Understanding the challenges of cancer and socio-economic inequality in Ireland

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The present report does not represent the collective views of TASC and MSD, but only of the respective author. The responsibility of TASC is limited to approving its publication as worthy of consideration.

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Abbreviations

FCT	Fundamental cause theory
MSD	Merck Sharp & Dohme Ireland (Human Health) Ltd
SES	Social-economic status
TASC	Think-tank for Action on Social Change
TILDA	Irish Longitudinal Study on Ageing
WOM	Word of mouth

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Executive Summary

Executive Summary

Merck Sharp and Dohme Ireland (MSD) initially commissioned the Think-tank for Action on Social Change (TASC) to examine how socio-economic inequalities influence access to and delivery of cancer services for specific cancers known to exhibit higher morbidity rates among disadvantaged and marginalised population groups; namely cancers of the lungs, stomach, head-and-neck, and cervix.[1] However, the central message from those working directly with cancer patients from disadvantaged groups is that much more consideration is needed in service delivery and design to the socio-economic barriers associated with the diagnosis of, treatment of, and recovery from all cancers experienced by those patients.

The differences in the economic and social resources available to individuals with cancer fundamentally determine their whole cancer journey including incidence and outcomes associated with certain cancer types. The barriers created by social inequality affect their experience from pre-diagnosis through to post-treatment. These include delays accessing primary services; less GPs in deprived areas, and direct and indirect financial costs of treatment, such as transport and loss of income. Disadvantaged patients also experience psychological barriers to accessing services, such as self-blame and stigma (which may be made worse by healthy lifestyle public health messaging) and the legitimate fear of the financial costs of becoming a cancer patient. The pandemic has aggravated these barriers. Patients, for example, have delayed reporting cancer symptoms for fear of contracting the virus while visiting GPs and existing cancer patients have been fearful of contracting Covid and then losing their jobs. In addition, as the report will discuss, having cancer exacerbates existing socio-economic inequalities.

This report argues that if cancer outcomes are to significantly improve, the Irish state needs to systemically redesign cancer care services. This includes strengthening the relationship between hospitals and community services and across cancer support services provided by different sectors. It also includes state investment in amenities, such as parks and gyms, the use of which is actively encouraged by current policy for the recovery and post-treatment stages of the cancer pathway. Such a redesign responds to and supports people in deprived groups, from pre-diagnosis to post-treatment. Without such a system-led acknowledgment of the impact of inequality on the cancer journey, technological advances in treatment will not significantly improve cancer outcomes for marginalised groups. Likewise, the findings presented here highlight the need for larger-scale studies which specifically address socio-economic inequalities in determining cancer pathways in Ireland.

The National Cancer Control Programme Plan (2022)[2] identified four determining groups of factors in cancer diagnosis in Ireland, focusing on the disease, the patient, health care professionals and the health system. This report contributes to policy, practice and further research by providing insight into two of those factors. The first is how policymakers can better identify structural barriers to individual patient cancer pathways in particular at the stages of early diagnosis, recovery and survivorship. The second is identifying structural and systemic inequalities in the Irish healthcare system at the individual, community and structural level.

The findings from the report are based on three areas of research:

1. Secondary analysis of literature on the link between cancer and socio-economic deprivation; policy measures to date; inequalities in incidence and outcomes associated with certain cancer types; access

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[1] This research was commissioned and funded by MSD. MSD have had no editorial influence, other than a review to ensure all content is non-promotional in nature.

[2] National Cancer Control Programme, 2022

to diagnoses and treatment for low-income communities, and how structural inequalities influence lifestyles and behaviours that can result in poor overall health.

2. Semi-structured interviews with those working directly with healthcare professionals, community health workers, oncology experts, and representatives of relevant charity organisations working with cancer patients in disadvantaged groups.

3. A roundtable event with experts and representatives of civil society organisations working with cancer patients.

The purpose of this report is to:

- understand the barriers to early diagnosis faced by vulnerable patients
- understand the barriers affecting cancer recovery and survivorship
- evaluate the tracking of cancer inequalities by healthcare providers
- evaluate healthcare services' effectiveness at reducing cancer inequalities
- contribute to policy, practice and further research on reducing barriers for vulnerable groups in their cancer care as well as improving the monitoring and reducing of cancer inequalities
- provide valuable qualitative input into the roll-out of the National Cancer Strategy in 2023.[3]

The research identifies that:

1a) Financial stress affects a wide range of people during cancer treatment including:

- those on low incomes
- higher numbers of older people on pensions
- middle to higher earners who lose income as a result of their diagnosis, subsequent treatment and unforeseen costs
- parents of young children
- those who cannot afford private insurance and are not eligible for medical-card coverage

1b) Characteristics of financial stress experienced by socio-economically disadvantaged people in Ireland include:

- The costs associated with cancer treatment and recovery tend to multiply over a person's cancer journey
- Facing a financial debt and health crisis simultaneously
- Associated costs interrupt continuity of cancer treatment, especially for those concerned with their additive expenditures
- Additional and unforeseen household energy and other costs because of having a cancer diagnosis
- Childcare costs for younger patients

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[3] Department of Health (2022)

2) Individual barriers to accessing services include:

- Reticence to come forward for testing even at the stage of experiencing symptoms
- Barriers accessing primary health care services: getting a 'foot in the door'
- A cycle of behavioural self-blame, shame, 'stigma and fatalism'
- Lack of confidence in services (fears of discrimination)
- Language and literacy barriers
- Moving residence, or being homeless, while on a waiting list for treatment, with the result that you are no longer in the catchment area
- In general, these barriers may affect screening uptake, decision making, risk perception (including fear of the cancer progressing), medication adherence and follow-up compliance

3) Insufficient financial support during delivery of cancer care services includes the following:

- Lack of recognition of a patient's indirect and direct costs associated with cancer diagnosis
- Lack of financial support with accommodation costs (if patients live too far away)
- Ambulance and A&E fees for third-tier patients without insurance or medical cards
- Lack of financial support with transport costs for travel to hospitals
- Continued obligation to pay parking fees, which are a major barrier for attendance at regular treatment

4) Barriers created by service provision (or lack of it) include:

- Underfunding of General Practice
- Inequitable geographical distribution of services: a postcode lottery with less services in deprived areas
- Inequitable model of clinical trials funding, affecting access to novel treatment
- Lack of screening services for some cancers, such as lung cancer
- Inconsistency in structure of pathways from diagnosis to relevant specialists
- Lack of system-led survivorship service design
- Lack of financial advisory point of contact at diagnosis
- Lack of access to and financial support with use of post-recovery amenities e.g. green space and gyms (as promoted by healthier lifestyle messaging on cancer)

5) Barriers created by data collection and management:

- A combination of paper-based and electronic data collection
- Lack of readily available and reliable population estimates
- Lack of real-time estimations of waiting lists by cancer type
- Lack of detailed reliable national statistics breaking down those receiving treatments by cancer type
- Lack of unique health identifiers and problems of double counting in registry data

- No consistent hospital collection of socio-economic identifiers

Policy responses

To improve the incidence and outcomes of cancers in Ireland, cancer services need to incorporate support for the financial, psychological and service created barriers experienced by disadvantaged groups. Policymakers also need to further investigate the ways in which inequalities create barriers for disadvantaged patients across the whole cancer journey, from pre-diagnosis to post treatment. Targeted investment is needed in developing better integration between hospital and primary care and greater capacity in primary care in deprived areas. This includes expanding cancer prevention and early diagnosis interventions in those areas (including using broader ways of screening); investing in localised and community facing services and fostering relationships between marginalised groups and local primary care. Finally, investment is needed, in line with the public health promotion of healthier lifestyles, in amenities that can be accessed by more disadvantage groups during post-treatment recovery.

Introduction

Introduction

This report provides further understanding of how socio-economic inequalities, especially barriers to early diagnosis and support services in post-recovery, can translate into inequalities in cancer care, which can then, in turn, exacerbate socio-economic inequalities.

Drawing on interview data and a roundtable with key practitioners, the report demonstrates that people on low incomes and marginalised groups are disproportionately affected by inequalities in cancer care provision. It outlines the range of barriers experienced by socio-economically deprived groups to early diagnosis and to post-treatment phases of a cancer journey and to what extent they are supported by services. The patients themselves, in addition to dealing with their physical health, may also experience a range of mental health barriers from pre-diagnosis to post treatment recovery. The report suggests that aspects of provision need to expand, and receive greater investment, before socio-economic inequalities are reduced in cancer care in Ireland.

