursuit of quality appears to depend *only* on human will. Quality improvement and subsequent quality assurance has been limited to a pocket of individuals in both practice and policy circles. However a culture of quality means that all members of staff are involved in improvement efforts, identified by participants in this thesis as a practice *"ethos"*. To embed quality improvement in the health care culture, GPs need to adopt a different kind of professionalism (300) known as civic professionalism (206). This way of thinking and doing extends the responsibility of the GP from the individual patient to the community as a whole, and engenders a

view of quality improvement as a professional obligation (206). The goal is to create the attitude among all professions that *"everyone in healthcare has two jobs at work every day: to do their work and to improve their work"* (p3) (35). Education and training is the foundation of this attitude and was identified as one of the key opportunities to develop diabetes care in the survey of GPs in Ireland. Part of education and training is allowing the time to try and test new ideas and skills however the increasing demands being placed on general practice has significant implications for this opportunity.

8.3 Implications of findings

Civic professionalism needs to be supported by the health service (300). There are a number of factors which can sustain quality improvement including opportunities and incentives for continuous improvement as well as governance arrangements for poor performance (300). One incentive for continuous improvement is the sharing of performance and experience among peers. The 'early adopters' of structured systematic diabetes care could provide a valuable source of peer learning and leadership on the ground. Investing in this group is essential for the dissemination of quality improvement innovations (299). The drivers of change identified at a local level should be emulated at a national level. This process has begun with the appointment of a national clinical lead for diabetes care under the auspices of the Directorate for Quality and Clinical Care.

Widespread interest and participation in quality improvement can only be expected when an infrastructure is put in place to support it, including IT systems for routine data collection and information sharing, incentives and continuing professional development (229), the physical manifestations of a quality culture (208). While quality has been at the heart of health care policy since 2001 nothing tangible has emerged to facilitate the evaluation and monitoring of quality. According one participant in the study of policy formulation to improve diabetes services; *"we're not there yet"* in Ireland. Yet a quality assurance infrastructure needs to be developed in tandem with proposed changes to the model of care delivery rather than as an after-thought. All quality improvement frameworks collect and utilise data to highlight deficiencies, evaluate needs, refine solutions and monitor outcomes. This is one of the predisposing factors to embedding and sustaining quality improvement in the health system (300). There is ample opportunity for international learning from countries such as Scotland and advances had been made in developing a core dataset for diabetes in Ireland however

progress has since stalled. Enhancing this capacity would enable health service managers and policy makers to evaluate change and to assure it equates to improvement.

8.4 Conclusion

This thesis presents a series of research on the organisation and coordination of diabetes care in general practice as a means of bridging the quality gap. The findings highlight the inconsistency and uncertainty of diabetes care in Ireland. While tangible investment is needed to improve the quality of diabetes care, attitudinal change is also required to create a culture of quality in the health system. The main barriers to optimal diabetes care centre on the organisation and coordination of care as a system-level with negative consequences for practice, providers and patients. However there are a number of enabling factors which could enhance care provision and promote quality improvement. Quality improvement initiatives need to stimulate a sense of ownership and interest among frontline service providers to address the local sense of inertia to national change. To date quality improvement in diabetes care has been largely dependent on *"pockets"* of special interest among health care professionals. The challenge for the Irish health system is to embed this activity as part of routine practice, professional responsibility and the underlying health care culture.

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10 APPENDICES

10.1 Appendix I: PhD Education & Training

HRB PhD Scholars Programme in Health Services Research

The thesis has been undertaken as a part of the HRB PhD Scholars Programme in Health Services Research. This four year structured programme encompassed taught modules such as health policy, health psychology and population health during the 1st year and continued training in grant writing, leadership skills and writing for publication during years 2-4. Additional training courses were undertaken tailored to the students own research which was conducted over the course of four years (Table 54). As part of the HRB PhD Scholars Programme a national placement was undertaken with the Diabetes Interest Group in Cork and the Haematology Department of Cork University Hospital. An international placement was completed at the Health Policy Unit of the London School of Hygiene & Tropical Medicine.

Table 54 Training courses undertaken during PhD

Year	Course
2011	• Systematic Reviews for Health Sciences Department of Epidemiology & Public Health, UCC
2010	• Meta-synthesis: systematic review of qualitative research Health Technology Assessment Conference, Dublin.
2010	• Writing and Publishing Qualitative Inquiry with Janice Morse Dublin City University Qualitative Summer School
2010	• Integrating Qualitative and Quantitative Methods (Mixed Methods) Qualitative Health Research Conference, Vancouver
2010	• Grounded Theory: Using it to your advantage as a research student. School of Nursing and Midwifery, Trinity College Dublin
2009	• Case Study Methodology University of Essex Summer School in Social Science Data Analysis & Collection
2009	• 'Creative Interviewing' Dublin City University Qualitative Summer School
2008/09	• Teaching & Learning for Graduate Students Department of Geology, UCC

Research Output & Dissemination

Research contained in this thesis has been published in peer-reviewed journals (Table 55) and presented at a number of national and international conferences (Table 57).

Table 55 Peer Reviewed Publications

Year	Peer-Reviewed Journals
Accepted	S Mc Hugh[1*], P Marsden[2], C Brennan[2], K Murphy[3], C Croarkin[4], J Moran[3], V Harkins[5], I. J Perry[1]. Counting on commitment; the quality of primary care-led diabetes management in a system with minimal incentives. *Accepted* to BMC Health Services Research.
2011	O'Mullane M, Mc Hugh S, Bradley C. Informing the development of a national diabetes register in Ireland: a literature review of the impact of patient registration on diabetes care. Informatics in Primary Care. 2011; 18(3):157-68.
2010	Mc Hugh S, Collins M, Perry IJ. Trying to Balance Quality: Can We Assume that Improving the Quality of Care Delivery also Improves Quality of Life? Journal of Clinical Metabolism & Diabetes. 2010; 1(2):35-42.
2009	Mc Hugh S, O'Keeffe J, Fitzpatrick A, de Siún A, O'Mullane M, Perry I, et al. Diabetes care in Ireland: A survey of general practitioners. Primary Care Diabetes. 2009; 3 (4):225-31.

Table 56 Other research output

Year	Type	Title
2010	Report	Murphy K, Mc Hugh S,M Kelly, Moran J. (2011) Diabetes Interest Group Audit Report 2009-2010. [In progress]
2010	Report	Marsden, P., Brennan, C., Mc Hugh, S., Harkins, V. (2010) Audit Report of the HSE Midland Diabetes Structured Care Programme. Department of Public Health, Health Service Executive Dublin Mid-Leinster.
2010	Article	Murphy K, Mc Hugh S, Kelly M, Moran J. Managing Type 2 in the community. Diabetes Professional. 2010.
2010	Article	Mc Hugh, S. Bridging the quality gap in diabetes care. The Boolean. Snapshots of Doctoral Research at University College Cork. Vol .1 (2010)
2009	Report	Murphy, K., Mc Hugh S, O'Keeffe, J. and Moran, J. (2009). Diabetes Interest Group Audit Report. Dec '07- May '08. (unpublished)

Table 57 Conference Presentations over course of PhD

Year	Title		Conference
2011	A case study of policy formulation in the Irish health system; "paper exercise" or a plan of action to improve diabetes care?	Oral	• Society for Social Medicine Annual Conference, Warwick
		Poster	• Translational Health Research Day, UCC June 2011
2010	"Improving the Quality of Diabetes Care; Exploring the GP perspective".	Oral	• Society for Academic Primary Care, UEA Norwich July 2010.
		Poster	• International Society for Quality & Safety in Health Care, Paris, Oct 2010 • Qualitative Health Research, Vancouver, Oct. 2010. • Social Science & Medicine, Belfast, Sept 2010 • Academic University Departments of General Practice Ireland Annual Scientific Meeting, RCSI March. 2010. • Translational Health Research Conference, UCC, June 2010.
2010	"Diabetes services across primary and secondary care settings"	Poster	• Society for Academic Primary Care, July 2010 • International Society for Quality & Safety in Health Care, Paris, Oct 2010 • Academic University Departments of General Practice Ireland Annual Scientific Meeting, RCSI March. 2010.
2009	"Diabetes care provision in general practice in Ireland"	Oral	• Society for Academic Primary Care, St. Andrew's, July 2009.
		Poster	• AUDGPI Annual Scientific Meeting, RCSI Feb. 2009. • Translational Health Research Conference, UCC, June 2009. • Optimizing Diabetes Management in Primary Care (DIG, UCC & HSE) Sept. 2009
2009	**"Diabetes care in General Practice: DIG- a GP initiative."**	Poster	• Translational Health Research Conference, UCC June 2009. • Optimizing Diabetes Management in Primary Care (DIG, UCC & HSE) September 2009. [2nd prize in poster competition]

10.2 Appendix II: Publications

- **Mc Hugh S**, O'Keeffe J, Fitzpatrick A, de Siún A, O'Mullane M, Perry I, et al. Diabetes care in Ireland: A survey of general practitioners. Primary Care Diabetes. 2009;3(4):225-31.

- **Mc Hugh S**, Collins M, Perry IJ. Trying to Balance Quality: Can We Assume that Improving the Quality of Care Delivery also Improves Quality of Life? Journal of Clinical Metabolism & Diabetes. 2010;1(2):35-42.

- **Mc Hugh S**, Marsden P, Brennan C, Murphy K, Croarkin C, Moran J, et al. Counting on commitment; the quality of primary care-led diabetes management in a system with minimal incentives. BMC Health Serv Res. 2011;11(1):384-93.

- O'Mullane M, **Mc Hugh S**, Bradley C. Informing the development of a national diabetes register in Ireland: a literature review of the impact of patient registration on diabetes care. Informatics in Primary Care. 2011;18(3):157-68.

10.3 Appendix III: Literature Search Methodology

Study Selection

The synthesis focused on studies evaluating the effectiveness of interventions aimed at improving the delivery of care through structural, organisational or professional change. Studies were excluded if they focused solely on patient-orientated interventions (e.g. lifestyle interventions, self management interventions, patient education). Studies in which a patient-orientated component was part of a larger multidimensional intervention were included.

Inclusion/Exclusion Criteria

Types of studies

Systematic reviews, randomised controlled trials, controlled clinical trials

Types of participants

Health care professionals (doctors and nurses) delivering care to adult patients with Type 1 or Type 2 diabetes.

