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The development and evaluation of an online dementia resource for primary care based health professionals

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ABSTRACT

Background: Primary care based health professionals struggle with many aspects of dementia care. General practitioners (GPs) find providing post-diagnosis information on services and supports particularly challenging. Likewise, people with dementia and their family caregivers feel they need more support from their GPs in this post-diagnosis period.

Objective: This study aimed to develop and evaluate an online educational resource for primary care health professionals that included a dementia specific services and supports directory.

Method: A previously conducted educational needs analysis informed the content of the resource. This content was further developed by a review of the literature and through consultation with an expert reference group and a stakeholder group. A mixed method approach was taken to the evaluation of the online resource which included analysis of the website traffic, qualitative feedback from stakeholders and evaluation by general practitioners.

Results: The online resource www.dementiapathways.ie was developed. Initial qualitative feedback obtained from potential end-users was positive. Data analysis was performed on over 4000 people who accessed the site. Finally, the online resource was demonstrated to 190 general practitioners in 36 workshops. All of the general practitioners surveyed felt that dementipathways.ie would be a useful resource for them. Several potential barriers to the successful development and implementation of a services and supports directory were identified.

Conclusion: This study provides a prototype for the development of an online dementia educational resource and demonstrates the value of a dementia-specific services and supports directory for primary care based health professionals.

1. Introduction

General practitioners (GPs) and community-based healthcare professionals play a pivotal role in the care of people with dementia (Downs 1996), however, they find dementia care challenging (Cahill et al. 2006; Travers et al. 2013; Jennings et al. 2017). A recent triangulated educational needs analysis of GPs' educational needs (Foley et al. 2017) explored multiple perspectives on what GPs' educational needs are in dementia care. In addition to GPs' perspectives on their educational needs, people with dementia and their carers were asked what they believed GPs should know in order to deliver optimal dementia care. The educational needs analysis established that GPs wanted access to up-to-date, GP-relevant, clinical information that would help them to manage a patient with dementia and offer optimal post diagnosis care to people dementia and their families. GPs were aware of the importance of social supports but they were often unaware of how to access them (Foley et al. 2017). Accessing these services and supports is very important to people living with dementia and their caregivers (Joling et al. 2015), however, in the educational needs analysis (Foley et al. 2017) the participating family carers and people with dementia reported that their GPs were often unable to suggest appropriate community based supports. These findings support previous research with people with dementia and their families that has shown that they value the role of the GP in this post-diagnostic period (Bridges-Webb et al. 2006), however, they would like more help and support from their GP (Innes et al. 2014).

Research has consistently identified that GPs find providing advice on local dementia services and supports to be a particularly challenging aspect of dementia care (Turner et al. 2004; Fox et al. 2014; Tang et al. 2016; Downs et al. 2000). Furthermore, research on the post-diagnosis care gap in dementia has highlighted the importance of mapping local post-diagnostic support services in order to enable GPs to sign-post patients and their families to appropriate services post-diagnosis (Fox et al. 2014). However, such information resources are limited and when

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they do exist health professionals are often unaware of them.

There are existing online dementia educational resources (e.g. www.scie.org.uk), however, as most of the dementia educational resources are designed primarily for the public they do not fully address health care professionals' educational needs. E-learning modules on dementia also exist and have been shown to be effective (Hattink et al. 2015). In the Irish context the research team was involved in developing e-learning dementia modules for the Irish College of General Practitioners. However, from our initial qualitative work with GPs (Foley et al. 2017) we found that GPs want quick access to clinical information on dementia within a consultation setting or during the course of a busy working day. Upon reviewing existing online sites we could find no such educational dementia resource developed specifically to address the educational needs of health care professionals working in the Irish healthcare system.

This study forms part of a wider research project named PREPARED (PRimary care Education, Pathways And Research in Dementia). PREPARED is part of the overall implementation of the Irish National Dementia Strategy and is tasked with developing education interventions for GPs (Foley et al. 2017) and primary care team members. This study aimed to develop an online resource which would address the educational needs of primary care based health professionals and provide them with access to information on local dementia specific services and supports. The objective of the online resource was to provide up-to-date, easily-accessible educational information and to develop a dementia-specific national services & supports directory.

