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Regional differences in experiences of patients with metastatic breast cancer in the Republic of Ireland and Northern Ireland: a comparative analysis (CTRIAL-IE 23-05)

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ABSTRACT

Introduction Metastatic breast cancer (MBC) presents significant psychological, social and financial challenges. Differences in the healthcare systems of the Republic of Ireland (ROI) and Northern Ireland (NI) may impact patient care experiences. This study aimed to explore regional differences in the experiences of patients with MBC between ROI and NI.

Methods A patient-developed cross-sectional survey titled 'Patient-led Metastatic Breast Cancer Survey' was administered online to patients with MBC in ROI and NI from July to October 2023. The survey included 76 questions addressing demographics, understanding of diagnosis, mental health, financial burden, time spent managing cancer care (time toxicity), palliative care, sexual health, exercise and access to information. These topics were selected by patients with MBC as being most impactful. Responses from 246 patients (196 ROI, 50 NI) were analysed using descriptive and comparative statistics.

Results Psychological distress was highly prevalent in both regions; however, NI patients were more likely to receive medications for psychological distress (51% NI vs 23.7% ROI, p=0.0008). Financial strain was more pronounced in ROI, with 77.5% feeling they had no control over their medical care spending, compared with 56% of NI patients (p=0.0124). Time toxicity was also higher in ROI, where patients reported more frequent visits to oncology day wards and acute oncology service units (p=0.0012) and spent more time in these settings (p=0.038). Participation in exercise programmes was significantly higher in NI compared with ROI (p<0.0001). Additionally, palliative care referrals were more commonly accepted or considered in NI than in ROI.

Conclusions This study, the first of its kind, highlights important disparities observed in this cohort of patients with MBC across ROI and NI. Bidirectional learning could enhance patient care experiences, with NI potentially focusing on psycho-oncology integration and ROI expanding strategies to reduce time toxicity and financial burden for patients.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Metastatic breast cancer (MBC) poses significant psychological, social and financial challenges for patients. Specific differences in the care experiences of patients with MBC between the Republic of Ireland (ROI) and Northern Ireland (NI) have not previously been explored.

WHAT THIS STUDY ADDS

⇒ This study, the first of its kind, highlights notable disparities in MBC care between ROI and NI, including differences in mental health medication use, financial burden, time toxicity, palliative care acceptance and participation in exercise programmes. The findings reveal common challenges and distinct areas needing targeted interventions in both regions.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The results suggest opportunities for bidirectional learning between ROI and NI to improve patient care. Policy makers and healthcare providers can use these findings to implement targeted strategies aimed at reducing disparities, enhancing psycho-oncology services, reducing time toxicity and improving financial support for patients with MBC. Future research should further explore the underlying causes of these disparities to drive effective, patient-centred policy and practice improvements.

INTRODUCTION

The partition between the Republic of Ireland (ROI) and Northern Ireland (NI) in 1921 marked the beginning of distinct healthcare systems in the two regions.[1] Healthcare in NI was transformed in 1948 with the establishment of the National Health Service (NHS) in the UK,[2] while the Health Service Executive in ROI was formed in 2005

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Table 1 Patient demographics

Demographics*		N=246 Total (N=246)	NI (N=50)	ROI (N=196)
Age (median, range)		52.5 (30–82)	53 (38–82)	52.5 (30–80)
Sex	Female	239 (98%)	50 (100%)	189 (97%)
	Male	4 (2%)		4 (2%)
	Non-binary	1 (<1%)		1 (<1%)
	Unanswered	2		2
Education	Tertiary level	197 (80%)	41 (82%)	156 (80%)
	Secondary level	46 (19%)	9 (18%)	37 (19%)
	Primary level	2 (1%)		2 (1%)
	Unanswered	1		1
Parents with children <18		105 (43%)	23 (46%)	82 (42%)
Clinical characteristics				
Breast cancer subtype	HER2+	92 (46%)	17 (43.59%)	75 (46.88%)
	ER/PR+	167 (81%)	37 (88.1%)	130 (78.79%)
	TNBC	20 (12%)	4 (11.76%)	16 (11.85%)
Year of MBC diagnosis	2005–2009	5 (2%)		5 (3%)
	2010–2014	16 (7%)	3 (6%)	13 (7%)
	2015–2019	63 (26%)	13 (26%)	50 (26%)
	2020–present	159 (65%)	34 (68%)	125 (65%)
	Unanswered	2		2

*Percentages based on those who responded in each category.
ER/PR+, Oestrogen/Progesterone receptor positive; HER2+, Human epidermal growth factor receptor 2 positive; MBC, metastatic breast cancer; NI, Northern Ireland; ROI, Republic of Ireland; TNBC, triple-negative breast cancer.