Types of outcomes

The review focuses on measures of;

- Health professional behaviour – process of care measures
- Patient outcomes – objective and self-report measures
- System performance - economic outcomes, hospital admissions.

Search Strategy

The following electronic databases were searched for English language articles published between 2000 and 2011: Medline; Cochrane Database of Systematic Reviews and the Clinical Trials Register; EMBASE; CINAHL and ERIC. The search strategy developed for MEDLINE was amended appropriately for each database. The search was supplemented with a search of the reference lists from relevant articles. The search strategy was constructed using a combination of medical subject headings (MeSH) and free-text terms.

Search Strategy for Medline (2000-2011)

1.	Diabetes Mellitus* /or Type 1 diabetes /or Type 2 diabetes
2.	Chronic disease*/ Chronic Illness
3.	"Health Care Quality, Access and Evaluation"* /or "Quality of Health Care"* /or Quality Assurance, health care/or Total Quality Management/or Quality Indicators, Health Care* /or "Outcome and Process Assessment (health care)" /or "delivery of health care" /or disease management*
4.	systematic.mp. or *Clinical Trials as topic/ or exp Randomized Controlled Trial* [pt]/ or exp Controlled Clinical Trials* /or Intervention Studies /or Evaluation Studies/ or *Feasibility Studies/ or exp Program Evaluation*
5.	1 OR 2
6.	[5] AND 3 AND 4

*MeSH exploded term Pt = publication type

Data Extraction and Analysis

Upon reviewing the titles and abstracts for relevance to the inclusion criteria, potentially relevant full-text articles were obtained. One reviewer (SMH) was responsible for all aspects of study selection and data abstraction. Studies were analysed qualitative and summarized as a narrative review.

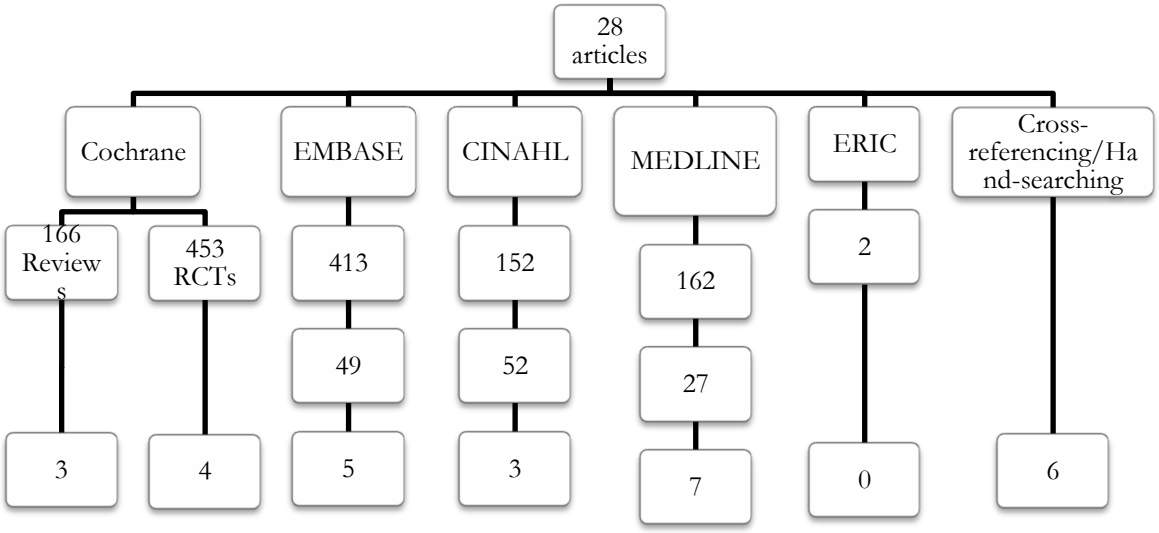


Figure 40 Search Results

10.4 Appendix IV: GP Survey

COMMUNITY SURVEY OF THE PROVISION OF DIABETES SERVICES IN IRELAND

Please complete all questions as fully and as accurately as you can. This should take no more than 20 minutes. If you have any questions please contact Anna de Siún on 087 631 0667. Please return by using the attached **FREE POST** envelope to Anna de Siún, The ICGP, 4/5 Lincoln Place, Dublin 2. *The questions should be answered on the basis of an overall practice policy rather than an individual doctor.*

Thank you for your time.

The survey has been approved by the Research Ethics Committee of the Irish College of General Practitioners.We would be grateful if you would answer the following questions by shading the answer that applies (e.g. ● Yes ○ No).

1. ABOUT THE PRACTICE

Q1. Would you describe the location of the practice that you predominantly operate out of as rural, urban or mixed?

○ Rural ○ Urban ○ Mixed

Q2. Do you have a practice manager? ○ Yes ○ No

Q3. How many doctors are in the practice (including you)? ☐☐

A. Are all doctors in the practice involved in delivering diabetes care? ○ Yes ○ No

B. If NO, how many doctors in the practice ARE involved in delivering diabetes care? ☐☐

Q4. Do you have a practice nurse? ○ Yes ○ No

Computer Systems

Q5. Does your practice have a computer system?

○ Yes *CONTINUE* ○ No *GO TO Q7*

A. If YES, which computer system do you have? (GP Mac, Dynamic GP, Health One etc.)

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

B. What is the practice computer system used for? *(Please shade all that apply).*

To maintain a register/ list of patients	◯ Yes	◯ No
To issue repeat prescriptions	Yes	◯ No
To issue acute prescriptions other than in consultations (e.g. telephone or desk requests)	◯ Yes	◯ No
To maintain continuation records of consultations	◯ Yes	◯ No
To issue acute prescriptions in consultations	◯ Yes	◯ No
To store reports from hospital laboratories	◯ Yes	◯ No
To store reports from X-ray departments	◯ Yes	◯ No
To store reports from specialists	◯ Yes	◯ No
To store other reports *(Please specify):*	◯ Yes	◯ No

To record antenatal care visits	◯ Yes	◯ No
To record Heart Watch visits	◯ Yes	◯ No
To record other forms of systematic care of patient groups (*Please specify*)	◯ Yes	◯ No

To make GMS claims	◯ Yes	◯ No
To make claims for ante-natal care	◯ Yes	◯ No
To make other claims (*Please specify*):	◯ Yes	◯ No

C. Who do you receive electronic reports from? *(Shade all that apply)*

Hospital laboratories	◯ Yes	◯ No
X-ray departments	Yes	No
Other hospital departments (*Please specify*):	◯ Yes	◯ No

Consultants (*Please specify*):	◯ Yes	◯ No

Others (*Please specify*):	◯ Yes	◯ No

D. Are these electronic reports filed in patients' individual electronic records?
(Shade all that apply).

◯ Automatically ◯ By Scanning ◯ Manually

E. Is the electronic record used routinely by GPs in the practice during consultations?

◯ Yes ◯ No

F. Have paper records been replaced in favour of electronic records for the following?

Continuation notes of GP visits	◯ Yes	◯ No
Laboratory reports	◯ Yes	◯ No
X-ray reports	◯ Yes	◯ No
Hospital discharge letters	◯ Yes	◯ No
Out-patient referral letters	◯ Yes	◯ No
Other (*please specify*):	◯ Yes	◯ No

G. Are you a 'paperless' practice? ◯ Yes ◯ No

Q6. Is there a diabetes module on your computer system?

◯ Yes *CONTINUE* No *GO TO Q7* ◯ Don't know *GO TO Q7*

A. If yes, is this module used? ◯ Yes ◯ No

Q7. With regard to questions addressing the number of patients in your practice, is the data provided based on:

◯ Your best estimate

◯ Actual numbers from the practice IT system

Q8. What is the total patient population of this practice approximately?

	☐☐☐☐☐
A. Total Number of GMS Patients (best guess).	☐☐☐☐☐
B. Total number of private patients (best guess).	☐☐☐☐☐

2. DIABETES CARE DELIVERY

Q9. Do you maintain a diabetes register in the practice? ◯ Yes ◯ No

Q10. What is the estimated number of individuals known to have diabetes in your practice?

Overall ☐☐☐☐

Type 1 ☐☐☐☐

Type 2 ☐☐☐☐

Q11. In 2007 how many patients were newly diagnosed with diabetes by your practice?

Type 1 ☐☐☐☐

Type 2 ☐☐☐☐

Don't Know ☐

Q12. With regard to questions addressing the number of patients in your practice with diabetes, is the data provided based on:

◯ Your best estimate

◯ Actual numbers

Q13. Are there any professionals in your practice with a special interest in diabetes?
(Please shade all that apply)

◯ GP ◯ Nurse ◯ Other

If other please specify

Q14. How many diabetic patients does the practice have in nursing homes /residential care?

IF NONE PLEASE GO TO Q15

A. From whom do these patients receive their medical diabetic care? i.e. reviewing HbA1c.

(Please shade all that apply)

GP from this practice

◯ Yes ◯ No

Hospital specialist service

◯ Yes ◯ No

Other

◯ Yes ◯ No

If other specify:

B. Do you have any comments/suggestions on providing diabetic services to patients in nursing homes/residential care in terms of practicalities?

Q15. With regard to questions addressing the number of patients with diabetes, in your practice who are living in nursing homes, is the data provided based on:

◯ Your best estimate

◯ Actual numbers from the practice IT system

Clinics

Q16. Does your practice hold specific clinics for diabetic patients?

◯ Yes *CONTINUE* ◯ No *GO TO Q16b*

A. If yes, how are these clinics led and how often are they held?
Please shade all that apply and complete details regarding frequency of each clinic;

GP Led

◯ Yes ◯ No

If yes, frequency of clinic

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months

Practice Nurse Led

◯ Yes ◯ No

If yes, frequency of clinic

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months

Combined practice nurse & GP

◯ Yes ◯ No

If yes, frequency of clinic

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months

Pharmaceutical nurse led

◯ Yes ◯ No

If yes, frequency of clinic

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months

Other

◯ Yes ◯ No

If yes, frequency of clinic

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months

If other please specify:

B. Other than specific diabetes clinics, when are patients with diabetes seen in your practice for diabetes care? *(Please shade all that apply)*

Patient initiated appointments specifically for diabetes	◯ Yes	◯ No
Doctor or nurse initiated appointments specifically for diabetes (recall for regular review).	◯ Yes	◯ No
Opportunistic appointments (patient is being seen for something else other than diabetes)	◯ Yes	◯ No
Other	◯ Yes	◯ No

Q17. Does the practice have a formal call and recall system for reviews of a patient with stable Type 2 diabetes?