Research methodology

This research report is based on qualitative data collected between March 2022 and June 2022 through:

1. Semi-structured interviews *(n=20)*, allowing for open-ended questions, with healthcare professionals, community health workers, oncology experts, and representatives of relevant charity organisations[4];

2. A closed roundtable event held in person engaging experts and representatives of civil society organisations *(n=12)* in a dialogue. Four prompt questions were used to guide the discussion.[5]

The participants in this study work directly with cancer patients and some explicitly with low-income and marginalised groups. It was important that respondents had a working knowledge of challenges faced by their sector. Sampling was nationwide, and participants were recruited to the study through purposive sampling[6] by email. Interviews were conducted either in person or via teleconferencing software. Interview length ranged between 30 minutes to 50 minutes. Informed consent was given for each interview. All data was transcribed and analysed using thematic ordering to explore common patterns across interviews.

The research also included secondary analysis to inform the qualitative research by providing a contextual description of the link between cancer and socio-economic deprivation; assessing the effectiveness of policy measures to date and identifying potential policy measures to reduce inequalities in incidence and outcomes associated with certain cancer types; and examining access to diagnoses and treatment for low-income communities, and how structural inequalities influence lifestyles and behaviours that can result in poor overall health.

The current study is limited to qualitative data and a small sample size, which do not allow for generalisability of findings. Studies have recently begun to look at inequalities involving socio-demographic comparisons such as gender and ethnicity when analysing inequalities in Irish healthcare. The findings presented here highlight the need for larger-scale studies which specifically address socio-economic inequalities in determining cancer pathways in Ireland.

[4] See Appendices 3 and 4 for information sheet provided to respondents and interview topic guide

[5] See Appendices 1 and 2 for information sheet on roundtable participants and topic guide

[6] Purposeful sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources (Patton, 2002). This involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Panlinkas et al., 2016)

Fundamental causes of health inequalities

Health inequalities are a global feature within and across populations. Inequalities in lifetime health and healthcare coverage manifest in high-income, medium-income and low-income countries around the world. Many Western countries are a long way off from offering healthcare which does not result in financial hardship, and which is both high quality and universally accessible. The WHO defines universal health coverage (UHC) as coverage whereby "everyone receives quality health services, when and where they need them, without incurring financial hardship"[7] and has sought to monitor progress towards Sustainable Development Goals in Health by looking at changes in the distribution of universal health coverage across countries. Ireland is unique in Europe for being a country more similar to the USA in the structure of its health system, in that there is no universal right to access free primary health care. Lack of equitable and universal access to healthcare is especially concerning given the rise in inequalities based on income and wealth levels within western populations.

The relation between health status and socio-economic status will be more strongly linked in countries which have privatised models of healthcare. There is growing evidence that pervasive socio-economic inequality, as experienced in the USA over the last few decades, has deepened health inequalities over peoples' lifetimes, and further, that wealth-based health inequality passes between generations.[8] Trends in the health effects of inequalities likewise encompass cancer outcomes. A US study used national cancer registry and longitudinal survey data to document socio-economic disparities in cancer mortality, incidence, and survival rates from all-cancers combined and major cancers from 1950 to 2014. Their estimates show that patterns in all-cancer mortality have been widening (dramatically for some cancers) over time – with people on lower incomes having a much higher mortality and incidence rates than their more affluent counterparts. The research also directly linked cancer mortality and incidence disparities to structural inequalities and associated behaviours, such as smoking, obesity, physical inactivity, diet, alcohol use, screening, and treatment.[9]

In the current report, we take a social determinants approach to health inequalities, while emphasising the structural causes of cancer outcomes. Fundamental Cause Theory (FCT), as proposed by Link and Phelan (2005),[10] offers a conceptual framework through which to interpret how divergences in health within populations are inextricably tied to socio-economic status (SES). In their theory, low socio-economic status confers a lower set of resources with which to combat or mitigate the consequences for health of stressful life conditions. They argue that understanding health outcomes has less to do with pinpointing specific pathways between for example, unhealthy or protective health behaviours, and the incidence of preventable diseases, and more to do with understanding the determining forerunner of health disparity. This disparity is a 'fundamental' cause of disease incidence and calls for highlighting in analysis of health conditions, social inequality of income, education, occupation and wealth.[11] The idea is that over time or in different countries, proximate risk or protective factors between disease and specific channels of disadvantage will change and be replaced, but the underlying association between fundamental SES, social inequality and health remains persistently in place.

FCT provides us with a departure point, and in the next section we explore how the literature has defined socio-economic inequality and used this measure to examine the myriad ways that cancer incidence and outcomes are impacted by this type of inequality.

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[7] Tracking Universal Health Coverage, 2021

[8] Chauvel *et al.*, 2021

[9] Singh and Jemal, 2017

[10] Link and Phelan, 1995

[11] Rydland *et al.*, 2020

Why socio-economic inequality matters for cancer care

Socio-economic status is a measure which is used internationally to capture inequalities in health and is covered in ten national and regional data collections in Ireland.[12] There are a number of different ways the literature defines socio-economic status, but the most frequent measures tend to be those more readily available in national observational or registry datasets such as people's education status, occupation, or a combination of the two. Income, wealth and social class also appear as indicators of socio-economic status. In Ireland, a common measure refers to social deprivation levels of a geographical area, namely the Pobal Deprivation Index which is constructed on the basis of census data by profiling demographic, social class and employment profiles of populations within small areas. In this qualitative report we make reference to the wide-range of socio-economic status markers as frequently appearing in policy and public debate, from education to income, class as well as social deprivation.

The National Cancer Strategy (2017-2026) has underlined the critical role of socio-economic status on cancer mortality rates across Ireland.[13] Certain cancers disproportionately affect low SES population groups. Among them are lung cancer, cervical cancer, stomach cancer and head and neck cancer.

Lung, stomach, head and neck, and cervical cancer

Socio-economic status is known to be closely linked to cancer incidence and outcomes, in particular in relation to certain types of tumours, including lung cancer and head and neck cancer. The National Cancer Registry of Ireland produced a report on cancer inequalities in 2016[14] which concluded that there is:

- Higher incidence of cancer prevalent in more deprived populations, overall and for stomach, lung and cervical cancers
- Lower survival rates of cancer patients from more deprived populations, overall and for six cancer types: stomach, colorectal, lung, breast and prostate cancers, and lymphoma
- Lower proportions of early-stage or higher proportions of later-stage cancers among more deprived populations for stomach, breast and prostate cancers and melanoma
- Lower proportions of patients surgically treated in more deprived populations, overall and for stomach, colorectal, lung, breast and prostate cancer

Once age and sex are controlled for, the stage of disease progression at which patients from the most and least deprived areas in Ireland present at diagnosis are particularly visible for stomach and breast cancer, for which there is a 7 percentage-point differential in patients presenting with stage IV stomach cancer from the 20% most deprived population compared with the 20% least deprived population in Ireland.[15]

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[12] Department of Health, 2017