to centralise healthcare management, replacing regional health boards and other agencies.[3] Cancer care in ROI saw significant progress with the 1996 release of *Cancer Services in Ireland: A National Strategy*, which led to a 15% reduction in cancer mortality among patients under 65 by 2001.[4 5] Building on this, the 2006 *Strategy for Cancer Control in Ireland* established the National Cancer Control Programme (NCCP), aiming to provide comprehensive cancer care covering prevention, early detection, treatment and follow-up.[5] The most recent *National Cancer Strategy 2017-2026*, published in 2017, expanded the focus to address rising cancer incidence, incorporating previously overlooked aspects of cancer care, including psycho-oncology, palliative care, cancer in adolescents and young adults, and survivorship and care for older cancer patients.[6] In NI, the 2008 *Regional Cancer Framework* aimed to enhance patient outcomes and experiences through prevention, early detection and screening, improved access to diagnosis and treatment, and better support for those affected by cancer, including research, information and audits.[7] The 2022 *Cancer Strategy for NI 2022-2032* continues this aim, with an emphasis on equitable access, multidisciplinary care, early integration of palliative care, workforce development and digital transformation for sustainable cancer care across NI.[8]

Due to the inherent differences in healthcare systems between ROI and NI, variations in the management and care of health conditions, including metastatic breast cancer (MBC), have emerged.[9 10] These variations present valuable opportunities for bidirectional learning between regions, offering insights that could enhance patient outcomes and ensure equitable access to treatment and support services across the island of Ireland. MBC management serves as an ideal case study for this learning, as it extends beyond cancer treatment to address significant psychological, social, familial and financial challenges.[11–18] While disparities in cancer care have been studied within the UK[19] and between the UK and Ireland,[20–22] specific differences in MBC care between ROI and NI have not been explored.

This study explored regional differences in MBC care between ROI and NI, with a focus on critical aspects such as mental health, financial burden, time toxicity, palliative care, sexual health, exercise programme participation and access to information. The data for this analysis were derived from a comprehensive patient-led survey designed to capture the multifaceted experiences of MBC patients.[23] Although the survey was not initially designed to focus on regional disparities, its cross-border nature allows for an investigation into these differences. The

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Table 2 Summary of key findings

Category	ROI (n=196, %)	NI (n=50, %)	P value
Prescribed mental health medication	23.7	51	0.0008
No control over medical spending	77.5	56	0.0124
View illness as financial burden	60.2	56	0.25
Frequent oncology visits	Higher	Lower	0.0012
Time spent in oncology settings	Higher	Lower	0.038
Palliative care referral acceptance	Lower	Higher	0.079
Sought medical advice for changes in sex life	26.5	9.4	0.0496
Received support for sexual health concerns	73.3	82	0.357
Dissatisfaction with menopausal symptom support	64	85	0.2052
Participation in exercise programmes	Lower	Higher	<0.0001
Access to medical records	37	26	0.131

NI, Northern Ireland; ROI, Republic of Ireland.

insights gained from this study may inform clinical practices and healthcare policies in both regions, while also highlighting opportunities to improve service provision.

METHODS

This study used a cross-sectional survey design to explore aspects of MBC care. The survey, titled 'Patient-led Metastatic Breast Cancer Survey', was collaboratively developed by patients with MBC, oncologists, allied health professionals, palliative care physicians and trainee doctors, ensuring comprehensive coverage of relevant care aspects. Co-constructed by 41 patients from ROI and NI, the final survey comprised 76 items addressing demographics, understanding of diagnosis, prognostic information need, mental health impact, financial burden, time spent managing cancer (referred to as time toxicity),[24] palliative care, sexual health, exercise and access to information—topics identified by patients as being most impactful (online supplemental appendix 1).

The online survey was administered via SurveyMonkey and distributed through cancer support centres, patient advocacy groups and healthcare institutions across ROI and NI from July to October 2023. It was promoted through social media channels and national media outlets, including television and radio. Eligibility criteria included a confirmed diagnosis of MBC, age 18 or older, and the ability to complete the questionnaire independently or with assistance. Incomplete responses were excluded from the analysis, and completion of the survey was considered as implicit consent. Anonymity was ensured with no tracking of personal information.

Data were summarised using counts and percentages for categorical variables, and means, SD, medians and ranges for continuous variables. As there was no formal sample size for this survey, it was not powered to detect any statistical differences. Responses were stratified by region (NI and ROI) and comparative analyses were undertaken using SAS V.9.4 (SAS Institute, Inc.).

RESULTS

A total of 246 respondents completed the survey, with 196 from ROI (80%) and 50 from NI (20%), which is proportionate to the population distribution across the island of Ireland (see table 1 for patient demographics and table 2 for a summary of key findings).[25 26]

Mental health impact

Mental health was a critical focus of the survey (questions 16–18). The majority of patients in both cohorts reported that their mental health had been impacted by their MBC diagnosis (90% in NI vs 86.7% in ROI). However, 51% of NI patients had been prescribed medication for mental health conditions, such as low mood or anxiety, compared with only 23.7% in ROI, a statistically significant difference (p=0.0008) (see figure 1).

The survey also explored emotional well-being, particularly focusing on anxiety, fear and depression before and after receiving scan results (questions 19 and 20). Although no statistically significant differences were observed, some notable regional variations emerged. A higher proportion of patients in NI (82%) reported anxiety before receiving scan results, compared with 72.45% in ROI. Similarly, more NI patients reported feeling fearful (46% vs 41.84%) and depressed (20% vs 14.8%) compared with ROI patients.