◯ Yes *CONTINUE* ◯ No *GO TO Q19*

A. How often would you recall a patient with stable type 2 diabetes?

◯ Never

◯ Quarterly

◯ Semi annually

◯ Annually

◯ Other

If other please specify:

B. If yes, please indicate the proportion of patients who usually attend for their reviews?

Proportion of Type 2 Diabetes Patients ☐☐☐ **%**

Q18. With regard to questions addressing the number of patients with diabetes in your practice attending reviews, is the data provided based on:

◯ Your best estimate

◯ Actual numbers

Q19. As part of a routine check- up of diabetic patients which of the following would you do?

TEST/PROCEDURE

	Review their medication	Yes	No
	Review of blood glucose monitoring diary	Yes	No
	Height	Yes	No
	Weight	Yes	No
	BMI	Yes	No
	Waist Circumference	Yes	No
	Blood Pressure	Yes	No
Blood Tests:	Fasting Glucose	Yes	No
	Random Glucose	Yes	No
	HbA1c	Yes	No
	Serum creatinine	Yes	No
	Lipids Dipstick	Yes	No
Urinalysis	Microalbuminuria	Yes	No
	Albumin: Creatinine Ratio	Yes	No
	Dietary Review	Yes	No
	Smoking status Aspirin	Yes	No
	therapy status	Yes	No
	Statin therapy status	Yes	No
	Foot examination	Yes	No
	If yes please give details:		

Eye examination:	Eye examination by GP	◯ Yes	◯ No
	Eye examination by a Community Opthalmic Physician (COP)	◯ Yes	◯ No
	Referral to an Opthalmic Surgeon or Medical Ophthalmologist	◯ Yes	◯ No
	Referral to an Optician/Optometrist	◯ Yes	◯ No
	Examination as part of a screening programme	◯ Yes	◯ No

Other tests & procedures; please specify	

Q20. When do patients have their bloods taken for their diabetic review?

◯ Prior to Review

◯ At the time of review

Q21. Are patients taught how to adjust their insulin treatment in the practice?

◯ Yes ◯ No

Q22. Is there space in your premises for display of educational/ health promotional materials for diabetes in your practice?

◯ Yes *CONTINUE* ◯ No *GO TO Q23*

A. If yes, what materials are currently available in your practice? *(Shade all that apply).*

INFORMATION

Posters

◯ Produced by the practice

◯ Produced by a commercial company

◯ Produced by Diabetes Federation of Ireland

◯ Produced by another organisation

◯ None

Continued on the next page...

INFORMATION

Booklets/Leaflets

- ◯ Produced by the practice
- ◯ Produced by a commercial company
- ◯ Produced by Diabetes Federation of Ireland
- ◯ Produced by another organisation
- ◯ None

Videos

- ◯ Produced by the practice
- ◯ Produced by a commercial company
- ◯ Produced by Diabetes Federation of Ireland
- ◯ Produced by another organisation
- ◯ None

Q23. Do you provide membership forms for the *Diabetes Federation of Ireland*?

◯ Yes ◯ No

Q24. Do you routinely provide patients within your practice with contact details for the hospital based diabetes team?

◯ Yes ◯ No

Q25. How do you manage a newly diagnosed (by you) Type 2 diabetic patient e.g. referrals, tests etc?

Would you refer right away?	◯ Yes	◯ No
Would you work up and refer right away? Would	◯ Yes	◯ No
you manage the patient in your practice until the need arises for additional care?	◯ Yes	◯ No

Screening

Q26. Do you screen patients for diabetes in the practice? (That is people without symptoms of the target disorder)

◯ Yes *CONTINUE* ◯ No *GO TO Q30*

Q27. If yes, which <u>factors</u> do you consider when screening your patients for diabetes?

Age	◯ Yes	◯ No
Ethnic Origin	◯ Yes	◯ No
Obesity	◯ Yes	◯ No
Patients with Hypertension	◯ Yes	◯ No
Family history of diabetes	◯ Yes	◯ No
Patients with ischaemic heart disease	◯ Yes	◯ No
Patients with peripheral vascular disease	◯ Yes	◯ No
Patients with cerebrovascular disease	◯ Yes	◯ No
Patients with recurrent infections (thrush/skin infection/recurrent UTI)	◯ Yes	◯ No
All pregnant women	◯ Yes	◯ No
Women with a history of gestational diabetes	◯ Yes	◯ No
Patients who have had a baby >4kg	◯ Yes	◯ No
If other please specify	◯ Yes	◯ No

Q28. If yes, what <u>tests</u> do you use when screening your patients for diabetes?

Urinalysis	◯ Yes	◯ No
Random capillary glucose	◯ Yes	◯ No
Fasting capillary glucose (using a glucose meter)	◯ Yes	◯ No
Random venous glucose	◯ Yes	◯ No
Fasting venous glucose	◯ Yes	◯ No
Glucose tolerance testing in the practice	◯ Yes	◯ No
Refer to hospital	◯ Yes	◯ No

Q29. How often does your practice re-screen patients with an increased risk of diabetes? *(Shade whichever applies)*

- ◯ Never
- ◯ Quarterly
- ◯ Bi Annually
- ◯ Annually
- ◯ Other

If other please specify

3. USE OF SERVICES

Q30. Do you have direct access to dietician services?

◯ Yes *CONTINUE* ◯ No *GO TO Q31*

A. If yes, do you routinely refer your patients with diabetes to this service?

◯ Yes *CONTINUE* ◯ No *GO TO Q31*

B. If yes, how long do these patients usually have to wait for an appointment? *(Shade whichever applies)*

- ◯ <1 Week
- ◯ <1 Month
- ◯ 1-3 Months
- ◯ 4-6 Months
- ◯ Other

If other please specify

Q31. Do you have direct access to chiropody services?

◯ Yes *CONTINUE* ◯ No *GO TO Q32*

A. If yes, do you routinely refer your patients with diabetes to this service?

◯ Yes *CONTINUE* ◯ No *GO TO Q32*

B. If yes, how long do these patients usually have to wait for an appointment?
(Shade whichever applies)

- ◯ <1 Week
- ◯ <1 Month
- ◯ 1-3 Months
- ◯ 4-6 Months
- ◯ Other

If other please specify:

Q32. Do your patients have access to a systematic population based retinal screening programme? (i.e. they are called and recalled on a planned basis).

◯ Yes *CONTINUE* ◯ No *GO TO Q33*

A. If yes, do you provide patient names for call and recall? ◯ Yes ◯ No

Q33. Do your patients have access to ophthalmic examination by:*(Shade all that apply)*

Community Ophthalmologists	◯ Yes	◯ No
Community Ophthalmic Physician	◯ Yes	◯ No
Ophthalmic surgeon	◯ Yes	◯ No
An Optician/Optometrist	◯ Yes	◯ No

A. If yes, do you routinely refer your patients with diabetes to this service?

◯ Yes *CONTINUE* ◯ No *GO TO Q34*

B. If yes, how long do these patients usually have to wait for an appointment?
(Please shade whichever applies).

- ◯ <1 Week
- ◯ <1 Month
- ◯ 1-3 Months
- ◯ 4-6 Months
- ◯ Other

If other please specify

Q.34 Do you refer the following patients to your local hospital based specialist team?
(Please shade the appropriate circles)

Transition to insulin in Type 2 diabetics	◯ Always	◯ Sometimes	◯ Rarely/Never
Any child with a suspected diagnosis of diabetes	◯ Always	◯ Sometimes	◯ Rarely/Never
Women with gestational diabetes	◯ Always	◯ Sometimes	◯ Rarely/Never

If other please specify:

Q35. If you have a patient with type 2 diabetes whom you think requires insulin, do you?
(Please shade the appropriate circles).

a). Refer to hospital.	◯ Always	◯ Sometimes	◯ Rarely/Never
b). Initiate therapy in your practice.	◯ Always	◯ Sometimes	◯ Rarely/Never
c). Initiate therapy in your practice depending on patient characteristics.	◯ Always	◯ Sometimes	◯ Rarely/Never

If you initiate therapy in your practice depending on patient characteristics, please specify relevant patient characteristics;

Q36. Do you use guidelines for the care of your patients with diabetes?

◯ Yes *CONTINUE* ◯ No *GO TO Q37*

A. If yes, which guidelines do you use?

Q37. Does your practice have a formal shared protocol with your local hospital based specialist diabetes team?

◯ Yes ◯ No

Q38. Has your practice <u>ever</u> held a joint meeting with the hospital based diabetes team?

◯ Yes ◯ No

Q39. Do you have <u>regular</u> joint meetings with the hospital based diabetes teams?

◯ Yes *CONTINUE* ◯ No *GO TO Q40*

A. <u>If yes</u>, how often are these meetings held?

◯ <1 Month
◯ 1-3 Months
◯ 4-6 Months
◯ 7-12 Months
◯ >12 Months
◯ Other

If other please specify;

Q40. Is your practice or are any health professionals in your practice members of the Diabetes Federation of Ireland?

◯ Yes ◯ No

4. OPPORTUNITIES IN DEVELOPING DIABETES CARE

Q41. What do you see as the principal opportunities for developing diabetes care in your practice?

*Please shade **3** from the following that you consider the most important;*

GP/Practice nurse training in diabetes care ○

Access to phlebotomy services ○

Easier access to specialist diabetic advice ○

Access for all diabetic patients to free GP care ○

Increased access to community services e.g. chiropody ○

Local guidelines on diabetic care ○

Easier access to laboratory results ○

Other, please specify ○

Q42. How do you think you should be remunerated for providing diabetic care?
*(Please shade **1** only)*

Grant to a practice ○

Target driven payments ○

Fee per patient episode ○

Capitation grant ○

Mixture of capitation & fee for item ○

Q43. We welcome your insight into diabetic care and thus any comments/suggestions for improvements you have are appreciated whether positive/negative;

9063237325

To allow the ICGP to follow up on non-responses, they will assign a unique ID number to each survey. This link will be held by the Irish College of General Practitioners (ICGP) and will not be passed on to the project researchers or anyone else involved in the project. All the information from the survey will be treated as strictly confidential. The final report will present aggregate anonymous data.

This national survey will be followed by a qualitative study investigating the provision of services in more detail. If you are happy for your practice to be contacted by research staff for an interview or to take part in a focus group, please complete the section below. Alternatively you can complete and return the enclosed name and address card to ICGP.