2. Methods

Ethical approval for this study was granted by the Social Research Ethics Committee in University College Cork [2015–006].

2.1. Development of the online resource

There were two discrete aspects to the development of the online resource; the development of the educational content and the development of the services and supports directory (see Fig. 1).

2.1.1. Development of the educational resources

The development of the educational resources was informed by the aforementioned educational needs analysis (Foley et al. 2017), literature review and an expert reference group. The results of educational needs analysis (Foley et al. 2017) was used to prioritise the educational content of the online resource. The educational content was informed by a literature review (Foley 2018) performed by two of the authors (AJ, TF), both general practitioners with a special interest in dementia care. The clinical content was further informed by dementia educational interventions developed for GPs and primary care teams as part of the wider research project (Quinn et al. 2017; Foley and Jennings 2016; Foley and Swanwick 2014). Once developed the educational content was reviewed by a multidisciplinary expert reference group. The expert reference group was purposively selected on the basis of their known interest in dementia care. The expert reference group included two general practitioners with an interest in dementia care, a physiotherapist, a nurse, an occupational therapist, a public health nurse, two geriatricians, two old age psychiatrists and an academic legal expert in dementia. The review of the clinical content by the expert reference group involved face-to-meetings, teleconferences and email conversations. The meetings were either audio recorded or extensive field notes were taken.

2.1.2. Development of the services and supports directory

The second phase of the resource development involved the development of the services and supports directory. This was an iterative process that required the formation of a stakeholder group. The stakeholder group included; eight national dementia advisors, representatives from the Alzheimer Society of Ireland (ASI) and representatives from existing dementia projects nationwide. The first phase of data collection involved collaboration with the ASI who provided access to their existing database of ASI specific supports and services. Phase two of data collection involved meeting with eight national dementia advisors who have knowledge of the on-the-ground supports available in each region. Phase three of data collection involved collaborating with various community based projects nationwide. All the information provided by the stakeholders was collated and a county-by-county database was created. This database was iteratively developed by continuous feedback from these stakeholders and added to by extensive internet searches. A searchable online tool was then developed that allows the user to search for services and supports by county and by type of service and support.

The data is updated on a monthly basis. The ASI updates their own ASI specific services and supports directory monthly and notify us of

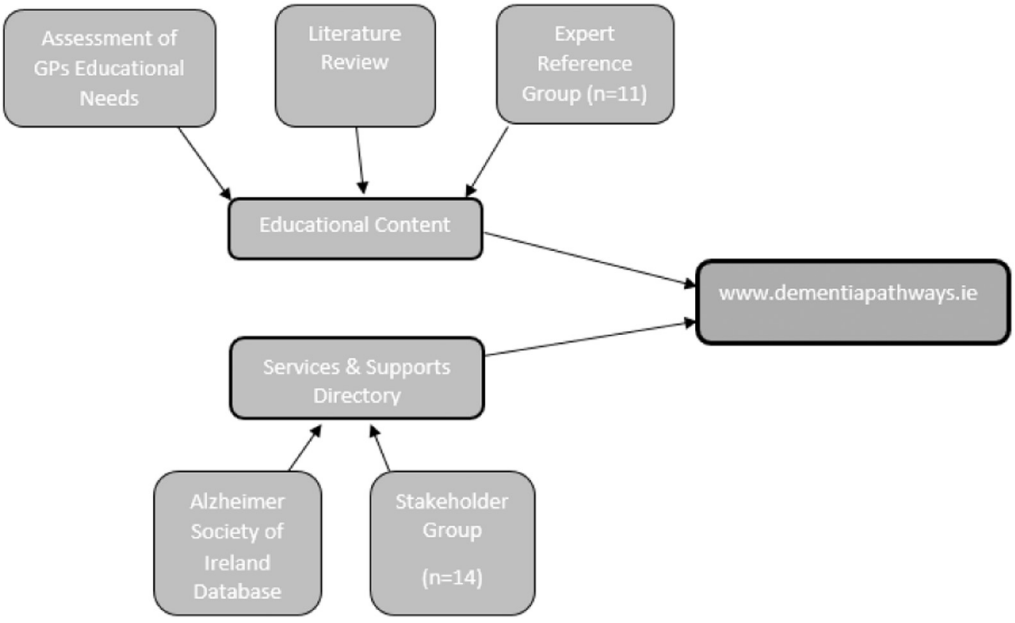


Fig. 1. The development of www.dementiapathways.ie.