Financial burden

Financial burden was another key area of the survey (questions 50–59), an important and frequently forgotten component of cancer care.[27] A significant difference was observed in patients' perceptions of financial strain, with 50% of NI patients disagreeing that they had sufficient savings or assets to cover treatment costs, compared with 40.8% in ROI (p=0.045). Additionally, ROI patients reported significantly less choice in care-related spending, with 77.5% indicating they had no choice, compared with 56% in NI (p=0.0124) (see figure 2). Despite these differences,

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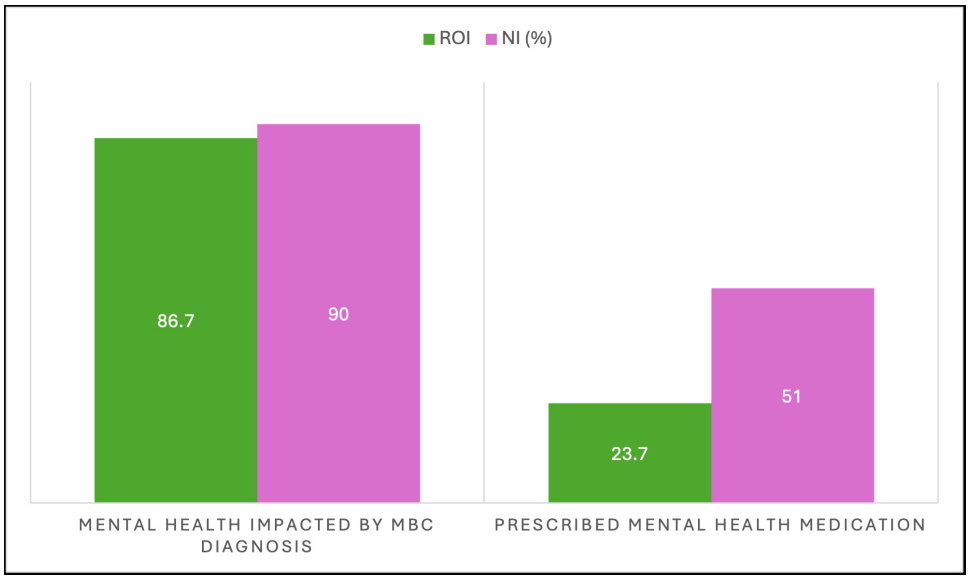

Figure 1 Proportions of patients with MBC in ROI (n=196) and NI (n=50) reporting mental health impacts and prescriptions for mental health conditions. MBC, metastatic breast cancer; NI, Northern Ireland; ROI, Republic of Ireland.

similar proportions of patients in both regions viewed their illness as a financial burden on themselves and their families (56% in NI vs 60.2% in ROI, p=0.250).

Time toxicity

Time spent on managing cancer care, referred to as time toxicity,[24] varied significantly between the regions (questions 60–76). ROI patients reported more frequent visits to oncology day wards or acute oncology service (AOS) units in the preceding 6 months compared with NI patients (p=0.0012). Additionally, ROI patients spent more time in these settings during the same period (p=0.038) (see figure 3).

Despite no statistically significant difference in overall hospital admissions, there was a noticeable trend: 30% of ROI patients had been admitted in the past 6 months, compared with 18% in NI (p=0.3964). Time spent travelling to hospitals also showed a significant regional difference, with shorter travel times reported by NI patients (p<0.0001) (see figure 4).

Palliative care

The survey also explored patients' attitudes towards palliative care services (questions 47–49). Although not statistically significant (p=0.079), there was a clear trend towards greater acceptance of palliative care referrals among NI patients. Specifically, 36.73% of NI patients indicated they would accept a palliative care referral, compared with 23.96% of ROI patients. Additionally, 42.86% of NI patients said they would consider a referral,

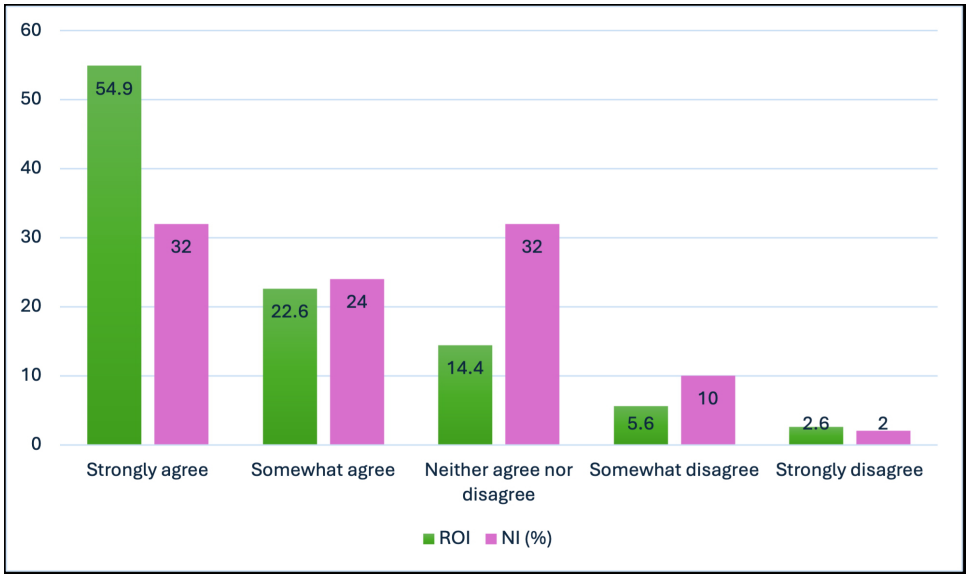

Figure 2 Financial burden: agreement with "I feel I have no choice about the money I spend on medical care" in ROI (n=196) and NI (n=50). NI, Northern Ireland; ROI, Republic of Ireland.