NAME: _____

ADDRESS:

PHONE NUMBER

EMAIL ADDRESS

THANK YOU FOR YOUR TIME. GO RAIBH MILE MAITH AGAT.

10.5 Appendix V: Questions contained in shortened GP Follow-Up Questionnaire

1. How many doctors are in the practice *(Q2)*
2. Do you have a practice nurse *(Q4)*
3. Does you practice have a computer system *(Q5)*
4. If yes which computer system
5. Is there a diabetes module on your computer system*(Q6)*
6. If yes is this module used
7. Do you maintain a diabetes register *(Q9)*
8. Are there any professionals in your practice with a special interest in diabetes *(Q13)*
9. What is your total patient population *(Q8)*
10. What is the estimated number of individuals known to have diabetes *(Q10)*
11. Does your practice hold specific clinics for diabetes patients *(Q16)*

10.6 Appendix VI: GP Survey open-ended responses

This section presents the main themes emerging from the open-ended responses contained in the questionnaire.

A. Caring for patients with diabetes in nursing homes/residential care

Respondents had the opportunity to expand on the issue of patients in nursing homes and residential centres. Out of the 262 respondents, 77 completed this open ended section (29% of sample). A distinction was made between comments on care (Table 58a) and suggestions to enhance care (Table 59a).

Table 58a Comments on providing diabetes care to patients in nursing comes

Theme	References	(% of respondents to Q)
Unique patient group	9	13
Protocols for providing care	7	10
Providing care for patients in the practice	5	7
Nurse visit nursing home	5	7
Patients require specialised care outside practice	3	4.5
Funding issues	3	4.5
Difficulties carrying out routine blood work	2	3
Nursing home providing care	2	3
No electronic system, difficult to audit	2	3
Replication of notes a big challenge	1	1
Practice time constraints	1	1
ICGP guidelines good for bed bound patients	1	1

Table 59a Suggestions on providing diabetic services to patients in nursing homes/residential care

Theme	References	(% of respondents to Q)
Protocol & training for nursing home staff & nurses	8	11
Community diabetes nurse	5	7
Visiting specialists needed	3	4.5
GP protocols	3	4.5
Training in diabetes	2	3
Appointment of specific medical officer Diabetic registrar to care for nursing home patients	2	3
Community ophthalmologist	1	1
Diet could be managed	1	1
Financial resources needed	1	1
	1	1

Nursing home liaise with Specialist Portable HbA1c machine	1	1

B. Using the practice computer

To record other reports

Regarding the storage of reports other than those listed in the questionnaire, a number of additional responses were elicited. Out of the 262 respondents, 110 completed this section (42% of sample) (Table 60a).

Table 60a Use of Practice Computer: Storing other reports

Sources of other reports	References	(% of respondents to Q)
Medical-legal insurance	35	32
Practice management	20	18
Clinical medical	17	15
Administrative	15	14
PMAs	11	10
A Paperless practice	7	6
Department of social welfare	4	4
GP support	1	1

To make other claims

Respondents outlined the other claims that were recorded on the practice computer. Out of the 262 respondents, 67 completed this section (26% of the overall sample).

Table 61a Use of Practice Computer: To make other claims

Making Claims	References	(% of respondents to Q)
Vaccines	18	27
Immunization	15	22
Practice system	7	11
Billing	6	9
'Heart Watch' initiatives	5	8
Health insurance	5	8
Methadone treatment scheme	4	6
STC	3	5
Barrier to technology and registry	1	1
Family planning	1	1

Palliative care claims	**1**	**1**
State benefits claims	**1**	**1**

To record other forms of systematic care of patient groups

Respondents had the opportunity to outline the other forms of systematic care that their practice computer was used for (Table 62a). Out of the 262 respondents, 134 completed this section (51% of the overall respondent sample).

Table 62a Use of Practice Computer: Recording other forms of systematic care

Other forms of systematic care	References	(% of respondents to Q)
Diabetes care & endocrine	23	17
Gynaecological maternity	22	16
Clinics	16	12
Vaccinations	16	12
Lung asthma Respiratory	11	8
Immunizations	6	4.5
Postnatal and children	6	4.5
INR	5	4
Coagulation	5	4
Coronary	4	3
Particular practice protocols	4	3
Sexual health	4	3
Paperless practice	3	2
Family planning	3	2
Heart Watch	2	1
Family history and personal info	1	1
General observations	1	1
Health promotion	1	1

C. Receiving electronic reports

Respondents had the opportunity to outline the other hospital departments they received electronic reports from (Table 63a). Ten percent of the overall sample gave examples (n=25). Six percent (n=15) elaborated on receiving electronic reports from consultants (Table 64a).

Table 63a Receiving electronic reports from other sources

Other sources	References	(% of respondents to Q)
OPD	8	32
Specific Hospitals	4	16
Specialist medicine i.e. consultants	3	12
GP network groups	3	12
A&E	3	12
Laboratories	2	8
Do not receive electronic reports	2	8

Table 64a Receiving electronic reports from consultants

Consultants	References	(% of respondents to Q)
Receiving electronic correspondence	3	20
Receiving electronic reports	3	20
Not offered by any consultants	2	13
Received from Dublin hospitals	2	13
Geriatric medicine	1	7
Neurology	1	7
Out-patient departments	1	7
Patient reports	1	7
X rays	1	7

Replacing paper records in favour of electronic records

Seventy respondents reported other types of records replaced in favour of electronic (27%) (Table 65a).

Table 65a Replacing paper records for electronic reports

Theme	References	(% of respondents to Q)
Paperless practice	15	22
Medico-legal	6	9
Mixed paper & electronic reports	5	8
Referral letters	4	6
Specialist reports	4	6
Immunisations	3	4
Patient reports	3	4
Personal Medical Assessments	3	4
Accounts	2	3
Back-up hard copies	2	3
Hospital letters	2	3
Maternity records	2	3
Medical certificates	2	3
Prescriptions	2	3
Social welfare	2	3
Vaccinations	2	3
Personal injuries reports	1	1
Receipts	1	1
Use computer for audit	1	1

D. Formal call and recall system

Of the 262 respondents, 30 provided additional comments on recalling patients for review and the frequency of review (11% of sample) (Table 66a).

Table 66a Comments on recalling patients for review

Recalling patients	References	(% of respondents to Q)
Recall for Annual review	6	20
Recall Biannually	3	10
As required	3	10
Recall unstable patients	3	10
Depends on HbA1c	2	7
Diabetes recall system but ceased now	1	3.3
Part of Diabetes watch programme	1	3.3
Monthly recall	1	3.3
New patients	1	3.3
No practice standard	1	3.3
OPD_diabetes clinic recall	1	3.3
Practice & hospital visits	1	3.3
Practice clinic not helpful	1	3.3
Prescription review	1	3.3
Public and private patients differ	1	3.3
Recall system problems	1	3.3
Review patient, not recall	1	3.3

E. Routine check-up procedure

Respondents were provided with the opportunity to expand on the details of foot examinations. Overall 171 respondents completed this open ended section (65% of the overall respondent sample).

Table 67a Comments on foot examination & how it is conducted

Delivering foot care to patients with diabetes	References	(% of respondents to Q)
Part of practice clinical exam	105	61
Provided by Chiropody service	18	11
Occasional opportunistic check ups	12	7
Annual check-up	12	7
Question & answer time for patient and education	8	5
Practice nurse providing care	5	3
Specialists visit the practice	4	2
Diabetic clinic OPD providing foot care	3	2
Diabetes podiatry clinic local hospital	2	1

As part of this question GPs had the space to outline other tests and procedures they had performed in the practice as part of the routine check-up of patients with diabetes. Out of the 262 respondents, 58 completed this open ended section (22% of sample).

Table 68a Other tests/procedures carried out in routine check-up

Tests & Procedures	References	(% of respondents to Q)
Referrals to Neurologist	7	12
Clinical and medical examinations	6	10
Referral to Endocrine/endocrinologists	6	10
Eye examinations	6	10
Retinal screening	6	10
Chiropody	5	9
Annual review	4	7
Optician	3	5

Diabetes Watch	3	5
Mobile screening programmes	3	5
Diabetes clinics	2	3
Education and advice	2	3
Retinopathy programmes	2	3
Vaccines	2	3
ECG	1	1
Hospital review	1	1
Ophthalmology	1	1
Podiatry	1	1
Unstructured review	1	1

F. Professionals with a special interest in diabetes

Of 262 respondents, 38 provided detail on individuals in the practice who had a special interest in diabetes care (15% of sample) (Table 69a).

Table 69a Professionals with a special interest in diabetes

Professionals with a special interest	Total N	(%)
Dietician	11	29
Specialist nurse	10	26
No professional	5	13
Chiropodist & podiatrist services	4	11
GP registrar	3	8
GP in practice	2	5
All Practice GPs	1	3
Practice nurse	1	3
Shared care with hospital specialist nurse	1	3

G. Screening

Table 70a outlines the factors considered when screening patients for diabetes in the practice (19%, n=51). Respondents also elaborated on the re-screening of patients for diabetes (20% of the sample, n=53) (Table 71a).

Table 70a Additional factors considered when screening for diabetes

	Total N	(%)
Renal failure/problems	17	32
Over 45 years old	4	8
Patient requests	4	8
Thyroid dysfunction	3	6
Eye disease	3	6
Fatigue	3	6
Steroid use	3	6
BMI	2	4
Neurological symptoms	2	4
PCOS	2	4
Current medications	1	2
Erectile dysfunction	1	2
Haemochromotosis	1	2
Menopause	1	2
Liver disease	1	2
Recurring infection	1	2
Routine blood tests; well person check ups	1	2
Visual problems	1	2

Table 71 Rescreening patients with an increased risk of diabetes

	Total N	(%)
Opportunistic	31	58
Annual/Biannually	7	13
Risk factors	6	11
Every 2 years	4	8
No policy or protocol	3	6
Age dependent	1	2
Impaired glucose tolerance	1	2

H. Access to diabetes related services

A number of GPs commented on the specific waiting times for appointments with dieticians, chiropodists and ophthalmology services. The responses were quantified and combined with the frequency analysis in the results section. Remaining responses relating to access to dieticians (8%, n=20), chiropodists (10%, n=25) and ophthalmology examination (12%, n=32) were coded and are outlined in Table 71a.