any changes or new supports. Monthly reminder emails are sent to all dementia advisors working nationally. In this email we provide the list we have of currently available services and supports in their area. We provide them with a form to indicate any changes in existing services and to inform us of any new services that they are aware of. Finally, we repeat our internet searches once a month to identify any new information. We also receive updates from the on-the-ground co-ordinators of the services and supports informing us of any changes. We are currently developing a tool that will allow visitors to our site to complete a form informing us of new services and supports or changes to existing ones.

2.2. Process evaluation of the online resource

To determine whether the online resource was implemented as intended a mixed-method approach was employed. This included; website analytics, qualitative feedback from potential end-users and evaluation by GPs.

2.2.1. Website analytics

Website analytics were used to capture the number of users on the site and assess the effectiveness of the online resource. When accessing the online resource for the first time the user is asked to select their professional background from a list of options. This allowed the capturing of demographic information on the people accessing the site.

2.2.2. End-user assessment

Potential end-users assessed the online resource and provided input into its design and content before the go-live date. This multidisciplinary group consisted of six GPs, two nurses, three allied health care professionals and three geriatricians, twelve family caregivers and five people with dementia. The family caregivers and people with dementia had all previously participated in the qualitative educational needs analysis of GPs educational needs (Foley et al. 2017). All the participants in this multidisciplinary group were provided with a log on and full access to the site. They were asked to review the online resource in terms of its usability, relevance and usefulness. They were given three weeks to respond. Their written responses were then thematically analysed by two members of the research team (AJ, TF). Minor refinements to the content were made in response to the evaluation by this group of potential end-users.

2.2.3. Evaluation by GPs

The online resource was evaluated as part of a wider educational intervention developed by the PREPARED research project. This intervention involved peer-facilitated, practice-based dementia workshops for GPs. These small-group case based workshops were delivered to GPs in their practices nationwide (Foley et al. 2017). During these workshops the online resource (www.dementipathways.ie) was demonstrated to the participating GPs. Upon completion of the workshop participating general practitioners were invited to complete a questionnaire to evaluate the workshop, part of which focused on evaluation of the web-resource. The questionnaire was developed by the research team and piloted with two practising GPs before use.

3. Results

The online resource named www.dementiapathways.ie was launched in July 2016. The educational content is displayed, where possible, in the form of a clinical decision aid or pathway (see Fig. 2). A split screen allows end-users to select a box within the pathway and further information on that clinical topic is displayed on the right hand column. This format allows quick access to the salient clinical points, an important feature for busy clinicians. Topics covered include; diagnosis of dementia, post-diagnostic support, management of behavioural and psychological symptoms of dementia, driving in dementia and legal issues.

The services and supports directory provides a searchable directory that can be accessed by health professionals, people with dementia and their families (Fig. 3).

3.1. Website analytics

Over the first 12 months since its launch the online resource was accessed by 4331 unique visitors. A breakdown of the different people accessing the resource in the first six months is given in Fig. 4. The online resource has been accessed by hospital doctors and family caregivers demonstrating the site's role beyond its intended target audience of primary care based health professionals.

3.2. End-user involvement in the design

Of the thirty-one potential end-users who were asked to evaluate the website, twenty-eight responded; six GPs, two nurses, three allied health care professionals, three geriatricians, nine family caregivers and four people with dementia. This represented a response rate of 87%. The feedback was universally positive (see Table 1). The importance of combining the service and supports directory with the educational resources was highlighted by several participants.

3.3. Evaluation by GPs

The online resource (www.dementiapathways.ie) was demonstrated to 190 GPs in 36 small group workshops nationwide. The GPs were asked to complete an anonymised questionnaire which rated on a 5 point Likert scale the extent to which they thought the dementiapathways.ie website will be a valuable resource in post-diagnosis dementia care. The median rating was 5 (strongly agree). Furthermore, an analysis of the qualitative feedback on this questionnaire, found that the online resource was highly valued by a large number of GPs (Table 2).

4. Discussion

The design of dementiapathways.ie was informed by the educational needs of its end-users. The educational component was developed after a literature review of best practice dementia care and was iteratively developed with assistance from clinical experts in the field. The development of the services and supports directory involved collaborating with existing stakeholders. A searchable database was created, its online format allowing for continuous updates. Both health professionals and the people in the community they care for were involved in the conception, development and evaluation of this online resource.

The website (www.dementiapathways.ie) extends the traditional boundaries of online dementia education for health professionals by including a services and supports directory. This juxtaposition of clinical educational resources with a services and supports directory highlights the pivotal role of GPs in signposting people with dementia and their families to these supports.

Maintaining the integrity of the data in the services and supports directory is a challenge. As outlined, efforts to ensure the accuracy of the information in the services and supports directory are resource-intensive. However, this project was successful in showing that such a repository could be created and, with appropriate resourcing, could be appropriately maintained. The Health Service Executive (HSE) provides public and social care services to everyone in Ireland and partly funded this project. As part of a public awareness campaign the HSE led the development of a website for the public on dementia. To ensure the integrity of the information provided on our service and supports directory is maintained beyond the life of our project, the HSE will incorporate our service and supports directory into their website for the

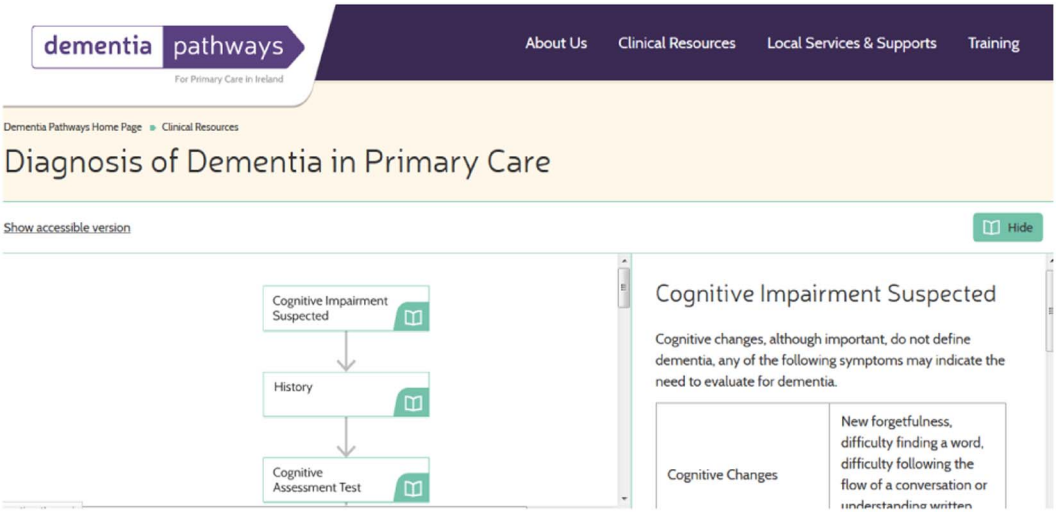


Fig. 2. Clinical decision aid.