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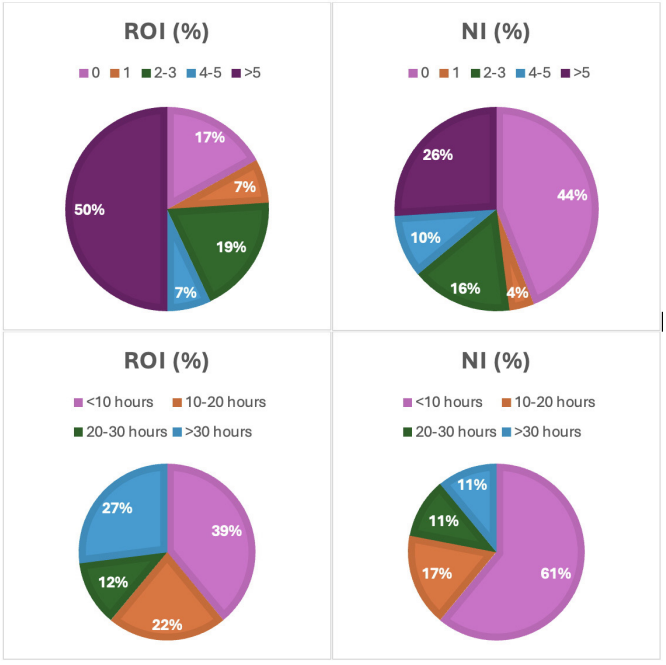

Figure 3 Frequency of visits to oncology day wards or AOS units and time spent in these settings among patients with MBC in ROI (n=196) and NI (n=50). AOS, acute oncology service; MBC, metastatic breast cancer; NI, Northern Ireland; ROI, Republic of Ireland.

compared with 37.5% of ROI patients. Notably, seven ROI patients (3.65%) stated they would certainly refuse a palliative care referral, while no NI patients expressed this view.

Sexual health, fertility and menopause

Questions related to sexual health, fertility and menopause (questions 36–40) revealed a statistically significant difference in the percentage of patients seeking medical advice for changes in their sex life. Specifically, 26.5% of ROI patients sought medical advice for changes in their sex life, compared with 9.4% of NI patients (p=0.0496). Additionally, a higher proportion of NI patients selected 'Prefer not to say' (10% vs 7.7%). Embarrassment was more commonly cited by NI patients as a reason for not seeking medical advice, potentially reflecting cultural differences. While there were no statistically significant differences in the support received for sexual health concerns (82% in NI vs 73.3% in ROI, p=0.357), the observed variations could have clinical relevance, particularly in tailoring support services to meet regional needs.

Regarding menopausal symptom support, 64% of ROI patients expressed dissatisfaction with the support offered, compared with 85% of NI patients (p=0.2052). Although not statistically significant, this could have clinical implications, highlighting a potential area for improvement in patient care in NI.

Communication needs during diagnosis

The survey explored communication needs, including who delivered the MBC diagnosis and the presence of support persons during this critical moment (questions 24–27). No statistically significant difference was found in who delivered the diagnosis (p=0.0981), with most patients in both ROI and NI receiving their diagnosis from a consultant (81% in ROI vs 72% in NI). Additionally, 60% of ROI patients had a family member present during their diagnosis, compared with 43% of NI patients (p=0.393). Although this difference is not statistically significant, it may reflect cultural or social differences, or differences in clinical practice, with ROI patients being more likely to have family support during the diagnosis process.

Exercise and physical activity

The survey also addressed the impact of cancer on exercise and physical activity (questions 41–46). Regarding

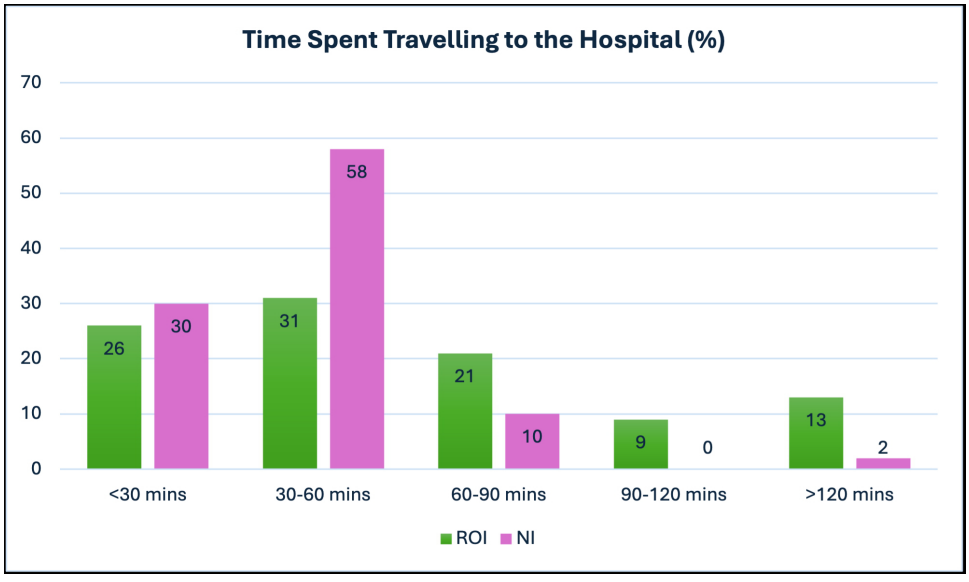

Figure 4 Comparison of travel times to hospital appointments for patients with MBC in ROI (n=196) and NI (n=50). MBC, metastatic breast cancer; NI, Northern Ireland; ROI, Republic of Ireland.

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increased exercise since diagnosis, some regional differences were observed, though they were not statistically significant (p=0.061). Specifically, 52% of NI patients reported increasing their exercise activities since diagnosis, compared with 37.4% of ROI patients. This difference may be partly explained by enrolment in medical exercise programmes, with NI patients reporting significantly higher participation (p<0.0001), suggesting better integration of exercise as a component of cancer care in NI. Notably, 40% of NI patients reported using the Move More programme offered by Macmillan Cancer Support.

Access to medical records

Finally, access to medical records was explored (question 10). Although the difference was not statistically significant (p=0.131), a regional variation was noted, with 37% of ROI patients having access to medical records compared with 26% in NI. Most patients in both cohorts expressed a desire for access to their medical records either all the time or upon request.

DISCUSSION

Despite the evolution of distinct healthcare systems in ROI and NI, notable similarities exist in the experiences of patients with MBC across both regions. A significant majority of patients reported that their mental health was impacted by their MBC diagnosis, with nearly identical rates (90% in NI vs 86.7% in ROI). These findings suggest that, regardless of healthcare structure, MBC has a profound psychological effect on patients across the island of Ireland. Similarly, both cohorts highlighted the financial burden associated with their illness, with 56% of NI patients and 60.2% of ROI patients reporting financial strain. These common challenges highlight the universal need for robust mental health and financial support systems for patients with MBC in both regions.

Additionally, both ROI and NI patients demonstrated openness towards palliative care referrals, with a notable portion in both regions indicating that they would consider or accept palliative care when suggested. Although there were regional differences in the acceptance rates of palliative care referrals, the trend suggests that many patients in both regions recognise its importance in managing the complex needs of advanced cancer. This need is already being addressed in the respective cancer strategies for each region; NI's *Cancer Strategy 2022-2032* emphasises increasing awareness and integration of palliative care, aiming for every patient with non-curative cancer to have access to a palliative care key worker.[8] Similarly, ROI's *National Cancer Strategy 2017-2026* prioritises specialist palliative care assessments for patients with stage IV cancer, with a target of 90% coverage.[6]

However, key differences between the healthcare systems of ROI and NI have led to significant disparities in certain aspects of care. One of the most striking differences is in the use of mental health medications: NI patients were more likely to receive medication for psychological distress (51% vs 23.7%, p=0.0008). This higher rate of prescribing in NI may reflect greater psychological distress among patients, or it could indicate a heavier reliance on pharmacological treatment in the absence of sufficient psycho-oncology services. The higher rate of antidepressant use in NI could be partly explained by broader prescribing patterns in the region. For example, during 2023/2024, approximately one in four females (26%) and 15% of males in NI received antidepressant medication, with prescribing rates in the most deprived areas being over one and a half times higher than in the least deprived areas.[28] These factors, coupled with the under-resourcing of psycho-oncology services and long waiting times for referrals,[8] likely contribute to an over-reliance on medication as a more immediate solution. In contrast, ROI has made significant strides in integrating psychological support into oncology care, establishing a more structured approach to addressing cancer-related distress through enhanced psycho-oncology services and the NCCP-led Alliance of Community Cancer Support Centres.[29] Cultural differences in how mental health is perceived and accessed across the regions may also play a role in these disparities.