Table 72a Open-ended responses on access to services

Dietetics	N (%)	Chiropody	N (%)	Ophthalmology	N (%)
Waiting List	16 (80)	Waiting list	13 (52)	Waiting List	23 (72%)
Public vs. Private	5 (25)	Public vs. Private	6 (24)	Public vs. Private	6 (19)
Community dietetics service	3 (15)	Other	4 (16)	Access	4 (13)
Patient factors	3 (15)	Variation in availability	4 (16)	Inconsistent service	3 (9)
Other	1 (5)	No service	3 (12)	Hospital based (service)	2 (6)
Effort to reduce waiting list	1 (5)	Public service	3 (12)	Lack of resources	2 (6)
Heart Watch	1 (5)	Diabetes Watch	2 (8)	Other	2 (6)
Hospital service	1 (5)	In practice (service)	1 (4)		
No replacement	1 (5)				

I. Referral to hospital based specialist team

A number of GPs elaborated on the referral of specific patient groups to the local hospital based team (n=15, 6%) (Table 73a).

Table 73a Comments on referral to the local hospital specialist

Theme: Patient Groups	N	%
Gestational	7	47
Patients with inadequate control	3	20
Newly diagnosed patients	3	20
Patients who are insulin dependent	2	13
Patients with Type 1 diabetes	2	13
Patients with complications	2	13

J. Characteristics considered when initiating insulin

Of the total sample, 34 GPs offered examples of characteristics considered when deciding to initiate insulin therapy in practice (13%, n=34). The emergent themes are outlined in Table 74a

Table 74a Characteristics considered when initiating insulin

Patient factors	N	%
Understanding	12	35
Stability	8	24
Compliance	7	21
Motivation	6	18
Ability to administer	6	18
Age	6	18
Education	5	15
Other	5	15
Complications	4	12
Co-morbidities	3	9
Ability to monitor	3	9
Support	3	9
Eye sight	3	9
Medication	3	9
Confidence	2	6
Reluctance to go to hospital	2	6
Able to attend practice	2	6
Advice from DNS	2	6
Knowledge	2	6
Access to hospital	1	3
Ethnicity	1	3
Co-operation	1	3

K. Regular meetings with the hospital based team

Eleven respondents offered comments on local arrangements with the hospital team or lack thereof (4%). Table 75a outlines the themes emerging from GPs opinions on contact with local hospitals.

Table 75a Comments regarding contact with the local hospital based team

Theme	N	%
Link between practice & hospital	5	45
No contact	4	36
Lack of resources	2	18
Information sharing	2	18
Informal arrangement	2	18
Engagement with specialist nurse	2	18
Waiting list	1	9
Reduced services (hospital)	1	9
Lack of interest	1	9

L. Principle opportunities for developing diabetes care.

When asked to choose the principal opportunities for developing diabetes care, almost 20% of GPs offered additional comments (18%, n=46) (Table 76a).

Table 76a Themes on the principal opportunities to develop care

Theme	References	% of Total References
Shared care	11	24
Dietician Access	8	18
Protocols	7	16
Remuneration	7	16
Ophthalmology	5	11
Resources	5	11
Dedicated nurse	4	9
Positive feedback	4	9
Hospital services	3	7
Screening	3	7
Podiatry	2	4
Time	2	4
Patient Education	1	2

M. Development of Diabetes Care

Respondents were asked for suggestions on ways to improve diabetes care in Ireland. Most elaborated on issues raised in the previous questions thus there is substantial overlap in the themes (n=93) (Table 77a).

Table 77a Comments/suggestions for improvements to diabetes

Theme	References	% of Total References
Incentives	27	29
Shared Care	24	26
Lack of Resources	20	22
Community Services	20	22
Secondary Care	18	19
Workload	15	16
Time	14	15
Balance between primary & secondary care	13	14
Clinics	11	12
Local Initiatives	11	12
Nursing staff	9	10
Positive aspects of care delivery	9	10
Support/help	9	10
Manpower	8	9
Technology	7	8
Training/education	6	7
Enthusiasm/Interest	5	5
Funding	5	5
Practicalities of delivering care	4	4
Prevention	4	4
Referrals	4	4
Specialist care	4	4
Patient behaviour/attitudes	3	3
Patient education	3	3
Recall/review	2	2

10.7 Appendix VII: Ethical Approval for GP Survey

icgp

Irish College of General Practitioners
5/6 Lincoln Place
Dublin 2

Prof. C. Bradley
Dept of General Practice
University College Cork

25/4/8

Re: Towards a National Diabetes Register for Ireland: Theory, Practice & Policy.

Dear Professor Bradley,

I write to inform you that on foot of the Research Ethics Committee Meeting of April 16th, the committee are happy to approve the GP Questionnaire Survey phase of this study.

Yours sincerely

Niall Maguire.

Dr Niall Maguire
Chair
ICGP Research Ethics Committee

10.8 Appendix VIII: Topic Guide for Qualitative Study

Diabetes Care Delivery; Barriers & Facilitators

Objectives of Interview

1. To explore GPs perspective on delivering diabetes care at present.

2. To elucidate models of care; practice procedures, links with secondary care, use of services.

3. To determine barriers and facilitators to delivering optimal diabetes care

4. To explore previous experiences of change within the health system

5. To assess attitudes to quality improvement, in particular attitudes to developing a national diabetes register and conducting audit.

Introduction (Script Sheet)

- Introduce the National Diabetes Register Project (information sheet)
- Confidentiality; the use of quotations (consent form)
- Recording and timing

Overview of Interview Topics

➔ Current care organisation

➔ Changes/Improvements that have been made

➔ How can care be improved?

➔ Establishing a register

➔ Ideal scenario

1. **Current Situation**

Get GPs talking about their experiences…

- **How do you currently manage your patients with diabetes?**
  - *Diabetes management relative to other illnesses in general practice*

    [Scale of problem, time taken to manage, workload; particular challenges of diabetes relative to other problems at GP level]
  - *How care is organised (model: involvement in shared care schemes etc)*

    [Feasibility, why does it (not) work?]
  - *Balance of care across settings (ownership)...*
  - Advantages/disadvantages of the GP setting

2. **Change**

Explore attitudes to change at a local and national level (may not necessarily be improvement)

- **What, if anything, has changed in the how care is delivered in your practice/locally/nationally?**
  - Dealing with barriers to change in care delivery
  - Facilitators/necessary conditions
  - Sustaining change/improvement

3. **Delivering Diabetes Care: Barriers & Facilitators**

→ *Explore barriers and facilitators → Introduce CHECKLIST?*

- **Check List - derived from GP survey**

Factors Influencing Diabetes Care	**Facilitators**	**Barriers**
Incentives		
Remuneration		
Shared care[2]		
Secondary care services		
Specialist community services		
Resources		
Time		
Workload		
Additional factors		

4. **Diabetes Register**

- Establishing a register: current use of a register & its maintenance

  ↳ Setting up a national register: what are the issues

  [IT, shared care, pathways of information, data extraction, coding, indicators]

  ↳ Advantages of regional vs. national register

5. FUTURE DEVELOPMENT

- **Wish-list for delivering care** to patients with diabetes (ideal world)

  ↳ How should care be delivered…?

  ↳ What needs to change? (attitudes)

  ↳ Thoughts for the future of diabetes care…

[2] For our information- prompt interviewee regarding the concept of sharing, sharing information etc.

10.9 Appendix IX: Prompt (modified checklist) used in interview

Factors influencing the delivery of care

Based on your experience, please indicate how the following factors promote and/ or inhibit efforts to provide and improve care.

- Incentives
- Remuneration
- Shared care arrangements
- Secondary care services
- Specialist community services
- Resources
- Time
- Workload
- Additional factors....

10.10 Appendix X: Invitation Letter for Qualitative Study

Ollscoil na hÉireann, Gaillimh
National University of Ireland, Galway

ucc
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Dear Dr X

Re: Qualitative study of diabetes care delivery in general practice

We are contacting you as part of a Health Research Board (HRB) funded project that is preparing the groundwork for the development of a National Diabetes Register in Ireland.

You may recall completing a survey on diabetes care during the summer of 2008, administered through the ICGP. Upon completing the survey you provided your contact details to indicate willingness to be contacted regarding a qualitative follow-up study. We would value the opportunity to discuss your experience of delivering diabetes care and to discuss the barriers and facilitators to improving the quality of care. We envisage that this research will inform future planning of diabetes services in your area and on a national level.

The interview will last approximately 20 minutes. We appreciate that you are very busy. Therefore, the researcher will arrange to visit your practice at a time that is most convenient to you. We will contact you shortly to see if you would like to be involved in this study and arrange a suitable time for the interview. If you decide to take part we will forward you an outline of the topic guide prior to the interview. We hope that you can find the time to participate. Any identifiable information will be kept confidential and only anonymous data will be reported. A summary of the findings will also be provided to each GP for his/her own information. You are free to withdraw from the study at any time.

If you require any further information regarding this project please contact Monica O'Mullane on 021-4205254 (email m.omullane@ucc.ie) or Sheena McHugh on 021-4205253 (email s.mchugh@ucc.ie).

Yours sincerely
Professor Colin Bradley
University College Cork



10.11 Appendix XI: Consent form &Information Sheet for Qualitative study

CONSENT FORM

Title of Study: Qualitative Study of Diabetes Care Delivery in General Practice.

Consent of Research Participant:

I_____of _____ agree to participate in the research study outlined by_____. The researcher has explained the objectives of the study to me and I understand its purpose. I understand that this study is for the advancement of health care and I am free to withdraw at any time.

- I give permission for my interview with_____to be tape-recorded ☐
- I understand that anonymity will be ensured in the write-up of the results by disguising my identity. ☐
- I understand that anonymous extracts/quotes from the interview may be used in the thesis and any subsequent publications. ☐
- I agree to quotation/publication of anonymous extracts from my data ☐

Signature of research participant:_____ Date: _____

Signature of Witness: _____ Date: _____

I confirm that I have explained to _____ the purpose and nature of this investigation and the risks involved.

Signature of researcher: _____ Date: _____

INFORMATION SHEET

Many thanks for agreeing to take part in an interview for the qualitative study of diabetes care delivery in general practice. Before giving written consent it is important for you to be aware of what will be involved. Please take the time to read the following information and ask me if there is anything that is not clear or you would like further detail.

What is this study for?