[13] Carroll *et al,* 2021

[14] Walsh *et al,* 2016

[15] Ibid

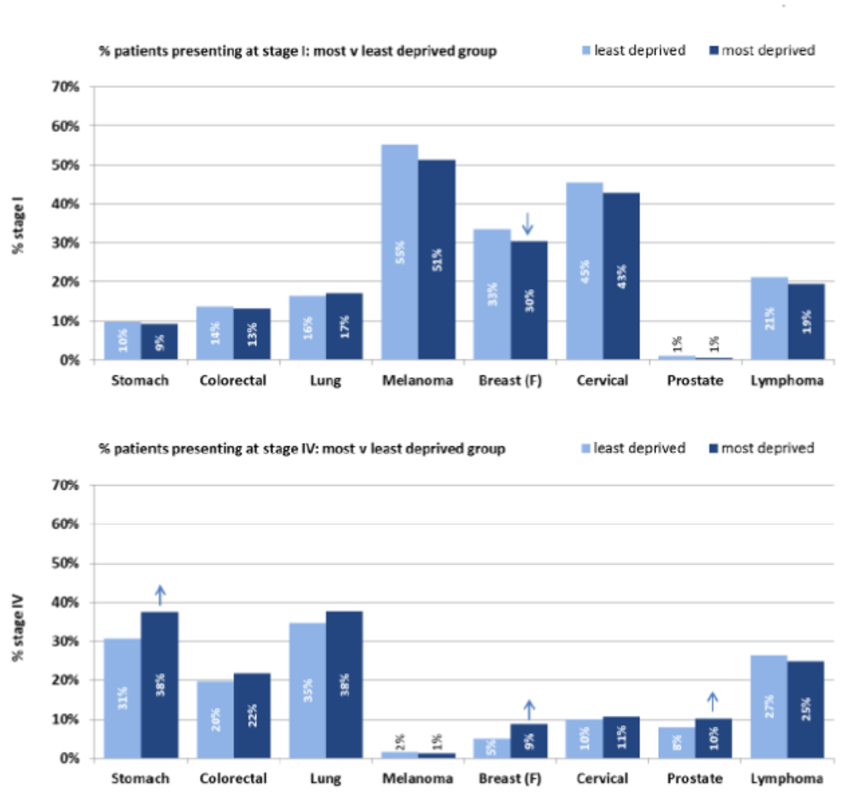

Figure 1: Percentage of patients presenting at stages I and IV, Ireland 2008-2012: comparison between the most and least deprived 20% of the population. Arrows indicate significant differences (adjusted for age and sex.)

Source: NCR 2016

The literature on cancer has begun to demarcate how much of cancer incidence can be attributed to particular modifiable behaviours in a population. One representative study of the four UK nations looked at cancer types and proximate factors of causation, ie., changing behaviours in the population including lung cancer, cervical cancer, and stomach cancer. Smoking (tobacco) and being overweight or obese were estimated to be the leading 'modifiable' causes of cancer incidence in the UK overall, with some differences noted the causal exposure links between men and women.[16]

Health inequalities in Ireland today

Structural inequalities influence particular lifestyles and behaviours and can result in poor overall health. For instance, Cancer Research UK has identified how particular behaviours are essential for lowering a person's cancer risk. These include: maintaining a healthy weight and a high-fibre diet with fruits and vegetables, consuming less alcohol and not smoking, wearing sunscreen and limiting sun exposure, eating less processed meat and red meat, and exercising.[17] Research has shown how each of these behaviours is socially determined, and those who are on a low income and economically disadvantaged are more likely to have unhealthy behaviours (thus increasing their risk of particular cancers) when compared with people on higher income.[18]

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[16] Brown *et al*., 2018; Cronin et al, 2022

[17] Cancer Research UK, 2020

[18] Marmot, 2019

A 2019 report by the Think-tank for Action on Social Change (TASC) found that "healthcare inequalities in Ireland are very much rooted in socio-economic factors. The ability to pay privately to access lung cancer and brain tumour diagnosis results in important differences between Ireland and [other countries]."[19] Recent estimates from the Irish Cancer Society show that just under two in three people who responded to their survey held private health insurance, however there were 9% of respondents who were in a vulnerable cost situation as they had neither cover from private health insurance nor did they have a medical card.[20] The costs incurred by cancer diagnosis in Ireland's mixed public-private healthcare system can be substantial, and financial distress among lung cancer patients featured in a qualitative study of cancer patients and hospital oncology social workers. Patient distress was found to be most severe among working people, parents with dependent children, as well as those with no savings to draw on (Timmons et al. 2013).[21] An ESRI report also documented that a negative financial impact remains for cancer patients who recover and attempt a return to work. Returning to work and the barriers faced along this journey were greatest among women, a large proportion of which worked in the public sector.[22]

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[19] Doyle et al., 2019
[20] Kantar 2019
[21] Timmons *et al.*, 2013
[22] Connolly, Russell and Henry 2021

Barriers to early diagnosis of cancer among socio-economically disadvantaged populations in Ireland

Barriers to early diagnosis of cancer among socio-economically disadvantaged populations in Ireland

"The first step in the door is the hardest"

Evident in the population studies outlined in the literature review, SES is a leading cause of differential diagnosis at early or late stages of lung cancer, head and neck cancer, cervical cancer, and stomach cancer, all of which affect low-SES and deprived populations disproportionately. Tackling socio-economic inequalities in cancer pathways among the population in Ireland therefore requires a deeper understanding of the multifaceted challenges which result in such skewed social gradients of cancer's disease advancement. From the data collected in our study, it is clear that major challenges appear long before the point at which people receive an official diagnosis of cancer.

First among those facing severe barriers are the most deprived communities in an Irish context. Frontline workers and advocacy groups working in the field of healthcare services provide services to marginalised communities across Ireland, encompassing ethnic minority groups such as Roma, asylum seekers, alongside Travellers, and homeless people. Speaking to them about this work, it was clear that a major barrier to adequate cancer care in the Irish context begins at the first entry point into the healthcare system or at the level of primary service access. As one respondent working with Traveller groups pointed out, the initial issue for the most deprived does not revolve around public-private healthcare divides but rather manifests as lacking a 'foot in the door.' Barriers to access to services are two fold. First, more deprived areas and communities have much less readily available access to local General Practice services than others. Second, marginalised communities face barriers to being referred by a GP for an appointment with specialised hospital cancer services. This was borne out by responses from hospital staff who argued that "when they're in the system, there's no difference [between public and private]" but that it was getting a referral from a GP that presented the greatest barrier for low-SES population groups.

The lack of capacity in the healthcare system at primary service level, particularly GPs, presents one of the greatest challenges to improving equality with reference to more or less advanced stages at which cancer is initially recognised, a patient is referred, and then diagnosed by a cancer specialist. In the words of one consultant, it is the waiting list that impedes access in the Irish health system:

"Access to care remains a problem. Once you get in the system, you're fine. But getting into the system is the problem […] the major barrier would be the beginning. A major barrier is general practice [..,] and then for general practice the barrier then will be, you know, we've 800,000 people on a {hospital} waiting list."

[Interview 1: Consultant, University Hospital]

Irish waiting lists are encountered at primary and secondary care level and are worse where the person cannot pay privately to shorten wait times. The first wait can be weeks or months waiting for a GP appointment depending on locality, especially where socially deprived areas have fewer or no available GPs. The second is the long waiting list described by the hospital consultant above, where patients who have been referred by a GP may be added to a waiting list for several months or years. Ireland's extreme waiting lists will adversely affect the majority of low SES groups in how early a malignant cancerous tumour is found. Yet the impact of delayed diagnostic stage will be the greatest among the most vulnerable populations, including those experiencing or at risk of experiencing homelessness and those with drug addiction issues. For these groups, there is an additional issue that any delay in referral, and especially a delay brought on by waiting for months to get an appointment, will mean the person is no longer living in the same catchment area and becomes unreachable.

"People feeling partly to blame"

The Covid-19 pandemic brought to light another barrier to the diagnosis of cancer in low SES groups in Ireland. Patients will frequently be reticent to come forward for testing even at the stage of experiencing symptoms. Many of our respondents singled out lung cancer in particular as one where the symptoms of disease are often ignored up until the point of emergency admittance to hospital with bleeding in the lungs. As Covid-19 is a respiratory disease, more people came forward to check their symptoms of a cough:

"I think Covid actually, in some ways, it probably helps diagnose patients quicker, because they can come in with symptoms of a cough and you know, symptoms of lung disease. And so, once they were seen, they were diagnosed a little bit quicker."

[Interview 14: Nursing Director, Irish Public Hospital]

An additional barrier to diagnosing lung cancer in particular is that there is no screening currently in place. Instead, doctors must wait for patients to exhibit, and then report symptoms to their GP or healthcare professional – if they have one – before a chest x-ray may be scheduled. Yet as one respondent noted, one problem with this strategy of waiting is that:

"Lung cancer is people feeling partly to blame for their own diagnosis"

[Interview 9: Policy Officer, Cancer Charity]

Two interrelated factors influence such perceptions about this type of cancer diagnosis. On the one hand, public health messaging nationally on 'healthy behaviours' and promoting smoking cessation has been strengthened over the years. On the other hand, there remains much higher smoking rates and much later diagnoses of lung cancers in low-SES populations.[23] These combined effects have meant lower survival rates from lung cancer within more socio-economically disadvantaged communities. This outcome feeds into a vicious cycle described by one respondent as a cycle of behavioural 'stigma and fatalism' for those suffering symptoms of lung cancer. People with acute symptoms, e.g., severe cough, might be more hesitant to voice the symptoms to themselves or family members, and likewise hesitate to present at a GP or clinic for testing, due to feelings of shame and/or fear of stigmatisation and self-blame for being a smoker or former smoker. Additionally, they may know a number of peers for whom diagnosis at late stages of lung cancer resulted in high morbidity rates – setting in place a fatalistic attitude of 'what's the point in knowing' whether the symptoms are caused by cancer or not, if they still lead to death.