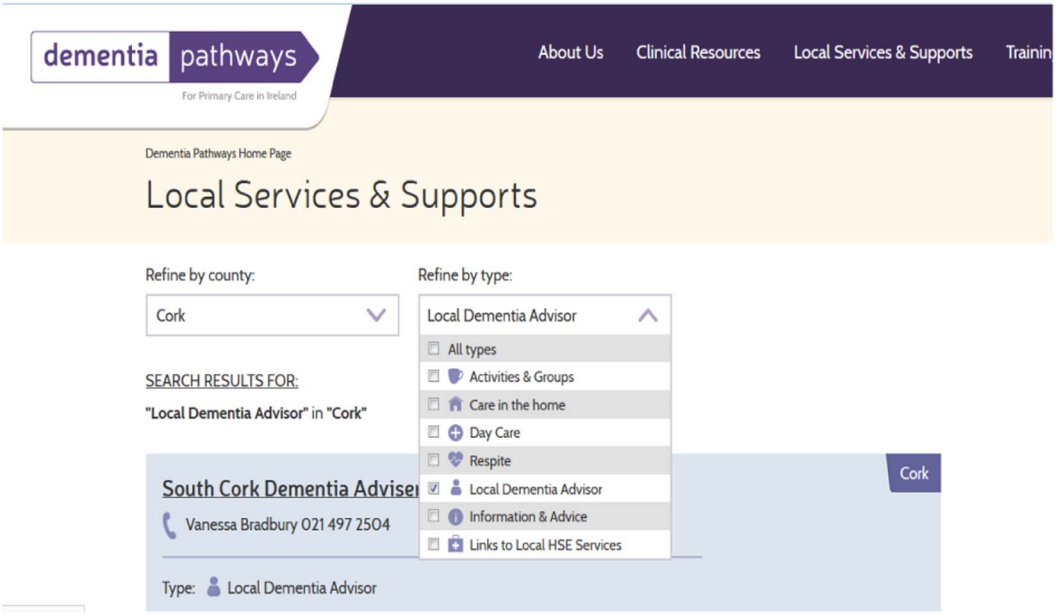
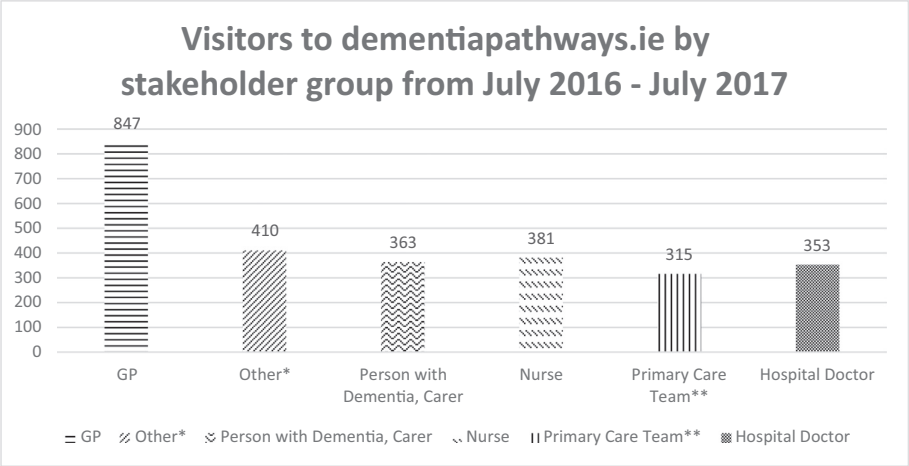


Fig. 3. Services and supports directory.

public and control data maintenance. In time, visitors to our service and support directory will be linked to the directory on the HSE website. Another potential barrier to the successful implementation of this type of educational resource is that the target end users may be unaware of its existence. Multiple attempts were made by the research team to promote awareness of the online resource. The dementiapathways.ie resource was demonstrated in national educational dementia workshops with both general practitioners and primary care team members. The resource was also promoted at national primary care and dementia conferences. An article introducing the online resource was published in the monthly journal of the Irish College of General Practitioners which is received by GPs nationwide (Jennings 2017). A third challenge to the successful implementation of an online service directory of this kind is the dearth of services and supports in some areas. The effectiveness of a dementia services and supports directory is, of course, influenced by whether any services or supports exist in an area. In developing the directory we did identify a large variation in the presence of supports and services in different areas.