This study is part of a programme of work being undertaken by the National Diabetes Register Project and funded by the Health Research Board (HRB). The project is exploring key issues that need to be understood before a national diabetes register can be successfully implemented. This proposed register would be used to drive forward improvements in the quality of diabetes care in Ireland. This qualitative study will lead to a better understanding of diabetes management in general practice and the barriers and facilitators to improving the quality of care.

What is involved?

The interview will last approximately 25 minutes. If it is agreeable with you, the interview will be recorded by the researcher

What about confidentiality?

All information obtained during the study will be strictly confidential. All identifiable information will be removed from interview transcripts and a study ID number will be assigned to your tapes and transcripts to maintain anonymity. Participants will be given the opportunity to review the transcripts and tapes will be destroyed after recordings have been validated by the participant. Only investigators named on this information sheet will have access to the data and it will be stored securely for 5 years after completion of the study.

What will happen with the results of this study?

The findings of this study will be written up for the HRB report and subsequent publications. The results will also be compiled and submitted as part of a PhD thesis. In all cases only anonymous extracts or quotes will be reported. Copies of the findings will be made available to participants.

Who has reviewed this study?

The proposal for this research was reviewed by (*the ethics committee of the Irish College of General Practitioners*).

If you decide to take part you will be given this information sheet to keep for your own records and be asked to sign a consent form. You are free to withdraw at any time. If you have any concerns after the interview, please do not hesitate to contact the researchers who will do their best to answer your questions.

Thank you for taking the time to read this information.

Lead Investigators: Prof. Colin Bradley (UCC), Dr Velma Harkins (Midlands Structured Diabetes Care Programme), Dr Sean Dinneen (NUIG), Prof Ivan Perry (UCC)

Contact for further information

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10.12 Appendix XII: Use of Memos in Analysis

Memos were written throughout the study but were most informative during the analysis phase. Included here are a number of examples of memo writing and how they informed the development and refinement of themes. The examples are based on a typology of recommended categories to reflect on (178). The early memos (Example 1) are free-flowing and suggestive. These are followed by examples of how memos led to the development and refinement of themes (Example 2 and 3).

Example 1: Early Memos written on individual transcripts:

- **Reflection on personal connection and ethical dilemma raised by study;**

"Luck"> GP103 talks about being lucky to have good relationship with hospital, lucky to receive care close by (p4). Shouldn't this be standard rather than luck? Do other GPs feel lucky or cheated even? (18.02.10)

"Luck implies almost a passive role by the GP when this is not really the case for GP103 (involved in setting up a shared and then structured care programme). Do you make your own luck? Is some care down to circumstance i.e. what GP you get, where you live even within the one city? Mentions proximity of services vs. contrast to distance facing patients of GP101

→Death by geography has been mentioned in the Irish health system before in relation to relocation of cancer services in the North West (home). Not necessarily death for diabetes patients but perhaps quality of care determined by geography? Some patients don't know how good it could be…Should they know the ideal standard of care if they are not receiving it..

- **Emergent patterns in data**

Register> GP103- I mentioned patient identifier not the GP, would they have considered this an issue otherwise? Vague responses to register questions. Note as you go along- did GPs have more questions than answers about register? (18.02.10)- Theme in itself

- **Emergent dichotomy between themes**

Recall> GP115 – Overlap with other GPs=reliant on patient to come back when appropriate, tries to avoid reminders (p3). This raises the idea that reminders take away from personal responsibility. Is there a danger that too much structure and support has a negative impact as patients become complacent and it reduces personal responsibility? But then this GP goes on to suggest that if she had a nurse she could have reminders, so is the barrier 1) personal attitude to responsibility for chronic illness 2) organisational issue of manpower, time etc. Different strategies would be required to tackle different barriers.

- **Contrast between themes**

Level of detail on provision of care> Nurse 104> Initial thought after reading transcript; emphasis on patient, paraphrasing patients, familiarity suggests regular contact and close relationship. Emphasis on support of GP i.e. supporting her work in clinics. Gives much more detail on the process of care and how it is delivered compared to GP102 for example – reflects engagement and involvement in provision. →Note: models may reflect the involvement of GP/Nurse in care delivery- how much do they know about it? (21.02.10)

←**Unfamiliar with patient hurdles** > GP115 – GP seems unfamiliar with hurdles facing patients e.g. doesn't know about chiropody services, presumes probably correctly that the hospital clinics are massive (p5). Model of care diagram is quite empty compared to others. I would have to question some GPs closeness to the delivery process. Lack of GP awareness could be a barrier for the patient and a barrier to better care.

- **Use of Language**

Heart Watch > GP106- Note language around Heart Watch is flexible = "framework", "type". A management programme as a guide or foundation rather than an enforced rigid structure (p4) (25.02.10)

Emergent theme: tentative attitude towards improvement initiative

Benefits of a register > 107> p9- Very unsure of benefits. Similar to other GPs vagueness and hesitation. Not proposing any benefits rather saying if reason/benefit then yes GP would support.

Reason + benefit = necessary conditions for buy-in. IF→THEN conditional statement

I propose planning services using a register; GP took opposite negative view of taking services away. Why? Past experience with surgical services, burned before. Suspicious? Antonym of allocation = take away, withhold. Synonym for 'take away' = downgrade, term used by the HSE.

- **Problems with study (data collection) and its role in the response of GP**

"Nature of General Practice" < GP114 – This could be a main theme. GP talks about chaotic nature of practice, previously had to cancel interview when I was in the practice because of an emergency. It has both advantages and disadvantages as a setting – it can be a barrier or a facilitator. GP as a setting emerging from the data, not on the prompt list. It is an environmental/cultural factor maybe; the culture of general practice to deal with all ailments.

- **Emergent or related existing theory**

Role of audit > GP108> seems to suggest audit is part of moral role of GP. What is a "real doctor", should audit be part of competencies? Look up literature around attitudes to audit and professionalism (29.03.10).

- **My research question**

Checklist > GP105 speaks mostly in the conditional tense, doesn't give me a sense of what his barriers are in reality. There is a mixed approach to the checklist. GP105 offered barriers and facilitators for each factor e.g. barriers to shared care are lack of communication systems. Other GPs have suggested which factors act as barriers or facilitators e.g. services are a barrier because they are hard to access. The latter approach addresses my research question 'what are the barriers and facilitators to providing care' rather than what are the barriers and facilitators to x, y and z. Perhaps change the checklist to a prompt… (27.03.10)

- **Social context of interviews and themes**

Financial context of interviews> GP112> refers to McCarthy report. He is discussing the feasibility of tendering for services. Is that like commissioning in the UK? The Mc Carthy report proposes to put out to tender services for GMS patients (dismantling the current contract) and introducing competition between GPs. The IMO are against this proposal. (20.04.10)

- **Final report of study & an emergent distinction**

Organising themes> Barriers to Quality of care (availability of services) vs. Barriers to Quality Improvement (incentives, attitudes to audit and registration). Is this a real distinction? Although there is overlap the attitudes to registration reflect broader concerns and scepticism of the GPs towards initiatives. Is it a necessary distinction? Provision and quality improvement/quality assurance should ideally go hand in hand but this is not always the case. Services may not be provided by the system (recruitment freeze) but there may still be efforts to reorganize practice for example.

<u>Example 2: Memos used to development of themes</u>

Memo: Nurse as a key ingredient (facilitator) for delivering optimal diabetes care in a structured way.

The nurse's role is central to adopting a structured approach to diabetes care in general practice i.e. organizing and delivering systematic and regular care to patients. The role of the nurse was intertwined throughout GP accounts of how care is delivered and the division of labour within the practice. Even those GPs who did not have a nurse in the practice noted the absence and suggested ways in which having a nurse could advance care.

→Theme=Presence of nurse facilitates the provision of structured regular diabetes care

Instances from memos on individual transcripts

- 14.02.10. GP101> Impact of not having practice nurse

The GP spoke about having changed nurses. The previous nurse had experience of running the Heart Watch programme in the practice. When this nurse left diabetes care "came back to an ad hoc thing" = regressed suggested a nurse is central to maintaining organisation and improving. The Practice Nurse was central to making Heart Watch programme work as it was problematic. When she left they "opted out". There appears to be a continuum of support for the GP from none to expert.

- 21.02.10> Nurse 104> Life before the nurse

Before PN it wasn't physically possible to develop a structured approach to diabetes but when the PN joined it facilitated change. The GP had own idea of what they wanted ≈plan is not always feasible until right/necessary factors are in place. This elaborates the role of the nurse to facilitating change also. [Note: Distinction between practical or physical barriers and attitudinal barriers.]

Emergent theme

- 30/04/10 > After grouping the individual codes together under 'Provision of Care', it was evident that the nurse was central within a number of provision codes (recall and the division of labour). For example the presence or absence of the nurse seems to facilitate regular recall. Furthermore the role was cited explicitly as a resource by some participants when discussing the barriers and facilitators to care provision. There was a sense from the accounts that something's are impossible or more difficult without a nurse.

➔ It felt contradictory to separate out the presence of the nurse as a facilitator given how the role was interwoven through GPs accounts. To reflect this thread of the nurse enabling delivery, I will highlight the areas where the nurse enables care as I go along and include the nurse's role as a feature of structured care.

Memo 3: Time

Drafted 29.04.10: following analysis of each interview looking across emergent themes.

➔ Time emerges in a number of contexts– importance of time in diabetes management

Memos on individual GPs:

21.02.10> Nurse 104: Emphasizes timing throughout> how long everything takes, waiting time etc. Refers to time patient is left on his/her own dealing with illness waiting for services (p3) [Time]. Diagnosis "kicks in" and thus is an important time point for patient and for intervention, clock starts for management once patient is diagnosed. Diagnosis is a window of opportunity to lay down foundation of

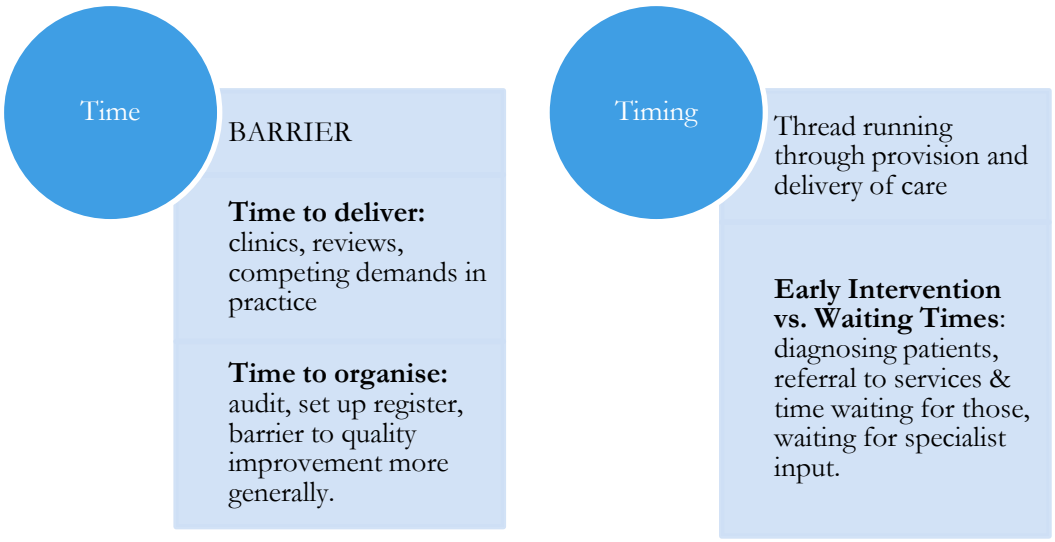
management – services etc [Timing]. Emphasizes that she refers immediately as she knows they will be ***waiting*** a while.