The medical practitioners interviewed wanted to acknowledge that waiting for symptomatic presentation for cancers that particularly affect low SES populations is especially problematic. A way forward would be to swap out unstructured cancer pathways that accompany symptomatic presentations of disease for more structured pathways of cancer care that might accompany screening presentations of disease that happen very early. Unstructured cancer journeys are those where patients are diagnosed after presenting at their GP with advanced symptoms, whereas structured cancer journeys could be said to

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[23] See Irish Cancer Society, 2019

follow where patients have been attending screenings on a regular basis, the checks locate malignant tumours or growths very early on and there is the possibility to quickly match the patient with a consultant specialising in the relevant area of oncology. The model of waiting for people to present with symptoms of disease brings with it a level of chaotic response to cancer care, as opposed to more preventative care actions.

As one doctor explained, unstructured cancer journeys mean that hospitals can be presented with higher numbers of advanced stage, symptomatic patients:

"You don't have control with people with symptomatic presentations […] it's a bit like a landmine, it can blow, you know, it can explode anywhere."

[Interview 1: Consultant, University Hospital]

Another suggestion by respondents was to improve and foster relationships between marginalised groups like low-paid migrants and GP or community healthcare clinics to improve understanding of cancer, generate trust in the Health Service, and highlight the importance of early diagnosis. More specifically, among certain ethnic groups, the fear of naming cancer as a possible sickness is both cultural and has to do with fear around loss of income or a job. Different immigrant populations will see, for example, cervical cancer screening as a routine health check that should occur on an annual basis, whereas others may fear naming cancer, or actively 'looking' for cancer. Similarly, lack of regular check-ups may undermine comprehension of cancer risks and falling ill. Where there is only one earner in a household, the recourse to receiving welfare benefits in lieu of working may not be feasible. Closer links between primary healthcare and migrant populations are therefore necessary to mitigate against particularly male immigrants not going for regular health checks. A respondent explained:

"[It's a] gender kind of thing […] on top of that would be a cultural thing. In lots of countries, it would be a male seen as a kind of provider and support and seen as being sick or kind of, there's been lots of dismissal of any suggestions that you need to go and do a check […] and I suppose I think there's a big role of GPs in that. Because people if they found a good GP, people do have relationships [and] would be more willing to listen to a GP."

[Interview 10: Manager, Community development organisation]

Likewise, the data showed how important it is to acknowledge how traumatic life circumstances or prior discrimination and poor relations between healthcare workers, vulnerable communities and individuals can lead to avoidance behaviour which hinders screening of cancers. Members of the LGBTQI+ community, individuals who have been diagnosed with severe mental disorders such as schizophrenia or bipolar disorders or with disabilities such as autism, deafness or those with hearing difficulties, or who have been sexually abused may hesitate to seek diagnosis. As one community health promotion officer noted, even the introduction of simpler measures can critically reduce the discomfort and fear felt among vulnerable groups, making the uptake of regular screening more likely. The cervical check model presents some promising ways with which community and health workers can ease the experience of screening among marginalised groups, and have done so through small, pragmatic changes in screening policies. An example was given as the 'best practice' instruction in the UK which can help sample takers of cervical swabs to be sensitive to past trauma, or to prior disclosures:

"So we would advocate for things like, in the UK, they use a little check sheet, and they hand it to the sample taker before they have their sample taken and that they don't have to verbalise it, but it's just a little cheat sheet to say, I'm finding this difficult."

[Interview 11: Health Promotion Officer, Community]

In sum, the earlier some cancers are found through screening and other preventative measures introduced in community care, the less dependent survival outcomes will be on behavioural components associated with SES status of patients. Reducing barriers that relate to a person's own chaotic life conditions, for example among those experiencing or at risk of experiencing homelessness, and reducing the more chaotic access issues at primary level in the Irish healthcare system, may prove a promising avenue for investment efforts to combat inequalities in early diagnosis for cancer.

Moving beyond survival ‘luck’ towards equality in survivorship

Moving beyond survival 'luck' towards equality in survivorship

Structural barriers to recovery

The post-treatment phase of a person's cancer journey, referred to as the survivorship phase, is the most affected by the socio-economic status of individual cancer patients and the social deprivation level of their residential community.[24] Respondents catalogued several reasons for the widening disparities they witnessed concerning survivorship. The first was that public information tended to focus on individual behaviours rather than structural inequalities in diagnosing and recovering from cancer. For instance, public health messaging for a "Healthy Ireland" stresses lifestyle requirements. While respondents lauded the promotion of a healthier lifestyle, which emphasises exercise, diet and nutrition, low alcohol intake and mental wellness, they wanted the focus on individual behaviours not to detract from policies targeting structural inequality as the fundamental cause of inequalities in cancer outcomes and incidence. A few respondents gave examples of exercise constraints for those in recovery, where public or fee-paying gyms proved inhospitable and uncomfortable for those in a vulnerable phase of their recovery:

"Public gyms are too daunting for somebody who's just going through cancer treatment, you know, because it's all about muscle"

[Interview 2: Manager, Cancer Support Centre]

Public health messaging campaigns that encourage the person living in disadvantaged circumstances to walk in their local neighbourhood, need to also consider that there might be concerns around safety, lack of access to walking grounds or even a footpath:

"I think often it suits the state to reflect in that way, right, is that we can look at the low hanging fruit, we can look at getting people up and moving. But equally, as I said before, the massive and significant infrastructure issues, which are existing around not just cancer, but a whole slew of health issues exist, right? So no matter how many people you get out for a walking group, if you don't have access to that service, or once you get into that service, your experience is dreadful, then, and where you can't navigate that service, because you don't have literacy, you know, those issues will continue to exist. And people in effect are set up for failure."

[Interview 13: Chief Executive Officer, Cancer Support Centre]

Cancer patients living in low-income households are less likely to have access to private gym equipment, safe parks and green spaces or private gardens. A clear need was identified for government investment in the provision of safe exercise spaces that offer recovery-friendly environments in the local community, either as part of community centres or specific spaces in cancer support centres.

The vulnerability introduced by cancer in the post-treatment lives of patients extends beyond physical to mental health. Mental health was seen as a priority area following a cancer diagnosis. Our respondents highlighted an expectation expressed by many people who have suffered a cancer diagnosis and are in the survivorship phase, which was that the end of their treatment rarely signalled the end of their support needs. Often this is when counselling is most urgently needed to combat the psychological fragility that cancer can cause people to experience. However, the use of voluntary sector support centres is still predominantly used by higher SES groups, those living in urban areas, those without any form of

[24] Cancer Research UK, 2020

disability, where access is more readily available or privacy concerns less an issue, and among women. This disparity stems in part from the way in which a number of support centres originated in Ireland's cancer landscape, which makes entering them as someone from a disadvantaged background much more intimidating:

"Most of those centres started out as breast cancer charities, and they were founded by women, white, middle-class women with breast cancer. And those can be really intimidating places for working class people or people of colour to go to. So there is still a very middle-class feel [...] They loved the furniture. They've been before. You know, it's all very nice, and everybody's very lovely [...] that can be a little bit of a barrier for people."

[Interview 16: Strategist, National Programme]

Targeting and supporting recovery for a better quality of life

The interviews and roundtable underscored the need to know more about socio-economic inequalities in the survivorship phase of the cancer pathway. One of the issues is how much low SES groups are specifically targeted and supported through strategic planning at this stage of cancer recovery. The message needing to be reinforced within socially deprived communities is that those having survived cancer are deserving of more than a 'lucky' escape from death and instead deserve a recovery of better quality of life - one without lingering pain or health problems post cancer treatment. A need to support vulnerable populations in searching out and attending rehabilitation courses or therapy and associated group courses was identified. Working with community representatives was seen as a way to combat difficulties in getting people to attend appointments. One respondent talked about the twofold barriers in Ireland to more equal uptake of services in the survivorship phase:

"Lower education and lower income are highly correlated with not getting sufficient rehab, both I know that they are linked with not receiving referrals, and also with not attending. So, there's a problem from them not being referred, and then a problem with them not having the support to attend."