Process evaluation is recognised as being a central part of the development of any intervention (Craig et al. 2008). In this study the evaluation helped to capture the fidelity and quality of the implementation (Moore et al. 2015). The acceptability of the online resource by healthcare professionals was highlighted and provided the research team with a better understanding of the intervention delivery and reach (Moore et al. 2014). The results of the process evaluation will inform future improvements to the online resource. The extent to which access to the educational resources or the service directory changed the health professional's behaviour was beyond the scope of the study. For example, we do not know whether access to this information resulted in the general practitioner signposting these supports to family caregivers. However, given that the educational needs analysis (Foley et al. 2017) found that the main barrier to general practitioners providing this information was knowledge of the existence of the service, it is hoped that access to this knowledge had a positive impact on practitioner behaviour. Similarly, we do not know whether access to the clinical information had a positive impact on other aspects of clinician behaviour, such as referral rates. However, this online resource was demonstrated to GPs as part of a wider educational workshop which was reported elsewhere (Foley et al. 2017). In evaluating the overall educational workshop we did find that that these workshops improved general



Other * includes; dementia advisors, medical students

PCT member ** includes; pharmacists, occupational therapists, social workers, physiotherapists, psychologists

Fig. 4. Visitors to dementiapathways.ie by stakeholder group from July 2016–July 2017
Other * includes; dementia advisors, medical students
PCT member ** includes; pharmacists, occupational therapists, social workers, physiotherapists, psychologists.

Table 1
Qualitative feedback from potential end-users.

Stakeholder	Feedback
General practitioner	"*The most GP-helpful and comprehensive website I've seen to date.*" (*GP_06*)
Clinical nurse manager in a nursing home	"*a super guide… found it easy to read and very helpful.*" (CNM_01)
Person with dementia	"*very good: very clear communication and very comprehensive information… it will be very useful.*" (PWD_02)
Family carer of a person with dementia	"*This is going to be helpful to me.*" (Carer_04)
Occupational therapist	"*so many useful resources and bringing together of so many sources of info into one space too.*"

practitioners self-reported knowledge and confidence in dementia care and that the website resource was particularly valued.

5. Conclusions

To our knowledge this is the first study to describe the process involved in the development and evaluation of an online dementia resource for healthcare professionals. Services and support directories for people with dementia are a rare entity due to the logistical challenges and knowledge management issues that are inherent to collating this information and the technical challenges of appropriately disseminating this information. As a result stakeholders in community dementia support services often work on their own and without co-ordination with other services (Heinrich et al. 2016). Information on

Table 2
Development of www.dementiapathways.ie.

Stage	Approach	Outcome
1. Educational needs analysis	A triangulated assessment of general practitioners educational needs in dementia care from the perspective of GPs, people living with dementia and their family caregivers	• Identification of importance clinical areas that needed to be addressed in future educational initiatives • Idea of an online resource to provide up-to-date, easily accessible material • The concept of a services and supports directory for each area
2. Development of educational content	Multidisciplinary expert reference group (n = 11) Literature Review	• Clinical pathways and educational dementia resources that have a primary care focus
3. Creation of services and supports directory	Stakeholder group (n = 14) Incorporation of existing Alzheimer Society of Ireland database Extensive internet searches	• A county-by-county guide to available supports and services for people with dementia and their caregivers.
4. Development of the online resource	Consultation with IT design experts	• Interactive clinical pathways in diagnosis and post diagnostic support. Resources on the management of behavioural and psychological symptoms of dementia (BPSD), driving assessment in people with dementia and legal issues in people with dementia. • Other features include an extensive collation of patient information leaflets and sign-posting to further resources for people living with dementia and their caregivers, embedded assessment tools and links to other resources.
5. Evaluation of the online resource	Website analytics Feedback from stakeholders; qualitative & quantitative	• High usage rate of the site since its launch (> 4000 unique visitors) • Multidisciplinary group accessing the site • Positive feedback from potential end-users • Rated highly by 104 general practitioners who felt it would be a valuable resource when caring for a person with dementia.

them is spread by word-of-mouth and health professionals are often unaware of their existence. A comprehensive, up-to-date, easily searchable online database of dementia specific services and supports for each area is an essential component of providing post-diagnostic care to people with dementia and their families. Although we have identified some implementation barriers this study demonstrates, that once adequately resourced, dementia specific services and supports directories can be developed and will be utilised by primary care based health professionals.

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