Financial strain was another area where significant disparities emerged. ROI patients reported a higher level of financial burden, with 77.5% indicating they had no choice over care-related spending, compared with 56% in NI (p=0.0124). This greater financial burden in ROI likely reflects differences in the healthcare systems. In NI, NHS cancer care is free at the point of contact, with minimal reliance on private sector oncology services. Patients in NI benefit from free prescriptions, complimentary parking for treatment appointments, and travel expenses under the Hospital Travel Cost scheme for those on benefits.[9 30] Additionally, the NHS in NI ensures relatively good access to drug treatments through the National Institute for Health and Care Excellence.[31] In contrast, one previous study by Collins *et al* highlighted the significant financial impact of cancer treatment on ROI patients, especially among women, those aged under 50, individuals living more than 25 km from treatment centres and patients without a medical card.[32]

ROI patients reported significantly more frequent visits to oncology day wards or AOS units and spent more time in these settings compared with NI patients, resulting in increased time toxicity (p=0.0012 and p=0.038, respectively). These differences in time toxicity have important implications for patient quality of life and overall satisfaction with care. The precise reasons for these disparities between NI and ROI remain unclear, but NI has implemented several services that likely contribute to reduced time toxicity. In NI, hospital Trusts operate an oncology telephone helpline, with three Trusts providing AOS assessment units. These units triage calls, providing patient assessment, treatment and either discharge or admission, which helps reduce emergency department visits and unnecessary hospital admissions.[33 34] Additionally, many patients with MBC receiving oral systemic

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Table 3 Considerations for other countries

Key issue	Lessons from ROI and NI	Recommendations for other countries
Psycho-oncology integration	A structured psycho-oncology service with multidisciplinary teams is preferable to reliance on medication alone.	Expand psycho-oncology services to prioritise therapy and holistic mental healthcare over medication reliance.
Financial burden support	Providing financial assistance for travel, medications, and loss of income can alleviate patient burden.	Introduce financial assistance programmes, similar to NHS travel support, to ease patient financial distress.
Time toxicity reduction	Implementation of AOS units and telemedicine can reduce unnecessary hospital visits.	Adopt telemedicine and regional AOS assessment units to minimise hospital visits and reduce time toxicity.
Palliative care access	Earlier and wider integration of palliative care services improves patient acceptance and experience.	Enhance palliative care integration, ensuring that referrals are encouraged early in the patient's care journey.
Sexual health support	Proactive communication, specialist support, and normalising discussions around intimacy and relationships improve sexual healthcare for cancer patients.	Develop comprehensive sexual health support services for cancer patients, including education, counselling and medical interventions, to improve quality of life and address unmet needs.
Exercise and rehabilitation	Exercise programmes embedded in cancer care, like NI's 'Move More' initiative, can improve quality of life.	Develop and promote structured, medically supervised exercise programmes tailored to cancer patients.
Medical record access	Digital access to medical records, as seen with NI's Encompass system, enhances patient autonomy and engagement in their care.	Implement digital patient record access systems to enhance transparency and enable patient self-management.

AOS, acute oncology service; NHS, National Health Service; NI, Northern Ireland; ROI, Republic of Ireland.

anti-cancer therapies (SACT), such as cyclin-dependent kinase 4/6 inhibitors, have pretreatment blood tests performed either at their general practitioner or cancer centre, with medications delivered in 3-month supplies through a home delivery service.[35] Virtual consultations are now the standard for most routine follow-ups, with in-person appointments mainly reserved for discussing scan results.

The discrepancy in hospital admissions indicates that ROI patients may experience more frequent hospitalisations, potentially due to differences in healthcare access, assessment systems, disease severity or other systemic factors. In ROI, the NCCP introduced an acute oncology clinical nurse specialist (CNS) role in each of the 26 hospitals providing SACT in 2020. The NCCP also established an AOS nursing forum to reduce emergency department visits and unnecessary hospital admissions.[36] However, in ROI, these CNSs are typically based in oncology day wards, unlike in NI where dedicated AOS units are more common, with Cork University Hospital being an exception. Differences in time spent travelling to the hospital may partly be explained by NI being a smaller geographic region than ROI, but they could also reflect better distribution of healthcare facilities or differences in healthcare planning strategies between the regions. Both NI and ROI use a hub-and-spoke model for cancer service delivery, but regional variations in facility distribution could influence patient travel times.[8 36]

There was a trend towards increased exercise activities among NI patients since their cancer diagnosis compared with ROI patients (52% vs 37.4%, p=0.061). Notably, enrolment in medical exercise programmes was significantly higher in NI than in ROI (p<0.0001), largely due to 40% of NI patients participating in the Move More exercise programme offered by Macmillan Cancer Support. In terms of medical record access, ROI patients showed a trend towards improved access (37% vs 26%, p=0.131), though the majority of patients in both regions expressed a desire for regular access to their records. In ROI, the Freedom of Information Act 2014 grants individuals the right to access personal medical records from public healthcare providers, but private hospitals are not covered under this legislation.[37] In contrast, at the time of the survey, NI patients were required to request medical records via Subject Access Requests under data protection legislation. However, NI is now implementing the new *Encompass* system, including the patient app MyCare, which provides direct access to appointments, test and scan results, and full medical records. The system was first launched in the South Eastern Trust in November 2023 and expanded to the Belfast Trust in June 2024, with full implementation across all Trusts expected by the end of 2025.[38] These findings highlight important regional disparities in the provision and management of healthcare services for patients with MBC.

A major strength of this study is its focus on a cross-border comparison, offering a comprehensive view of MBC care across the island of Ireland. The sample size, comprising 246 respondents, reflects the population distribution between ROI (80%) and NI (20%),

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enhancing the representativeness of the findings.[25 26] The inclusion of similar patient cohorts in both regions strengthens the study's comparability. However, the absence of a formal sample size means the survey was not powered to detect statistical differences, and the smaller NI sample size (50 respondents) further limits statistical power in some analyses. Additionally, past MBC studies in Ireland have excluded NI, complicating direct comparisons with historical data.[12] The survey's original design did not specifically target regional disparities, and the use of multiple statistical tests and p values raises the potential for identifying differences that may not be meaningful (ie, due to multiplicity). Despite these limitations, the study offers valuable insights into regional healthcare differences that could guide future research and policy development.

The findings from this study offer several important implications for the next cancer strategies in both ROI and NI, particularly in addressing disparities in MBC care. In ROI, there is a pressing need to reduce time toxicity and alleviate the financial burden faced by patients with MBC. Initiatives that streamline care through telemedicine or community-based services, along with the rollout of AOS assessment units on an all-island basis, could help reduce hospital visits and unnecessary admissions, easing the strain on patients. These initiatives may be particularly helpful for patients living in remote or rural areas, where longer travel times and reduced access to specialist care can exacerbate time toxicity and financial strain. Additionally, targeted financial support mechanisms for patients with metastatic cancer should be prioritised. While NI has seen a higher reliance on mental health medication, this does not equate to better psychological outcomes, and both regions should aim for a balanced approach that enhances access to psycho-oncology services. Expanding access to structured exercise programmes in ROI could further benefit patients, improving overall outcomes. Equitable access to palliative care, psycho-oncology, medical social work and other support services should be a cornerstone of the next cancer strategies in both regions, ensuring that patients with MBC receive consistent, high-quality care. Future research should aim to further explore these disparities and gather data to inform policies that lead to more effective, patient-centred interventions across the island of Ireland. Additionally, lessons from this study highlight targeted interventions that can inform cancer care strategies internationally (see table 3 for considerations for other countries).

CONCLUSIONS

This study is the first of its kind to explore regional differences in MBC care between ROI and NI, highlighting both common challenges and distinct disparities in patient experiences. Conducted as a patient-led initiative, the study prioritised the voices and perspectives of individuals with MBC to ensure a comprehensive understanding of their care experiences. While both regions face similar psychological and financial burdens, differences in mental health medication use, time toxicity, palliative care and exercise programme participation suggest opportunities for targeted interventions. Addressing these disparities through bidirectional learning and cross-border collaboration could lead to more equitable and comprehensive care for patients with MBC across the island of Ireland. Future research should focus on understanding the root causes of these differences to enhance patient outcomes and quality of life in both regions.

Patient and public involvement

Patients with MBC were involved at every stage of this research process. The project was conceived and co-led by a former research scientist and patient with MBC. Patients played a central role in developing the research questions and outcome measures by identifying and prioritising topics they felt were most important, reflecting their lived experiences and priorities.[39–41] Advocacy groups facilitated recruitment by promoting the survey through their networks and social media channels. Furthermore, patients reviewed and contributed to the writing of this manuscript, ensuring that the findings were presented in a way that aligned with their perspectives. The results of the survey have informed several patient-driven recommendations on improving the management of MBC in ROI and NI.[23 42]

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REFERENCES

1 Townsend C. The partition. Ireland divided, 1885-1925. Allen Lane; 2021.
2 UK Parliament. National health service bill. Official report of house of commons (hansard). 1946.
3 Health Service Executive. HSE annual report. 2005.
4 Cancer Strategy Group. Cancer services in Ireland: a national strategy. 1996.
5 National Cancer Forum. National cancer strategy, a strategy for cancer control in Ireland. 2006.
6 Cancer Strategy Steering Group. National cancer strategy, 2017-2026. 2017.
7 Department of Health Northern Ireland. Regional cancer framework – a cancer control programme for NI. 2008.
8 Department of Health Northern Ireland. A cancer strategy for NI 2022-2032. 2022.
9 Connolly S, Brick A, O'Neill CJ, *et al*. An analysis of the primary care systems of Ireland and Northern Ireland. The Economic and Social Research Institute (ESRI), Dublin; 2022.
10 Pierse T, Barry L, Glynn L, *et al*. A comparison, for older people with diabetes, of health and health care utilisation in two different health systems on the island of Ireland. *BMC Public Health* 2020;20:1446.
11 Aranda S, Schofield P, Weih L, *et al*. Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *Eur J Cancer Care* 2005;14:211–22.
12 Battley JE, Beamish R, O'Connor M, *et al*. PO145 ICORG 13-01 ABC SURVEY: ARE WE MEETING THE NEEDS OF PATIENTS WITH ADVANCED BREAST CANCER (ABC) IN IRELAND? A NATIONWIDE SURVEY. *The Breast* 2015;24:S71–2.
13 Docherty C, Lester L, O'Reilly S. Attitudes toward Palliative Care and End of Life Issues: A Prospective Survey in Patients with Metastatic Cancer. *Ir Med J* 2016;109:405.
14 Fallowfield L, Starkings R, Palmieri C, *et al*. Living with metastatic breast cancer (LIMBER): experiences, quality of life, gaps in information, care and support of patients in the UK. *Support Care Cancer* 2023;31:459.
15 de Ligt KM, de Rooij BH, Hedayati E, *et al*. International development of a patient-centered core outcome set for assessing health-related quality of life in metastatic breast cancer patients. *Breast Cancer Res Treat* 2023;198:265–81.
16 Fallowfield L, Boyle FM, Travado L, *et al*. Gaps in Care and Support for Patients With Advanced Breast Cancer: A Report From the Advanced Breast Cancer Global Alliance. *JCO Glob Oncol* 2021;7:976–84.
17 Roberson ML, Henricks A, Woods J, *et al*. Re-imagining metastatic breast cancer care delivery: a patient-partnered qualitative study. *Support Care Cancer* 2023;31:735.
18 O'Sullivan CC, Larson NL, Vierkant RA, *et al*. Advocate-BREAST: advocates and patients' advice to enhance breast cancer care delivery, patient experience and patient centered research by 2025. *Arch Public Health* 2024;82:119.
19 Arık A, Dodd E, Cairns A, *et al*. Socioeconomic disparities in cancer incidence and mortality in England and the impact of age-at-diagnosis on cancer mortality. *PLoS One* 2021;16:e0253854.
20 O'Reilly D, McLaughlin R, Ronayne C, *et al*. Cost and public reimbursement of cancer medicines in the UK and the Republic of Ireland. *Ir J Med Sci* 2023;192:541–8.
21 Lohfeld L, Sharma M, Bennett D, *et al*. Impact of the COVID-19 pandemic on breast cancer patient pathways and outcomes in the United Kingdom and the Republic of Ireland - a scoping review. *Br J Cancer* 2024;131:619–26.
22 Mclaughlin RA, O'Reilly D, Ronayne C, *et al*. 152P Analysis of patient access to breast cancer drugs in the USA and Europe with a focus on the UK and Ireland. *Ann Oncol* 2021;32:S86.
23 Gaynor S, O'Meara Y, Mulvaney E, *et al*. A patient-led survey on information and communication needs of patients with metastatic breast cancer in Ireland and Northern Ireland (CTRIAL-IE 23-05). *Breast* 2025;79:103837.
24 Baltussen JC, Cárdenas-Reyes P, Chavarri-Guerra Y, *et al*. Time toxicity among older patients with cancer treated with palliative systemic therapy. *Support Care Cancer* 2024;32:621.
25 Central Statistics Office. Census of population 2022 - summary results. 2022.
26 Information on Census 2021 in Northern Ireland. Northern Ireland statistics and research agency. 2021.
27 Ngan TT, Tien TH, Donnelly M, *et al*. Financial toxicity among cancer patients, survivors and their families in the United Kingdom: a scoping review. *J Public Health (Oxf)* 2023;45:e702–13.
28 Department of Health Northern Ireland. Publication of general pharmaceutical services for Northern Ireland, annual statistics 2022/23. 2024.
29 National Cancer Control Programme. NCCP best practice guidance for community cancer support centres (2nd edition). 2022.
30 National Health Service. Healthcare travel costs scheme (HTCS). 2023. Available: https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs
31 Fitzpatrick OM, Khan MR, McNevin CS, *et al*. 1553P Access to EMA approved drugs in Europe, disparities across a border. *Ann Oncol* 2024;35:S944–5.
32 Collins DC, Coghlan M, Hennessy BT, *et al*. The impact of outpatient systemic anti-cancer treatment on patient costs and work practices. *Ir J Med Sci* 2017;186:81–7.
33 Putt L, Jones P. The role of the specialist acute oncology nurse in the new acute oncology services. *Clin Oncol (R Coll Radiol)* 2014;26:125–7.
34 Reid J, Porter S. Utility, caller, and patient profile of a novel Chemotherapy Telephone Helpline service within a regional cancer centre in Northern Ireland. *Cancer Nurs* 2011;34:E27–32.
35 Vidall C. Providing community oral chemotherapy services. *Eur J Cancer Care (Engl)* 2010;19:29–34.
36 National Cancer Control Programme. NCCP systemic anti-cancer therapy model of care. 2022.
37 Government of Ireland. Freedom information act 2014. 2014.
38 Department of Health Northern Ireland. Digital revolution for NI patient records. 2023. Available: https://www.health-ni.gov.uk/news/digital-revolution-ni-patient-records
39 Jackson T, Pinnock H, Liew SM, *et al*. Patient and public involvement in research: from tokenistic box ticking to valued team members. *BMC Med* 2020;18:79.
40 A Spears P. Patient Engagement in Cancer Research from the Patient's Perspective. *Future Oncol* 2021;17:3717–28.
41 Costa Alencar AB, Selig WKD, Geissler J, *et al*. Adopting recommendations for implementing patient involvement in cancer research: a funder's approach. *Res Involv Engagem* 2023;9:6.
42 Gaynor S, Duane FK, Mulvaney E, *et al*. Self-expressed needs and gaps in our care of metastatic breast cancer (MBC): An all-Ireland patient-led online survey (CTRIAL-IE 23-05). *JCO* 2024;42:12058.

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