[Interview 18: Chartered Physiotherapist, Oncology Team]

In the last few years, there has been much greater recognition of the need for psycho-oncology services in the Irish healthcare system.[25] However, targeted education for low-SES populations on how to positively and proactively approach mental ill health through therapy and counselling services is still far less developed.

Respondents spoke of the high uptake of therapeutic courses among those from higher SES backgrounds, whereas this was not mirrored to the same degree among those from lower SES backgrounds. There seemed to be a consensus that if patients were routinely assigned a counsellor or trauma-informed healthcare worker upon being diagnosed with cancer, there might be more equality in the quality of life that people would experience on recovering from cancer. Peer modelling and visible roles in the community advocating a survivorship phase that re-establishes and rebuilds a person's healthy identity, both physically and mentally, was thought to be vital in encouraging disadvantaged groups to seek out help post treatment.

In short, while rates of survival for cancer patients across Ireland have risen significantly over the past few decades, there are still large imbalances, in terms of where cancer journeys end and these endings correlate strongly with levels of socio-economic disadvantage. In addition, low SES patients are significantly less likely to reach survivorship phase.

[25] Greally *et al.*, 2020

The costly crisis of cancer pathways

The costly crisis of cancer pathways

Direct financial costs of cancer

A consistent theme throughout our qualitative interviews was the financial burden which cancer placed on individual patients, their families and the patients' wider social networks. The costs associated with cancer treatment and recovery tend to multiply over a person's cancer journey, but as one respondent noted, a "monetary crisis begins at diagnosis." The nature of Ireland's two-tier health system makes visible clear divisions between those patients who can afford to pay for private health insurance, and those using public health services. Given the pay structure of care in Ireland, holding a medical card to cover the majority of expenses directly related to cancer treatments becomes imperative for low-income households. However, as the data show, there are also many patients who comprise a "third tier" – a group of people who cannot afford private health insurance, but find themselves in a financial crisis when, prior to diagnosis they could not meet the national criteria for receiving medical card coverage, but neither can they pay for a series of spiralling costs as their cancer treatment progresses.

Individuals who are ill face other costs like household bills for heating and electricity. Cancer can affect a person's ability to keep warm, necessitating greater use of heat to combat a lack of circulation while undergoing or recovering from chemotherapy or radiation therapies; and the use of showers and increased laundry (due to, for example, bedsheets needing to be washed). In a context of a cost-of-living crisis, the adjustments which cancer causes within households can lead to unmanageable expenditures on a monthly basis. As pointed out by one oncology nurse with extensive experience directing charity services:

"Somebody with a cancer diagnosis may feel the cold more and may need the heat on more. We all know right now where we are with the cost of heat and the cost of oil and gas, and tie that in with somebody who now may be out of work."

[Interview 3: Oncology nurse, Assistant Director CSO]

Currently there are no Irish charities which provide a means of access to substantial grants around capital funds that may be needed even by those living in stable housing conditions. An example given was that of a cancer patient obligated to upgrade their heating and plumbing systems. As such, the cost crisis brought on by a cancer diagnosis also highlights the important gradient of financial devastation for households at different income levels. The devastating impact of a cancer diagnosis on a patient from the Traveller community who is without an income and living without access to reliable electricity is immediately clear. There is also a slower but likewise distressing effect on those who may have been earning middle-to-higher incomes, who find their incomes halved and without disposable income for unforeseen cancer costs.

Amongst older people, the financial burden may be more severe, as they may be reliant on pensions and affected substantially by the high direct costs of diagnosis. Pensioners have little leeway in accommodating unexpected costs on fixed pensions. One example offered by a respondent was the financial burden that changes in dietary requirements placed on cancer patients who have had their stomachs removed. This type of forced and long-term lifestyle accommodation will present a financial strain for low and middle-income households alike.

For people whose incomes drop by way of job or wage loss, or whose fixed incomes are stretched by way of requisite lifestyle changes, the waiting time when – and if – they do apply for medical cards is also a time where treatment can be interrupted by concerns over its associated financial costs. Respondents mentioned that the direct costs of cancer diagnosis include significant parking fees, accommodation fees - if travelling great distances, and the fuel or public transportation travel costs. Parking in hospitals was one of the costs mentioned as being significant for those receiving any type of cancer treatments in public (and some private) hospitals.

One expert in our roundtable event noted the absurdity of believing that a person's likelihood of turning up to every treatment or scheduled hospital appointment was not adversely affected if they have to pay for a day's travel, a day's parking and fuel for a doctor's consultation that potentially only lasts 30 minutes. Cancer support centres in rural Ireland mentioned the costs of travel to hospitals as a major barrier for attendance at regular treatment. For daily treatment courses over 6-to-7 week stints, costs for their patients who had the means to drive themselves to hospitals could stretch into hundreds of euros in expenditure per week on petrol and parking.

Respondents also cited the additional cost factor of overnight stays forced by an inflexible system for scheduling of chemotherapy sessions and other hospital treatments. This meant some rural charities were attempting to help patients travel during the night to arrive for early-morning appointments in Dublin at specialist cancer units. These associated costs can, and do, interrupt continuity of cancer treatment for people, and especially those concerned with their additive expenditures.

Lung cancer patients in particular faced financial challenges. The qualitative interviews illustrated that among low SES populations, the diagnosis will often have been made in a state of emergency. The health crisis caused by acute symptoms (e.g. coughing up blood) often forced people from low SES backgrounds to be rushed to hospital Accident & Emergency departments. This represents a strain on the health system. It also means that the patient incurs inpatient emergency oxygen charges and/ or ambulance charges. For patients without a medical card, any hospital charges at first diagnosis can set off a financial and health crisis simultaneously. As one civil society representative highlighted, the situation can lead to patients falling into debt at a time of vulnerability, where hospitals had passed on their names to collection agencies for such ambulance fees:

"It's very traumatic for people who, the first time they shared that they had cancer was with a debt collector because they were so taken aback by the fact that they were being pursued for those charges."

[Interview 9: Policy officer, CSO]

The way in which hospitals respond to patients incurring A&E and ambulance fees is, according to one respondent, a 'postcode lottery'. Different hospital accounts departments were said to be more or less likely to pursue these charges and quickly involve debt collection agencies. Consequently, those patients making up a 'third tier' of those without medical cards, in the process of applying for medical cards, and without private health insurance are also ones subject to crisis cancer scenarios.

Indirect financial costs of cancer

While there are numerous direct costs associated with cancer onset and diagnosis, there are also indirect costs which place households at risk of debt and entering into greater socio-economic deprivation. As cancer risks are higher in low SES populations, more people will be diagnosed at younger ages with cancer. One of the major implications of such earlier disease susceptibility and onset is that cancer patients from low-income households may also be those households with young children in the home. The issue of indirect costs accompanying cancer for a patient with young children is acute, A respondent highlighted how the compensatory coping mechanisms which families engage in, attempting to minimise the distress for their children of a cancer diagnosis, present a "catch-22" for those with no disposable incomes or those trying to reduce their spending to meet rent payments, mortgage payments or other such monthly expenditures. The associated reasoning within families was described as follows:

"There can be a bit of compensation as well within a family so if a child is sick, yeah. Then what they need are extra treats, or the brother and sister need extra treats, or if the mother is ill, or father is ill, […] can dictate whether we have to treat our child here now because we're coping with this. That can be a spending on the budget. So, it's a catch 22 - you're saying, 'We have no money for the mortgage? Can we get a moratorium? Or oh, can we get a reduced payment or interest only payment?' However, you have to see on the other side of the balance is there are extra costs here."

[Interview 15: Financial Advisor, National Charity]

As is evident from the above discussion, these direct and indirect costs have the potential to set in motion a financial crisis that is extremely difficult for patients and their families trying to cope with the news of a cancer diagnosis. These varied costs also represent barriers for those in more disadvantaged financial circumstances, who risk falling into debt from diagnosis through to post-treatment and recovery stages. There should be greater awareness of how best cancer patients can be helped to cover these costs, or at a minimum, how they might plan to minimise them once they have a diagnosis. No person's cancer journey should begin with a personal debt crisis.