03.03.10> GP107- time pressures of Heart Watch. Cause and effect of time demands.

Nurses time to do programme→ GP doing bloods→ pressure on practice→ sick patients waiting

Other GPs talked about getting patients early, stopping progression of illness (GP103) before development of complications, again reemphasizing early intervention [Timing]. GPs talked about the burden of diabetes management in terms of practice time taken to do full review etc. Time is an investment for the GP (Nurse 104). This was also mentioned in relation to setting up a register and conducting audit – time to provide care and time to organize care. [Time]. Competing time demands: cervical cancer screening being rolled out at that time. GP101 referred to his nurse being caught up with that but hoped to move on to diabetes. ("The next big thing")

Emerging distinction: Significance of timing vs. Lack of time



Timing is more of a thread or undercurrent than a specific theme reflected in the quotes on how care is delivered. Time or lack of is a specific barrier to delivery and improvement.

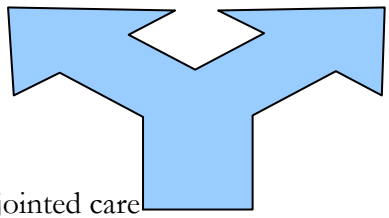
10.13 Appendix XIII: Sample of triangulation between team of analysts

✦ **Models of Care**

Team Meeting: 30.06.10 with CB

SMH suggested models of care ranged between structured approach (register and recall etc) to ad hoc and opportunistic. This is a dimension in itself. Rather than a preconception of structured to shared care, shared care is not the ultimate model but rather an aspect or feature of the ideal. MOM had another distinction between formal care with structure (i.e. in a formal initiative) and informal structured care (not in an initiative but doing it off their own bat). CB recommended that we conceptualise it in a different way, that there are two types of structured care and then disjointed or ad hoc care at the other end. SMH agreed with the distinction and had also differentiated formal and informal (independent) initiatives. (Diagram prepared by MOM);

Structured care Structured care



Ad hoc, opportunistic, disjointed care

Correspondence 08.07.10

CB suggested the two pronged approach was right but that it should be on its side and that the distinction was more between hospital-led structured care and primary care led structured care. A third prong was also suggested; 'shared care' in which both hospital and primary care provide structured care with a degree of coordination between them.

Correspondence 21.07.10

SMH put together a diagram based on these suggestions and developments to capture the different care arrangements emerging. It is based on MOMs two prongs but taking into account CB's distinction between hospital and GP-led care. SMH had 2 instances of hospital-led care which was somewhat structured in the practice. One instance was a formal shared care programme so I would consider 'shared care initiatives' as hospital-led but also structured at GP level. This is distinct from GP-led care which is shared (informal, not a shared care scheme in the traditional sense we know in Ireland). GP111

is floating on the diagram because this GP is ad hoc but becoming more structured yet still not really sharing care with the hospital. Sharing encompassed those who spoke about sharing with the hospital, those with informal arrangements & communication (e.g. GP107 and GP101). SMH did not count simple referral as sharing hence there is a group of ad-hoc GPs with ambiguous links to the hospital. It was agreed that this model capture the layers of delivery and the different guises of diabetes care in Ireland.

✦ Breaking down the relationship with Hospital

Team Meeting: 30.06.10 with CB

Although it was originally conceived as part of the provision or model of diabetes care (a preconception perhaps), SMH began to delineate this category by looked at relationship in terms of types of patients being referred to hospital, how the access to hospital is, etc. This constitutes the model of care/care pathway between the hospital and the GP. While the model of care is an aspect of the relationship with the hospital, the broader issue is one of interfacing between settings which can be a challenge with or without a care pathway in place. Thus a sub-theme has emerged of 'lack of coordination or integration between settings.' Even where communication is good between settings and typically positive relationships, there's still a problem of coordination i.e. risk of people falling through the net, duplication etc.

- lack of coordination is a barrier
- Consequences of lack of coordination: duplication etc. (examples, patients sent from pillar to post)
- suggestions for greater integration (e.g. Could be shared care model like the ante-natal one with shared care cards)- SMH has termed these mechanisms for integrating settings

CB suggested that this group of categories be re-named 'Primary Care and Secondary Care Interface Issues'

✦ Absence of Barriers ≠ Facilitator

Analyst Meeting: 22.09.2010

SMH questioned MOM's theme of the lack of incentives as a facilitator and would argue that just because something is not a barrier for a GP does not automatically make it a facilitator. A facilitator is something which assists the GP to provide optimal care.

The argument was based on the view of a GP in her group; *"…there were no barriers, there were just no incentives." (GP112, P5.3).* While money was not a particular barrier for this GP there were no particular incentives in terms of recognition or additional resources to establish a systematic structured approach to diabetes care. Upon reflection the attitude expresses by some GPs in MOM's interviews was that additional remuneration was not necessarily warranted as diabetes care as part of their job. It was decided to categorise these opinions under the theme of '*General Practice is a business so how important is money?*

✦ **Unique insight into the practice ethos.**

Analyst Correspondence 25.09.10

During the analysis a theme of trust and teamwork emerged from practices that had made a change to the way they managed diabetes care. It was particularly evident in an interview with a Practice Nurse who gave the impression that she did not want to take all the credit for the advances in the practice and conveyed the team effort in her story. Indeed the GP had been invited to take part but passed the invitation on to the nurse who responded to the letter. The theme was further echoed by GP108 in his discussions of visiting Diabetes Nurse Specialists to his practice to run clinics. While this theme did not emerge from MOM's analysis it was supported by the narrative of SMH's participants ["If you're not supported in setting up specialized time to do it you can't take it on your own bat to get off and do it" (Nurse 104, p8.1)] and thus was included in the final results.

10.14 Appendix XIV: Ethical Approval for Qualitative Research

18th June 2009

Prof. Colin P Bradley.
Department of General Practice,
Brookfield Health Science Complex,
University College Cork,
Cork.

RECEIVED
29 JUN 2009

The Irish College of General Practitioners

Coláiste Dhochtúirí Teaghlaigh Éireann

Re: Toward a National diabetes Register for Ireland: Theory Practice and Policy

Dear Prof. Bradley

I wish to confirm that the above study was reviewed by the Research Ethics Committee on Wednesday 17th June 2009. The committee approved the study in full.

We wish you every success with the study.

If you have any queries please contact Aine O'Brien – aine.obrien@icgp.ie

Yours sincerely,

PP. Aine O'Brien
Research Ethics Committee

4-5 Lincoln Place, Dublin 2
Tel: (01) 676 3705/06
Fax: (01) 676 5850
e-mail: info@icgp.ie
www.icgp.ie

Regd. in Ireland at The Irish College of General Practitioners Limited
Registration Number 100456
F Ó Cuinneagáin
Chief Executive

10.15 Appendix XV: Comparison of Audit Data

Data recorded	Midlands	DIG	Diabetes Watch
Patient Details			
GP	√	√	√
Patient Number	√	√	√
Sex	√	√	√
DOB	√	√	√
Classification of DM	√	√	X
DM control	√	√	X
Year of diagnosis	√	√	X
Date of Enrolment	√	Audit Date	X
Lifestyle			
Smoking Status (Y/N)	√	√	X
Alcohol (Units/wk)	√	√	X
Physical Activity(Min/wk)	X	√	X
Measurements			
HbA1c	√	√	√
Serum Creatinine	√	√	X
Proteinuria	√	√	X
Microalbumin	√	√	X
Total Cholesterol	√	√	√
HDL	√	√	√
LDL	√	√	√
Triglycerides	√	√	X
BMI	√	√	√
Weight	X	√	√
Height	X	√	√
Waist Circumference	X	X	√
Systolic BP	√	√	√
Diastolic BP	√	√	√
Screening/Complications			
Seen Ophthalmologist/	√(past 18 mnths)	-	X
Retinopathy Screening	-	√(Where)	X
Retinopathy present	√	√	X
Laser Treatment	√	√	X

Chiropodist/Podiatrist past yr		√	√	X
Foot Assessment recorded		√	√	X
Risk Classification of Foot		√	√	X
Dietician past yr		√	√(Where)	X
	OPD visits with DM	√	√	X
		(number of,	(Y/N, Where, Other)	
		incl CVD)		
Renal OPD/Clinic		√	√	X
	Hospital Admissions	√	√	X
	Diabetes related	√	√	X
	Cause e.g. DKA	√	√	X
	Complications	√	√	X
	Amputations	√	√	X
	Microvascular	√	√	X
	Macrovascular/ CVD Events	√	√	CVS Risk
	Hypoglycaemic Events	√	X	X
Prescribing	Medication	X	√	√

10.16 Appendix XVI: Policy Study Invitation Letter, Consent & Information Sheet



ucc
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Re: Study of the Diabetes Policy Process

Dear ,

I am contacting you to invite you to participate in a study of the policy formulation process in the Irish health setting. My name is Sheena Mc Hugh and I am a PhD student funded by the Health Research Board as part of their PhD Scholarship Programme in Health Services Research. Together with Professor Ivan Perry (UCC), Professor Colin Bradley (UCC) and Prof. Ruairi Brugha (RCSI), I am interested in examining how policy is developed in Ireland and wish to use the Expert Advisory Group Report on diabetes care as an instrumental case study. I would value your opinion and experience of diabetes care in Ireland and the policy process. I envisage that this study will inform future policy formulation for chronic illness and health services and build on a foundation for policy analysis in the Irish health system.