Introducing system-led change: Tracking and reducing cancer inequalities in Ireland

Introducing system-led change: Tracking and reducing cancer inequalities in Ireland

Data requirements for systematic improvement in monitoring inequality

The measurement of cancer patients along any cancer-care journey presents various difficulties: whether the data collection is carried out at organisational or national level, whether the data arises from administrative registration data across hospitals or care facilities, whether the nature of data collection is prospective, or retrospective, and whether data collection is conducted through observational surveys or on the basis of randomised control trials. Likewise, the scattered mix of paper-based and electronic data collection in health systems across Ireland impedes readily available and reliable population estimates.

As one respondent pointed out, Ireland is a forerunner in having a National Cancer Registry.[26] Some European countries do not have this population-wide registry data to hand. However, this data is still limited in what it can provide in tracing cancer patients across healthcare facilities and in terms of real-time statistical analysis. Real-time estimations of waiting lists by cancer type, or breakdowns by cancer type of those segments of the Irish population receiving particular treatments with sufficiently reliable data at national level, are scarce. There are problems of double-counting in registry data, wherein for example a patient is referred for cancer in one healthcare site but receives their treatment in another healthcare site. The consequence is that in Ireland:

"[…] We're not really getting real-time information as to diagnosis. So we do get good projections. But we're not getting the real-time information that maybe we need that can inform health and cancer policy."

[Interview 9: Policy Officer, Cancer CSO]

The health identifier introduced during the vaccination programme and significant investment that went into e-health transformations in rapid response to the Covid-19 pandemic were identified in the research as a driving mechanism of moving Irish healthcare towards a more systematic and system-led collection of unique micro-data to track cancer.

Beyond collection, the collation of informative cancer data revolves around the choice of relevant indicators of inequality to record for cancer patients, and the reasoning behind this type of data being recorded. Across our interviews, there was an awareness among respondents of how reliable and detailed data on inequality in cancer, if collected, would help to delineate efficient investment avenues and policies that would be most effective in an Irish setting. Yet, to date, the data required is still not being captured adequately. As one respondent working with Traveller groups summarises it:

"How can you, I suppose, identify where the gaps are, and remedy that, you know, and I think, for us, that means […] focusing on population-based health, right? But how can you plan for a population if you don't know the needs? And if you don't have the data?"

[Interview 12: Policy Evaluation Officer, Charity]

Of inequality indicators, the ones most frequently mentioned in the roundtable and interviews as being most relevant for better understanding cancer inequality in Ireland were education level, ethnic background, language spoken in the home, and geographical residence (postcode). The measurement

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[26] https://www.ncri.ie/

of social deprivation, social class, income and wealth would be another key avenue for data collection, though generating these indicators requires close attention to definitional issues for statistical purposes.

In fact, only anecdotal or small-scale studies hint at how a different set of inequalities are affecting the flows of cancer patients presenting across these care settings. An experienced doctor expressed their surprise at the disproportionate number of cancer patients in their clinic who presented with low levels of literacy:

"[…] Until the patient is in front of us, someone telling you they can't read, it is not something you go to find out very quickly. We did a survey of our breast cancer patients recently, and 20% of them had not completed secondary school […] It never occurred to me that 20% of the people I see had not completed secondary school."

[Interview 1: Consultant, University Hospital]

In addition, equity analysis of more novel cancer treatments in Ireland is only in the beginning phases. For cancer trials across Ireland, there has not been a study evaluating equality in access. There is some observational data available from the Irish Longitudinal Study on Ageing (TILDA),[27] but this does not cover all population age groups and is not as comprehensive as registry data would be. There are, to date, no annual data breakdowns carried out at government level which empirically demonstrate how patient uptake of clinical trials or new cancer drugs differs according to household wealth or income across the Irish population. Investing in the systematic collection and recording of socio-demographic and socio-economic data in the Irish healthcare system, and tying this to unique health identifiers for individuals, would present a supportive structure to plan cancer strategies across primary, secondary and tertiary levels of service provision.

Supports to improve models of cancer care and financial continuity

More equitable funding support for health professionals was one way in which respondents felt that inequalities might be reduced. For novel clinical trials there are limitations that relate to unequal allocations of staff time, research assistance, and a lack of system-led distribution of government grants to host trials in hospitals across the country. The current model of funding bids means those hospitals where staffing issues are most acute, predominantly in rural Ireland, lose out to Dublin-based hospitals. A respondent proposed it as follows:

"The [cancer] outcomes are better in centres where clinical trials are active and where research is happening. You know because I suppose patients are offered those clinical trials."

[Interview 19: Doctor, Health advocacy organisation, University Hospital]

Changing this type of hosting and funding model for clinical trials would mean reducing financial and cancer inequalities. The distribution and availability for cancer patients of cutting-edge cancer research groups might in this way depend less on the time-allocation decisions among one or two consultants, and instead be standardised across healthcare sites.

Ireland's healthcare system relies on three elements working in tandem, that of the public system, private system, and smaller charities and civil society organisations within the voluntary sector. This complex networked system immediately presents coordination issues for providing cancer patients with viable

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[27] https://tilda.tcd.ie/

and continuous cancer care paths. The interviews elicited a number of possible ways with which present-day models of cancer care could be improved in Ireland. In the last decade, the voluntary sector has been updating cancer care practices towards ever greater levels of standardisation, and cultivating collaboration between organisations within the charity sector. The past few years have seen great strides made in collaborations that span across the public sector divide, e.g. partnerships between Daffodil centres[28] and a number of hospitals nationwide. Yet, there remain several areas in the Irish healthcare system that are clearly lacking a system-led design. It is here where frontline workers identified opportunities to better support cancer patients, and, in so, doing close gaps in care which have consequently fallen along socio-economic fault lines.

Closing the gaps would entail greater standardisation and interaction across private and public health services and community services. When a national strategy on cancer care was first introduced in Ireland during the mid-2000s, there was little standardisation across the voluntary sector in terms of standards and codes of practice, training of staff, or nationalised quality checks that could be objectively verified. As one respondent noted, this contributed to a reluctance among healthcare workers in professional settings in the public sector, but particularly in the private hospitals, to partner with community-based services, or to signpost cancer patients to resources outside of official hospital and primary care service sites.

Private hospitals in general do not always have social workers, which further reduces the links patients will have to community services. The social worker in public hospital settings is frequently a crucial point of contact, liaising between hospital sites and services in a patient's local community.

Another constructive, and logical, step in enabling recovery and greater equality in general in accessing cancer services would be to progress localisation of healthcare. One of the central tenets of Ireland's Sláintecare healthcare reforms is a move from hospital sites towards a localised model of care, one offering community-based provision of cancer screening, care and treatments. The last two years of the Covid-19 pandemic made such a strategy imperative, since more people were either being discouraged to utilise hospital services and A&E, or were avoiding them of their own accord due to reported outbreaks in hospital wards and the associated contagion risks of the airborne coronavirus.

Respondents noted however that much use of community-based services still relied heavily on word-of-mouth (WOM) models of visibility. As such, supportive structures most needed across Ireland revolve around the design and implementation of a system-led model of providing universal health and associated services, such as financial aid services, in collaborations across public, private and charity sectors. This would entail making awareness of the community services by regional and neighbourhood area a priority and would also mean introducing a specific 'mapping' of community networking and service provision into the training and onboarding models for healthcare staff in the private and public system. As the Irish healthcare system operates currently, there is an over-reliance on having one knowledgeable worker who has built up their own community networks on self-initiative and can point and link cancer patients in with relevant community services outside of hospital settings, or can ensure that patients or patients' families know how and where to apply for the requisite welfare benefits which they may be entitled to claim. One manager with years of experience in community-based service provision voiced this idea and noted that the present form of the Irish system:

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[28] Daffodil Centres are based in hospitals. Provided by the Irish Cancer Society's local cancer information and support centres, they are staffed by nurses and trained volunteers on hand to answer your questions and provide a confidential listening service and information on everything from local support groups to help for the travel or financial problems cancer can create. See: https://www.cancer.ie/cancer-information-and-support/cancer-support/find-support/daffodil-centres

"[is only] as good as the individual in the hospital or in the care setting […] the GP secretary or social worker."

[Interview 2: Manager, Cancer Support Centre]

There were suggestions in the research about building a portal for the general public and healthcare workers alike. It would be a government portal to access information on available community services in operation across all areas of the country. The portal would be regularly updated with a click-through system to map data and information on a geographical basis; providing a visually engaging and easy-to-navigate site that pinpoints cancer and related supports in a map of Ireland. The ability to access this site should in principle bring much greater awareness of available resources while simultaneously highlighting where gaps in services appear in certain rural or socially deprived areas. It would also require a dedicated funding stream and would need to involve community workers, healthcare professionals and cancer patients in the design and implementation feedback phases.

Indeed, a respondent in the research is co-designing with cancer patient representatives and delivering web resources; this will be a dedicated webpage of service lists on a hospital server but the webpage will be accessible by the general public. Their motivation to generate web resources was based on observing a knowledge gap in the Irish healthcare system regarding access to therapeutic services or healthy recovery groups, for example walking groups, at the survivorship phase of cancer recovery. The respondent stressed, the "services are out there:"

"A big driver I think of the inequality in these kinds of survivorship outcomes is a lack of awareness of what's out there."

[Interview 18: Chartered Physiotherapist, Oncology Researcher]

A step forward in removing cancer inequalities in Ireland would therefore involve progressing the healthcare system from depending too heavily on individual, and unequally distributed healthcare workers – comprising a rotating and overstretched workforce. Instead, what is needed are evidence-based policies to implement a system-led design for training models and public mapping of cancer and associated services that increase knowledge distribution and provision of care country-wide, and particularly in more disadvantaged residential communities. Greater investment in community liaison staff would nevertheless be required, as well-designed community-based care is a way to ensure additional targeted supports are provided so that low SES groups benefit from such a mapping service.

Conclusion

Conclusion

The overarching aim of this report has been to underscore the need for a better understanding of challenges that people in Ireland face all along the cancer pathway, challenges which are caused by socio-economic inequalities and the associated imbalances in the Irish healthcare system. Cancer care and recovery across Ireland are reliant on a triage of services coordinated over three sectors – the public, private and voluntary sectors. Further, a feature of Ireland's healthcare model is the fee-paying structure of access to care at primary level. This results in a number of areas in the Irish healthcare system at which socio-economic inequalities enter and impact on people's cancer incidence and outcomes.

Our research has located two stages at which disparities by socio-economic status appear largest in Irish cancer pathways: that of diagnosis and the survivorship phase. The qualitative findings illustrate the significant imbalance in early diagnosis of cancers between lower and higher SES groups in Ireland. They highlight the structural and individual patient factors that need to be addressed through increased government investment, and which would reduce the widening of SES related cancer inequalities across e.g., lung and stomach cancers. First, increasing capacity within the system of GPs and community-based primary healthcare services in Ireland, particularly where access to diagnosis issues among the most vulnerable minority groups are acute e.g., for Travellers, migrant populations, the homeless, or those suffering from drug addiction. Second, increasing targeted screening services and setting up structured cancer pathways so as to combat low-SES groups being overly represented among those presenting at emergency departments with advanced cancer symptoms, and waiting for months for correct specialist hospital services.

A theme emerging from the findings was how psychological responses to cancer such as fear, shame and fatalism lead to avoidance behaviours when it comes to ignoring or checking disease symptoms. Building up closer relationships between community health workers, and GPs, in vulnerable communities will leave less room for differences between SES groups to appear in the rates of voluntary presentation with symptoms of cancer at GPs or hospitals thereby curtailing the basis for this type of inequality in Ireland.

Socio-economic inequalities are magnified in the survivorship phase. There is, however, a lack of sufficient national level data which would allow us to document exactly how great the disparities among cancer patients are at this stage of post-treatment recovery for different SES groups across Ireland. The findings contained in this report also hone in on the urgent need for a unique health identifier that would allow for real-time data collection across healthcare sites and for the analysis of socio-economic identifiers in cancer analysis that go beyond area-level deprivation to delineate specific patient level factors such as education, income, wealth and occupation. Nonetheless, respondents working in various healthcare settings and cancer support centres across Ireland were vocal about illustrating the point that the pathway to recovery from cancer does not end with finishing treatment. Alongside the physical vulnerability that cancer causes, the other major vulnerability which cancer introduces into people's lives is the potential for mental health consequences to follow a diagnosis with a life-threatening disease such as cancer. The expectation that patients return to feeling normal following surgery or chemotherapy, in post-treatment, has been shown to be unrealistic.

The findings in this report demonstrate the need to take the barriers associated with socio-economic inequalities as the fundamental starting point in systemically redesigning the model of cancer care in Ireland for disadvantaged patients. Understanding the impact of the barriers detailed in this report, on patients from pre-diagnosis to post-treatment, will not only significantly improve the incidence and outcomes of cancer in lower socio-economic status groups but will also transform their experience from simply 'getting through' their cancer treatment to experiencing an improved quality of life.

Policy recommendations

Policy recommendations

Respondents stressed the importance of measures that need to be taken which run the gamut of health and education services. These include, for instance, the introduction of prevention campaigns in schools which stress the detrimental health to young people of smoking and the funding of smoking cessation campaigns which are sensitive to people's social circumstances and that provide non-judgemental peer groups.

Another example would be acknowledging the inequality in disposable income available to patients for changing diets after surgery and understanding root causes of obesity rates among low SES populations. This would translate into the introduction of courses which target those in recovery from more socially deprived areas to show them both how to buy healthier foods on restricted budgets, and how to cook these in restricted living conditions or limited kitchen access.

Specifically, the recommendations emerging from the report include the following:

1. **Set up a Socio-economic Equality in Cancer taskforce to:**
    a. Gain a deeper understanding of the multifaceted challenges which continue to result in certain cancers disproportionately affecting low SES population groups
    b. Acknowledge and investigate the major challenges that appear long before the point at which people receive an official diagnosis of cancer
    c. Identify the lack of capacity in the healthcare system at a primary service level
    d. Further develop public health policy that focuses on structural inequality
    e. Further develop policy relating to the survivorship phase of a person's cancer journey which is the least equal according to individual socio-economic status and the social deprivation level of their community
2. **Target policies on structural inequality as the fundamental cause of inequalities in cancer outcomes and incidence. This includes:**
    f. Identifying the geographical areas where there is less access to local GP services
    g. Further investing in GPs/primary care for marginalised groups in deprived areas
    h. Reducing barriers that relate to a person's own chaotic life conditions, for example among those experiencing or at risk of experiencing homelessness
    i. Developing cancer prevention and early diagnosis interventions in more deprived populations
    j. Investing in the provision of safe exercise spaces that offer recovery-friendly environments in the local community, either as part of community centres or specific spaces in cancer support centres

k. Developing targeted outreach/education and awareness public health campaigns with marginalised groups on healthier lifestyles and smoking cessation

3. **Develop cancer services that:**

   l. Implement cross-service policies that reduce barriers to a person's own chaotic life conditions, for example among the homeless populations

   m. Create more structured pathways of cancer care that include early screening

   n. Better integrate hospital cancer services with primary care and local services to ensure seamless patient pathways, before, during and after treatment

Healthcare providers are recommended to:

1. **Explore broader ways of providing screening services**

   a. Explore options for screening outside of healthcare settings, such as the fecal immunochemical test for colorectal cancer

   b. Incorporate other healthcare professionals, such as community health workers, into the screening process, with GP supervision and training them to identify cancer symptoms

   c. Create rapid access clinics in deprived areas to improve early diagnosis

   d. Increase flexibility around screenings (e.g. screenings that fit into different employment patterns)

   e. Explore options for telemedicine to facilitate essential patient-provider communication throughout the screening process

   f. Providing digital support to those who are digitally excluded

2. **Provide financial support**

   g. Minimise patients' direct financial costs (e.g transport and parking costs; accommodation costs)

   h. Improve awareness of and support for indirect financial costs. (e.g. childcare, covering mortgage costs with loss of income; heating bills)

   i. Develop awareness of 'third tier' patients: those who cannot afford private health insurance but do not meet the national criteria for receiving medical card coverage

   j. Develop access to capital funds for adaptation to housing because of cancer status

   k. Provide further financial support as soon as cancer diagnosis is made

   l. Set up specialist financial and debt advice for cancer patients

   m. Develop consistent policies across hospitals on addressing A and E and ambulance fees

n. Increase flexibility of appointment scheduling so that overnight stay costs and parking are minimised. There should be no fees and accommodation cost to patients driving from another county to an early morning appointment

3. **Work in partnership with community and primary level services**

o. Map cancer and associated services (particularly in deprived areas) for public use

p. Invest in recruitment of community workers in cancer services to strengthen the link between hospitals and community services, including trauma-informed healthcare workers

q. Work with local communities to understand the cycle of behavioural 'stigma and fatalism' for those suffering symptoms of lung cancer

r. Improve and foster relationships between marginalised groups and GP or community healthcare clinics

s. Provide closer links between primary healthcare and migrant populations to mitigate against particularly male immigrants not going for regular health checks

t. Provide additional support for cancer patients after diagnosis (survivorship programmes and psychosocial services)

u. Develop peer modelling and visible role models in the community advocating a survivorship phase to re-establish and re-build a person's 'healthy' identity, targeted at low-SES groups and immigrant groups to seek out help post-treatment

4. **Develop use of data in improving socio-economic inequalities in cancer care**

v. Develop use of real-time data in planning treatment, building on e-health advances during the pandemic

w. Improve monitoring data on the incidence of cancer and risks among the population as a whole

x. Improve collection of nationally representative data on inequality indicators among cancer patients at a national level

y. Improve disaggregation of data for national mapping purposes

z. Systematically record and consider the inequities component in any policies aimed at improving cancer outcomes (including for earlier detection or new treatment)

5. **Invest in interventions that are localised and community facing:**

a. Community level messaging campaigns in deprived areas

(national messaging campaigns without these community components risk widening inequalities)

b. Public facing information and awareness raising campaigns on screening, preventative healthier lifestyles

c. Accessible screening services close to where socio-economically disadvantaged groups live with flexible appointment scheduling

d. Staff trained in working with vulnerable client groups

e. Financial services (advisor to be assigned on diagnosis)

f. Language interpreter, disability and cultural support services

g. Investment in community health promotion and social workers

h. Public facing and culturally appropriate awareness raising campaigns

i. Post-treatment support tailored for vulnerable client groups

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Appendices

Appendices

Appendix 1: List of roundtable participants

Participant	Organisation
Shana Cohen	TASC (Chair)
Emily Murphy	TASC (Facilitator)
Emma Harte	Irish Cancer Society
Mary Collins	Pavee Point, PHCW
Bernadette McDonagh	Pavee Point, PHCW
Gwen Harris	MABS
Dr Christopher Carroll	Department of Public Health, HSE Dublin 8
Dr Bríd Shanahan	Summerhill Primary Care Clinic NEIC Dublin
Emma Casey	Purple House Cancer Support Centre
Audry Deane	Independent Consultant
Catherine Heaney	Dublin City Community Cooperative
Professor Luke Clancy	Tobacco Free Research Institute Ireland & TU Dublin
Dr Louise Brennan	TCD Trinity Exercise Oncology Research Group
Rebecca McLaughlin	Irish Men's Sheds Association

Appendix 2: Roundtable topic guide

1. Where are the greatest opportunities in the Irish welfare or healthcare system to minimise costs for patients and their families associated with a cancer diagnosis?

2. What would an Equality in Cancer Care and Prevention Taskforce look like?

3. How best can the state collect nationally representative and reliable data on cancer and socio-economic status?

4. Thinking of each of the following types of cancers:

   - lung cancer, head and neck cancer, cervical cancer, and stomach cancer

   - what measures could be taken to improve outcomes (early detection to lower mortality rates) among the most deprived populations in Ireland?

Appendix 3: Participant information sheet

STUDY: CANCER INEQUALITIES IN IRELAND

PARTICIPANT INFORMATION SHEET

Lead Researcher: Dr Emily Murphy, Senior Researcher TASC

Study Background and Aims:

This study has received funding from MSD Ireland and investigates the causes and consequences of cancer inequalities in Ireland. We will focus on the ways that socio-economic deprivation relates to cancer patients and survivors and their access to diagnoses, access to treatments, access to post-treatment therapies and recommended lifestyle changes. Additional attention will be given to four cancer types: lung cancer, head and neck cancer, cervical cancer, stomach cancer.

Our main objective is to develop clear policy recommendations to address cancer inequalities. To meet this aim, TASC is carrying out focus groups and semi-structured interviews with experts and representatives of relevant charity organisations, those that work directly with cancer patients and those who work with low-income and marginalised groups, in order to gain an understanding of the scope of cancer inequalities and the effectiveness of existing supports and services in Ireland.

Your Participation in the Study:

We are hoping to interview you as a representative of [X ORG] to better understand the possible factors that may affect and exacerbate cancer inequalities (including those socio-economic factors outside of the health service such as work life, home life, household debt, health issues, transport and cost); what is available in terms of current services and supports for cancer patients and their families; and what (if any) additional supports, public interventions, and services are needed.

For example, we will be asking specific questions such as the following:

- Can you tell us about your organisation and the supports/ services you provide?
- How, in your view, does Ireland's two-tier health system impact the access to cancer diagnosis, treatment and care?
- What are some of the specific challenges that your service users face – in particular cancer patients from low-income households/ public system?
    - Medical card holders?
    - Members of migrant communities and Traveller communities?
- What do you think would be most helpful in reducing any challenges encountered by low-income cancer patients?
- How effective are existing public interventions and supports?
- What (if any) additional interventions and supports are needed?

What we are doing with the material we gather:

Our discussion will form part of a final report that will be launched next year.

Other logistics:

- If you agree to take part, you will remain anonymous in the final report and we will use a false name if attributing any quotes to you.
- If you agree, the interview will be recorded so we can quote you directly in the report. If you do not want the interview to be recorded that is alright.
- Preferably the interview will take place on the phone, via video-conferencing or in person (if possible). We are willing to travel to a location that is convenient for you.
- We hope to meet with you sometime in March - May 2022.

Lead Researcher Contact Information:

Emily Murphy E-mail: emurphy@tasc.ie

Please get in touch with me if you have any questions or concerns about this study.

Appendix 4: Interview topic guide

STUDY: CANCER INEQUALITIES IN IRELAND

*Interview Discussion Guide**

*Note that questions will vary slightly based on the organisation and the services they provide

Introduction

- Interview length
- Consent / recording
- Confidentiality of data

Organisation/association & Profile of cancer patients, service or support users

- Can you tell us about your organisation and the supports/ services you provide?
- How do your services cater specifically to those who are low-income/ from marginalised or disadvantaged communities?
- Role of association in meeting needs/ extent to which your services are in demand?
- Do responses to cancer diagnosis or treatment differ by service user group? If so, how?
    - Level of information about their diagnosis/ about their treatment options

Access to cancer supports and services

- How does Ireland's two-tier health system impact the access to cancer diagnosis, treatment and care?
- What are some of the specific challenges that your service users face – in particular cancer patients from lower income households/ public system?
    - Medical card holders?
    - Members of migrant and Traveller communities?
- What are some of the specific barriers that public patients face (versus private) when accessing cancer diagnosis and treatment?
- What are some of the specific barriers these patients face when accessing post-treatment services?
- In addition to medical costs (if in the private system), what costs do your service users incur related to their cancer diagnosis?
- What, in your opinion, can be done to tackle any challenges and barriers lower income cancer patients face?

Policy approaches to cancer risks

- Preventative public interventions versus treatment
- How effective are current public interventions and supports?
- Have there been any policy changes or interventions in the last few years that you would identify as effective?
- What (if any) additional supports and interventions are needed?

This report demonstrates that people on low incomes and marginalised groups are disproportionately affected by inequalities in cancer care provision in Ireland.

Drawing on interview data and a roundtable with key practitioners, it outlines the barriers experienced from early self-diagnosis to post-treatment phases in their cancer pathways and to what extent they are supported by services. To reduce socio-economic inequalities in cancer care, services need to provide more financial and psychological support; develop better integration between hospital and primary care and build greater capacity in primary care in deprived areas.

This includes expanding cancer prevention and early diagnosis interventions (including using broader ways of screening); investing in localised and community facing services and fostering relationships between marginalised groups and local primary care.

Finally, investment is needed, in line with the public health promotion of healthier lifestyles, in developing amenities in deprived areas for post-treatment recovery.

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