Please find enclosed an information sheet outlining the details of the study and two consent forms (personal copy and researcher copy). If you agree to participate, the interview will last approximately 45 minutes. You will be forwarded an outline of the topic guide prior to the interview. While diabetes policy will be employed as a case study, the focus of my research will be the policy process therefore your views and opinions will be presented to protect your anonymity. Any identifiable information will be removed from interview transcripts and your responses will be anonymised. Participation is voluntary and you are free to withdraw from the study at any time.

I appreciate that you are very busy so I would arrange to meet you at a time and location most convenient to you. If you are interested in taking part please return the consent form enclosed and I will contact you to arrange a suitable time to conduct the interview. I hope that you can find the time to participate. If you require any further

information regarding this project please contact Sheena Mc Hugh on 021-420-5253 (s.mchugh@ucc.ie).

Yours sincerely

Ms. Sheena Mc Hugh

Prof. Ivan Perry

Prof. Ruairi Brugha

Prof. Colin Bradley



Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Participant Information Sheet

Research Project:

An analysis of the policy formulation process to improve diabetes care in Ireland

Investigator Directing Research: Professor Ivan J. Perry Phone: 021 490 1589

You are being invited to participate in a research study conducted within the Department of Epidemiology & Public Health in University College Cork. This leaflet provides information about the study so that you can make an informed decision about whether or not you wish to participate. Please feel free to ask any questions you may have at any point.

Your participation is strictly voluntary and you may withdraw at any time without having to give a reason. Non-participation or withdrawal will be treated as a confidential action with no consequences for you.

What is this study for?

The purpose of this study is to understand the policy formulation process in the Irish health context, thereby informing future policy formulation in other areas as well as highlighting barriers and facilitators to this stage of the policy process. The study aims to examine the formulation process behind the development of the Expert Advisory Group Report on the management of diabetes in Ireland. It also aims to examine the explanatory value of alternative theories to explain the policy process.

Who is organising and funding the study?

The study is funded by the Health Research Board (HRB). It is being conducted as part of a programme of work for a doctoral thesis by Sheena Mc Hugh a HRB PhD Scholar in Health Services Research at University College Cork. The study and thesis are being supervised by Professor Ivan Perry (UCC), Professor Colin Bradley (UCC) and Professor Ruairi Brugha (Royal College of Surgeons in Ireland).

How will the study be conducted?

The study will commence in August 2011 and the interviews are expected to conclude in November 2011. A pilot interview will be conducted to test the suitability of the topic guide. It is anticipated that between 20 and 25 participants will be interviewed.

What is involved?

You can select a suitable time, date and location for the interview and the interviewer will travel to you. The interview will last approximately for 45 minutes. If it is agreeable with you, the interview will be audio-recorded by the researcher to assist with transcription. Tapes will be destroyed following transcription.

You are permitted and will be given an opportunity to review and edit the transcript from your interview. If you request to review your transcript, we will contact you when the transcripts are ready to be reviewed whereupon you will be given a 3 month period within which you can request edits. If you agree, the researcher may telephone you to clarify any points from the interview.

What about confidentiality?

All interviewee responses will be anonymised. Any identifiable information will be removed from interview transcripts and a study ID number will be assigned to your tapes and transcripts to maintain anonymity. This ID number will be stored securely and separately from the identification code key. Details from the consent forms will also be stored securely by the study researcher in UCC. The data will be kept electronically on the secure UCC server and will be password protected. Only investigators named on this information sheet will have access to the data. In accordance with the Data Protection Act the interview data transcripts will be kept for 7 years after which time they will be deleted.

What are the benefits of taking part?

The study aims to build knowledge around the formulation stage of the policy process using diabetes policy as a case study. This should inform the future development of policy in this area and be relevant to policy making for other chronic diseases. It will also benefit the future policy process for health services nationally and internationally.

What will happen with the results of this study?

The findings of this study will be part of a doctoral thesis in Health Services Research which will be submitted to University College Cork. The results may also be drafted for publication in a peer-reviewed journal or report. In all cases only anonymous extracts or quotes will be reported with identifiable information removed. Copies of the findings will be made available to participants.

Who has reviewed this study?

The proposal for this research was reviewed and granted approval by the Clinical Research Ethics Committee, University College Cork.

Statement of consent

If you agree to take part we would appreciate it if you could confirm by returning the consent form by email or in the pre-paid envelope. Thank you.

Contact for further information

If you have any concerns after the interview, please do not hesitate to contact us:

Sheena Mc Hugh:	Tel: 021 420 5252	Email: s.mchugh@ucc.ie
Prof. Ivan Perry:	Tel: 021 490 1589	Email: i.perry@ucc.ie
Prof. Colin Bradley	Tel: 021 490 1547	Email: c.bradley@ucc.ie
Prof. Ruairi Brugha:	Tel: 01 402 2434	Email: rbrugha@rcsi.ie

Thank you for taking the time to read this information.

Ms. Sheena Mc Hugh

Prof. Ivan Perry

Prof. Ruairi Brugha

Prof. Colin Bradley



CONSENT FOR PARTICIPATION IN RESEARCH PROTOCOL

SECTION A

Protocol Number: Participant Name:_____

Title of Protocol: .....

An analysis of the policy formulation process to improve diabetes care in

Investigator Directing Research: Prof. Ivan J. Perry Phone: 021 490 1589

Nominated Researcher: Sheena Mc Hugh Phone: 021 420 5253

You are being asked to participate in an interview, as part of a research study. The research team at University College Cork, supported by Professor Ruairí Brugha from the Royal College of Surgeons in Ireland, is undertaking an analysis of diabetes policy formulation processes. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, and you will be given an opportunity to ask questions about it. Once you understand the study, you will be asked to sign this form if you wish to participate.

SECTION B

I. **NATURE AND DURATION OF THE STUDY:**

The purpose of this study is to examine how policy is formulated in Ireland using the Expert Advisory Group Report for Diabetes as a case study. The research will be conducted by Sheena Mc Hugh, a PhD student based in University College Cork. You are invited to take part in an interview with Sheena to explore issues relating to the development of the policy over time.

II. **POTENTIAL RISKS AND BENEFITS:**

The interview will be an opportunity for you to share your experience and opinion on the development of policy for diabetes care in Ireland. There is minimal risk attached to taking part. Your identity will be kept confidential at all times and only anonymised data will be reported.

III. **POSSIBLE ALTERNATIVES:**

Your participation in the study is entirely voluntary and you are free to withdraw at any time without having to give a reason and without any personal consequence.

SECTION C:

AGREEMENT TO CONSENT: **Please tick the appropriate answer:**

	Yes	No
I confirm that the research project and the interview associated with it have been fully explained to me.	☐	☐
I have read and understood the attached Participant Information Sheet dated 16/08/10 and have had an opportunity to ask questions concerning any and all aspects of the project, to which I have had satisfactory answers.	☐	☐
I am aware that participation is ***voluntary*** and that I may withdraw my consent at any time without having to give a reason. I am aware that my decision not to participate or to withdraw will not have any personal consequences for me.	☐	☐
Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.	☐	☐
I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.	☐	☐
I have received a copy of this consent form and the participant information sheet for my records.	☐	☐

I, the undersigned, hereby consent to being a participant in the above described project conducted at the University College Cork. I understand that if I have any questions concerning this research, I can contact the researcher listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork. After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

.....	.....	.....
Participant Signature	Name in Block Capitals	Date
	SHEENA MC HUGH	
.....	.....	.....
Researcher Signature	Name in Block Capitals	Date

.....

10.17 Appendix XVII: Topic Guide for Policy Study

TOPIC GUIDE

PARTICIPANT & EAG	Your position now & then How did you get involved (Who asked you) Who decided EAGs & why? What led up to EAGs? Why now? Why diabetes? Were there particular challenges for diabetes then
MEMEBERSHIP	Other members selected Remit for group, brief * Your role within group (did it change) *Your* objectives/priorities Your expectations for the group
DEVELOPING POLICY	Objectives from the outset… How were priorities identified- who brought them to table What issues were to the forefront, most occupied with? How recommendations developed (…prompt)
ALTERNATIVES	Alternative solutions discussed: sharing ideas? How were alternatives evaluated Why disregard them Topics of confusion or disagreement How were differences of opinion handled? (consensus) Was there bargaining involved? In what way…
CONTENT + EVIDENCE	Existing/ available evidence or Efforts to produce/gather evidence Types of evidence drawn on: expertise, international, research How did presentations inform report? Was info used?
SUB-GROUP	Tell me about that…Why that subgroup/topic (Integrated care, how was that model developed?) Bringing ideas to the larger group for discussion/agreement?
FINALISING REPORT	Any crisis points in the process? How did the approval process work with the HSE?- request changes?
RELATIONSHIPS	How did people get on working together Some more influential than others Leaders who stand out Partnerships within group People resisting/enabling Other B & F
CONTEXT	Key milestones/crises in diabetes Previous efforts – was this process different, adv/disadv of this attempt Influence of other policies, changes in HSE… Financial implications/ Economic situation Current resources: staff, skills, organisation. Media Role?

IMPLEMENTATION	What was the expectation once recommendations were agreed? Reaction of diabetes community: widely accepted? Critical factors for implementation Should the content differ? What could have been done differently Balance of goals & priorities Use of EAGs for policy making

10.18 Appendix XVIII: Ethical Approval for Policy Study

UCC
Tel: + 353-21-490 1901
Fax: + 353-21-490 1919
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee
Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Our ref: ECM 4 (x) 07/09/10

18th August 2010

Professor Ivan Perry
Head of Department of Epidemiology
& Public Health
Brookfield Health Sciences Complex
University College Cork
College Road
Cork

Re: An analysis of the policy formulation process to improve diabetes care in Ireland.

Dear Professor Perry

Expedited approval is granted to carry out the above study in:

- University College Cork.

The following documents have been approved

- Application Form
- Study Protocol Version 3 dated 16th August 2010
- Consent Form Version 3 dated 16th August 2010
- Participant Information Leaflet Version 3 dated 16th August 2010
- Invitation Letter Version 3 dated 16th August 2010
- Topic Guide Version 3 dated 16th August 2010.

We note that the co-investigators involved in this study will be:

- Professor Ruairi Brugha, Professor Colin Bradley and Sheena McHugh.

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals