



**WE ARE
MACMILLAN.**
CANCER SUPPORT

NHS
Greater Glasgow
and Clyde

**Wheatley
Group**

**Edinburgh Napier
UNIVERSITY**

cordia
DELIVERING FOR GLASGOW



Glasgowlife™



Improving the Cancer Journey

More than the Sum of its Parts

Second report from a five-year evaluation by
Edinburgh Napier University

Glasgow
CITY COUNCIL

Nhs
GG & C

**Wheatley
Cordia
&
Other Charities**

**Macmillan
Cancer
Support**



Executive summary

Improving the Cancer Journey (ICJ) is a proactive community response to the needs of people in Glasgow with cancer. Shortly after diagnosis, people with cancer are sent a letter of invitation for a holistic needs assessment (HNA). HNA consists of a visit with a link officer to establish any physical, emotional, social, financial, family, spiritual or practical problems the person may have. Once these needs are identified the link officer either signposts or refers on to relevant agencies to support the person and their individual needs.

Since inception in 2014 ICJ has seen 2413 people, 53% women and 47% men. The average age is 63.5 years but it ranges from 24 to 100 years old. Lung cancer is the biggest diagnostic category, followed by breast, prostate and bowel, with these four accounting for 50% of all users. Most (82%) individuals described their ethnicity as 'white¹', 54% had at least one co-morbidity and the vast majority were from the most deprived areas of Glasgow. Sixty-one per cent of ICJ service users come from the lowest SIMD² (SIMD 1). For comparison Glasgow City has 48% of its population in the bottom SIMD and Glasgow has more people in the most deprived areas than any other area in Scotland. ICJ is helping some of the most disadvantaged people in the country.

Most visits by the link officer took 60 or 90 minutes with the average taking 68.6 minutes. A total of 13,168 needs have so far been identified, an average of 6.3 concerns per person. The top three concerns overall remain: money and housing, fatigue/tired/exhausted and getting around. 1039 people (43%) declared they experienced financial difficulties and 209 had housing issues.

Most people were referred to Macmillan, Self-Management services, the NHS, Glasgow City Council, or ICJ. Self-Management represented 13% of all referrals. People were referred to a total of 220 different agencies.

Level of concern as identified through the HNA reduced significantly between the first assessment visit and last review carried out by the link officer. Scores went down from average 7.15 (out of 10) to 3.85, a statistical and clinically significant drop. The majority rated the outcome of their referral as 'very helpful', giving it 9 out of 10 on average.

As ICJ is helping those most in need it is difficult to use comparisons to show 'quality of life' improvements. This is because the people using ICJ are more in need than any comparable cohort. From the routine data and the client interviews we saw that

¹ Including White Scottish, White Other British and White Irish

² The Scottish Index of Multiple Deprivation (SIMD) identifies concentrations of deprived areas across Scotland. SIMD 1 is the most deprived. For more information: <http://www.gov.scot/Topics/Statistics/SIMD>

a significant area of support for people receiving ICJ is financial and housing support. Yet, in our questionnaire we focused on proxy measures of these such as quality of life, social support, and well-being, rather than direct measures of, for example, financial support. Consequently, we will review how suitable our questionnaire measures are before the next phase of data collection.

The client interviews revealed in detail the benefit of ICJ to the individual. Being able to deal with everything 'in one place' was seen as beneficial especially when they had little energy during their treatment. The fact that ICJ could navigate the support systems with and for them was helpful. Most were worried about money and either did not know about any of the help available prior to meeting with ICJ or felt it was inappropriate to raise these concerns in a health setting. Consequently, having an accessible expert to guide and support someone through the cancer care system provided security, reassurance and the confidence to self-manage.

The previous report³ identified the key components of success: strong leader, strong buy-in from all partners, a skilled workforce using a workable system. This analysis holds. What this report adds is the background machinations within the partner agencies and their motivations to make ICJ succeed. Readers looking to better understand the process to develop similar services should read chapter six in particular.

In summary, ICJ stakeholders see it as a model service, a working example of government aspirations to operationalise person-centred care through closer joint working across services. The importance of this is hard to overstate. Historically, health and social services have been trying to work together since aspirations of a 'seamless service' first appeared 40 years ago. The fact that ICJ is a working example makes it extremely important to understand.

Partners see the proactive person-centred vision of ICJ as key to buy-in in the first instance. Joint working across the organisations enabled a more appropriate and efficient use of staff resource and ultimately improved coordinated care and greater access to services for the individual. The positive feedback from early successes further enthused partners, and so effort was rewarded then redoubled and so on. There is emerging evidence that the service is beginning to free clinical staff time because the most appropriate person is dealing with identified needs. This will be evaluated further. If generalizable, this is not just better for the patient, it is also more efficient for the health service. As a model to follow the components remain very simple: strong leader, strong buy-in from all partners and skilled workforce using a workable system.

³ https://www.macmillan.org.uk/_images/Glasgow-improving-the-cancer-journey-programme-summary_tcm9-301275.pdf

The Scottish Cancer Strategy set out nine statements under the heading: 'What would success look like'. The first report mapped success against these statements and that exercise is repeated here. In summary, ICJ continues to succeed. It addresses health inequalities by providing a more equitable access to services and treatment; over 77% ICJ service users come from the most deprived areas of Glasgow (SIMD 1 & 2). This is notable as people from socioeconomically disadvantaged groups are less likely to make use and benefit from the care system.

The Nine National Health and Wellbeing Outcomes provide a framework for improving integrated services in Scotland. ICJ aligns seamlessly with the principles of this framework by adopting a personal outcomes approach. Through the HNA the support provided to ICJ service users is based on their need. This recognises the multifaceted consequences to receiving and living with a cancer diagnosis allowing the individual to shape the care and support they receive. ICJ delivers across all nine Health and Wellbeing Outcomes⁴. For example, ICJ has a dedicated housing professional within the team who ensures people are prevented from homelessness and are supported to live in their own home independently and for longer. ICJ has so far prevented 26 people becoming homeless as a function of their cancer diagnosis. There is no doubt ICJ is having a significant positive impact across Glasgow consistent with the objectives of government policy.

In summary, the results have been presented at the service, individual and cultural level for clarity but they are all intertwined. The routine service data provides a profile of service usage. Through this we understand more about the reach of ICJ, the range and severity of concerns for ICJ service users and where people go next in their 'journey'. The client interviews provided depth to these figures. Moreover, they gave insight into the experience of using the service from the perspective of the ICJ client. Finally, from a cultural perspective ICJ was seen to be a working example of government aspirations to operationalise person centred care through closer joint working across services.

Recommendations and Next Steps

1. Continue to fund ICJ

We recommend ICJ should continue to be funded. ICJ helps the most vulnerable people in society at a time when they need the help most. It does this proactively, systematically and (inter)professionally. It is a working model of integrated care at a time when most service providers are wondering how to operationalise the idea. For example, the Chief Medical Officer talks about the NHS delivering 'Realistic Medicine'. Realistic Medicine:

⁴ See Appendix 1 for a mapping exercise conducted by ICJ that aligned the service to the 9 outcomes

... puts the person receiving health and care at the centre of decision-making and encourages a personalised approach to their care.

ICJ is already doing this. The fact that it does it so comprehensively makes it a model to follow.

2. Further explore the clinical significance of the drop in ‘level of concern’

This report is the first to show objective benefit of ICJ using the metrics available within the HNA. It showed that average ‘level of concern’ reduced from nearly seven to below four. Given the HNA was developed from the distress thermometer (DT), and any such drop in DT is considered clinically significant, then this finding should be explored in more detail in the next report.

3. Create a matched sample to compare outcomes between ICJ and a non-ICJ cohort.

There is a small window of opportunity to create a matched cohort in other Scottish cities so that service usage could be meaningfully compared between an ICJ and non-ICJ sample⁵. Permissions are in place to do this, and strict control should be placed on the parameters ‘time since diagnosis’ and deprivation category given these factors are so instrumental to quality of life.

4. Measure financial well-being

There is a possibility that the tools we chose to measure impact are not relevant to ICJ. We chose proxy measures: ‘well-being’, ‘general health’ and ‘quality of life’, partly because economic evaluations could be constructed from these measures. However, it is fair to say that so far, they have not been useful in articulating what is important to users of ICJ. The next evaluation will incorporate measures of financial well-being, given this is such an issue for this cohort.

5. Understand the carer experience

The Scottish Government talks about people with cancer ‘and their families’ being cared for. The next report will focus on the carer experience to examine the degree to which ICJ helps them.

6. Understand the impact of outreach

ICJ now has outreach in acute care. The setting the HNA is delivered in may have an impact on concerns raised and user experience. We recommend this be evaluated from all perspectives.

⁵ Previous attempts to match cohorts for this purpose resulted in wide disparities in deprivation categories and time since diagnosis, such that the ‘control’ group was considerably better off and further on with their recovery. This prevented meaningful ‘like for like’ comparison.

7. Explore the prevalence and impact of signposting and referral

In order to 'close the loop' we need to understand what happens to people who have used the service. For example, if someone actively engages with a service after being signposted or not. Evidence suggests that once people know about ICJ they will use it again if they need to. This will also be followed up.

8. Saving clinical time

This evaluation found compelling but anecdotal evidence for clinical time being utilised more productively. The next evaluation will gather empirical evidence.

9. Consistent data entry and reporting across all areas adopting the ICJ model to enable UK comparisons and service provision

Consistency of reporting will be key to understanding future changes. Data has not historically been consistent, both within ICJ and more widely, making reporting difficult. We recommend Macmillan Cancer Support and Glasgow City Council set up a short working group, including evaluators from Edinburgh Napier University, to ensure all data are consistently entered and recorded.

Author details

Professor Austyn Snowden
Professor in Mental Health
Edinburgh Napier University
A.Snowden@napier.ac.uk

Jenny Young
Research Fellow
Edinburgh Napier University
J.Young3@napier.ac.uk

Acknowledgements

We would like to thank the following people for their invaluable help in compiling this report:

Jan Savinc, research assistant and macro specialist at Edinburgh Napier University for his skill and patience merging many incompatible databases into one functional database. Thank you, Jan.

Thanks go to all our participants, for completing questionnaires, taking part in interviews or just providing your time.

Finally, thanks go to the ICJ evaluation group, for always providing context and explanations, but most of all for understanding the need for impartiality.

Contents

Executive summary	2
SECTION ONE: Overview	8
Introduction	8
The Scottish Cancer Context.....	9
Policy initiatives	9
Report structure.....	11
SECTION TWO: The ICJ Service	12
Uptake of the service	12
Holistic needs assessment	12
SECTION THREE: Aim and Method	13
Method	13
SECTION FOUR: The Service Level	16
Overview.....	16
Typical client pathway	24
Focus on money: Housing	25
SECTION FIVE: The Individual Level	31
Overview.....	31
Results	31
The experience of using ICJ	34
SECTION SIX: The Culture	41
Overview.....	41
Method	42
Results	42
SECTION SEVEN: Bringing it all together	49
SECTION EIGHT: Recommendations	51
References	53
Appendices	54
Appendix 1- Alignment between ICJ and 9 National Health and Wellbeing Outcomes.....	54
Appendix 2- The Concerns Checklist	56
Appendix 3- Induction for Link Officers	57
Appendix 4- The Questionnaire	61
Appendix 5 Stakeholder Interview Schedule	69

SECTION ONE: Overview

Introduction

Improving the Cancer Journey (ICJ) is a multi-agency approach to care aiming to improve the outcomes of people affected by cancer in Glasgow, Scotland. It does this by providing structured individualised support to *all* local people diagnosed with cancer. It is led by Glasgow City Council and the main partner in investment and support is Macmillan Cancer Support. Currently, other partners include NHS Greater Glasgow & Clyde, Glasgow Social Work Services, Cordia Services, The Wheatley Group, Glasgow Life and The Beatson Charity. The service has been commissioned for five years.

ICJ has established a referral protocol with the NHS and the Information Services Division (ISD). ISD sends a letter of invitation to all individuals in the city with a confirmed diagnosis or disease reoccurrence. The letter offers a Holistic Needs Assessment (HNA) with a link officer from ICJ. Alternatively, individuals may be referred into the service by a health and social care professional or they may self-refer.

HNA is an assessment that covers physical, emotional, social, practical spiritual and lifestyle needs (Appendix 2). It provides an opportunity for the person affected by cancer to discuss what issues may be causing them concern. The link officer can then offer support according to individual need. The HNA is offered in a community setting, such as a local library or the individual's home, a hospital outreach setting or within a Glasgow City Council office. Offering the HNA in a community rather than a clinical setting is novel. To our knowledge this is the first proactive cancer support service of its kind in the UK.

ICJ was launched in February 2014. It has won awards⁶ for its approach and has been recognised internationally by organisations such as The Kings Fund, Stanford University, The Japanese Cancer Centre and CCTV, which is China's National TV Station. In particular, for the services approach to integration. To that end, it is named in the Scottish Government's current cancer strategy as an example of excellent practice:

"The Improving the Cancer Journey experience in Glasgow is an example of how an integrated approach to health and social care can lead to an improvement in quality of life, person-led post-treatment rehabilitation and ability to self-manage."

(p48, 2016, Scottish Government. Beating Cancer, Ambition and Action)

⁶ <https://awards.themj.co.uk/winners>

The Scottish Cancer Context

Every year, about 30,000 people in Scotland are told they have cancer. ISD predict that this number is likely to rise to almost 35,000 in 2016-2020 (Information Services Division, 2017). The total number of people diagnosed with cancer is increasing year on year, largely due to the increasing number of older people in the population and the fact that life expectancy is increasing. In 2015, just over 75% of cancer diagnoses were in people aged 60 and over (Information Services Division, 2017).

Within Scotland, Glasgow has poorer health and shorter life expectancy than other comparable areas (Watt & Ecob, 2000). Mortality rates have been found to be significantly higher (30%) than the rate for other equally deprived cities in the UK such as Liverpool and Manchester. The socio-economic composition of Glasgow is different compared to other areas of Scotland. Deprivation figures show that Glasgow has 48% of its total neighbourhoods categorised within the most deprived socio-demographic quintile (Scottish Government, 2005).

Individual variation in lifestyle, environmental influences, socio-economic factors and genetics will have an impact on an individual's likelihood of developing cancer. In Scotland, there are also large variations in cancer survival rates between the least and most deprived communities. People living in deprived communities are dying from cancer at a higher rate. While the relationship between deprivation and cancer is multi-faceted the type of cancer may account for this. For example, the least deprived groups have a higher incidence in the better prognosis cancers, such as breast and skin cancer and the most deprived groups have a higher incidence in the poor prognosis cancers such as lung and head and neck (ISD, 2017). In addition to the greater likelihood of being diagnosed with certain cancers there is lower participation in screening uptake in the most deprived areas (ScotPHO, 2017). Subsequently, the need to tackle cancer inequalities has been recognised by policy. Health organisations now have a statutory duty to consider these disparities (NHS Health Scotland, 2017).

Policy initiatives

To improve the health of Scotland, policy initiatives have recognised the need to move away from a 'fix and treat' approach to health and social care to one based on anticipation, prevention and self-management (Calderwood, 2017). This approach recognises the multifactorial underlying factors that can affect health. Consequently, services need to be designed around how best to support individuals, families and their communities. Accordingly, joint working and integration are central to government policy in the UK. In Scotland, there is a legislative requirement to integrate adult health and social care services with the aim of improving outcomes for individuals and their communities (The Public Bodies (Joint Working) (Scotland) Act 2014).

Within health care, The National Clinical Strategy has set out a framework for developing health services across Scotland in the next 20 years (The Scottish Government, 2016a). At the centre of this policy is a change in the delivery of acute, primary and community care. The strategy recognises that community and hospital-based care needs to be integrated. For example, The 9 National Health and Wellbeing indicators focus on improving the experiences and quality of services for people in the community. The importance of making a difference to people's lives through integration is a central objective. It aims to achieve tangible improvements to outcomes for people and to the quality of services across health and social care (Scottish Government, 2015).

Similarly, The Scottish Government's cancer strategy published in March 2016 contains over 50 actions to improve cancer services across Scotland (The Scottish Government, 2016b). The strategy aims to ensure that people affected by cancer have support to live well and, when the time comes, die well. This will be achieved by ensuring there is capacity within health and social care services to address any unmet needs of people affected by cancer. Its key objectives are in figure 1.1.

To this end, the Government has proposed to invest £9 million over 5 years to support access to health and social care services during and after treatment to provide support in the most deprived communities in Scotland. Specifically, ICJ was recognised in this document as an example of a service that is already successfully supporting individuals across health and social care.

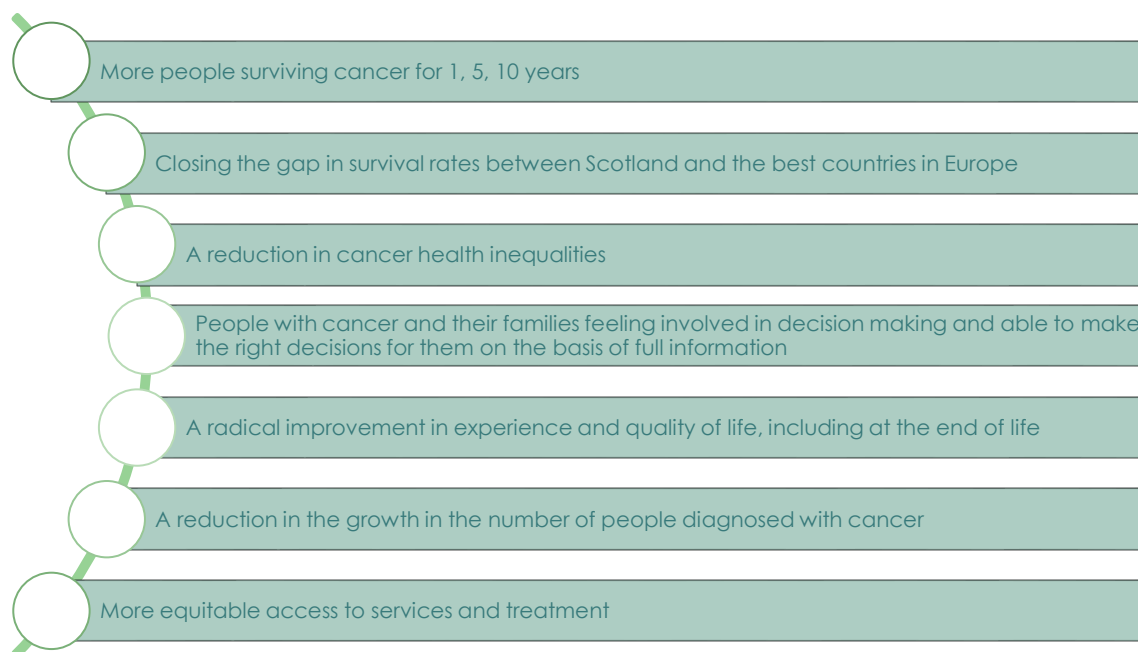


Figure 1.1. *What would success look like? Objectives of the 2016 Cancer Strategy*

It is against this socio-political backdrop that this report is positioned. In our first report, we evidenced the components of ICJ's success (figure 1.2): partners bought in to the vision, a skilled workforce using a workable process under a strong leader. Of significance was that ICJ had moved beyond being an example of policy into a *driver* of policy. One year on we return to gather more detailed and where possible new evidence to explore the impact of ICJ.

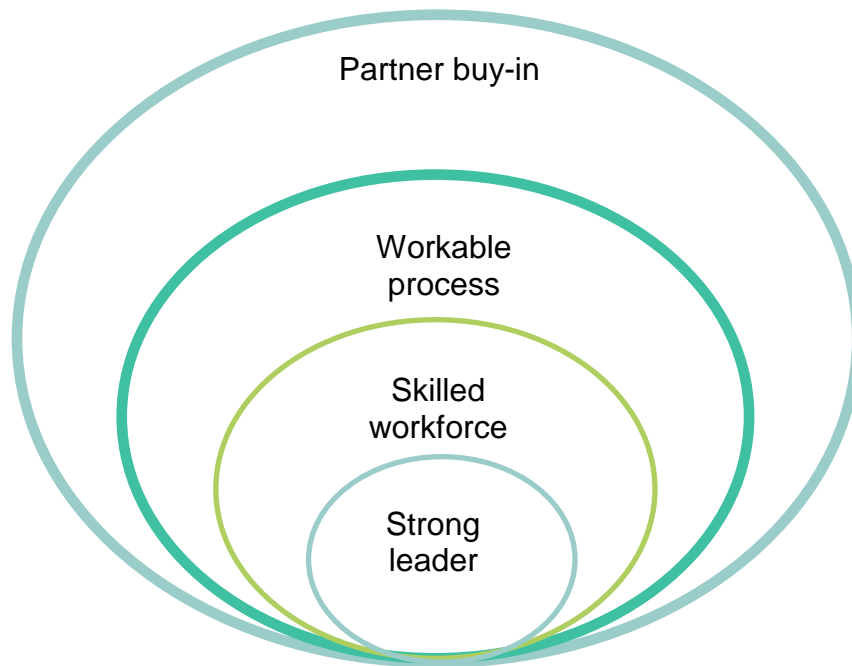


Figure 1.2. *Key components of ICJ success*

Report structure

This first section has summarised the social and political context to demonstrate how the principles of ICJ align with the current political agenda. The second section describes in more detail the background to ICJ and how it has developed since its launch in 2014. The third section describes the aims and methods used within this stage of the evaluation. The next three chapters detail the evidence gathered. These are broken down and discussed across three levels; the service level, the individual level and the cultural level. Doing this draws out what the experience is like for the individuals who have used the service in contrast to the perspective of the professionals who are involved in its delivery. Section seven then discusses the key elements of all the results concluding with next steps and recommendations.

SECTION TWO: The ICJ Service

'Improving the Cancer Journey' (ICJ) was launched in 2014 to support people affected by cancer. It is led by Glasgow City Council. The main partner in delivery and investment is Macmillan Cancer Support UK. Further partners include: NHS Greater Glasgow and Clyde, Cordia Services, Glasgow Life, The Wheatley Housing group and The Beatson Cancer charity. It has been commissioned for five years. The overall aim of the service is to:

'Develop and deliver clear, seamless and accessible pathways of care that are accessed timeously and appropriately, across organisational and professional boundaries, based upon a robust holistic assessment of need'.

Uptake of the service

ISD posts a letter of invitation to everyone diagnosed with cancer in the Glasgow City Council area. Alternatively, people can self-refer or be referred by their clinician. ISD and ICJ have been working in partnership since January 2016. Figures from ISD indicate that from April 2016⁷ to June 2017 ISD issued 2019 letters of invitation for ICJ. In that same period 1491 people used the service. The number of people who have used the service is not a direct result of the letters as referrals into ICJ can come from multiple sources. Nevertheless, the figures demonstrate a high uptake of the service.

Service Delivery

People who take up the offer complete a HNA with a dedicated 'link officer'. After discussion, a plan is put in place to best support the identified needs. ICJ currently⁸ employs 5 full-time link officers. When they first join the service, there is a 3 month induction period where each officer becomes familiar with their role and completes a range of training (see appendix 3 for induction checklist). Currently all officers are working towards being accredited with a Level 3 SVQ in healthcare support to reflect their competencies in this area. Their ongoing learning and development is provided by Macmillan every 6 weeks through action learning sessions. This is supplemented with ad hoc refresher training provided by the service partners.

Holistic needs assessment

Holistic Needs Assessment is an assessment that covers physical, emotional, social, spiritual and practical needs such as housing, financial and employment issues (see appendix 2). The HNA is offered in a community setting, such as a local library, an outreach clinic or the individual's home if they prefer. The assessment is recorded on a tablet and concerns are scored from 1 to 10 reflecting the severity of that concern for the participant. The link officer revisits each case; the timing of this depends on the client's circumstances. At this review the HNA scores are taken again.

⁷ ISD began recording figures in April 2016 meaning there is a gap in data from January-March 2016

⁸ As of September 2017. Recruitment of 2 more link officers is planned in the coming months

SECTION THREE: Aim and Method

The aim of this evaluation is to answer the question:

Overall Aim

‘How does this service improve outcomes for people affected by cancer?’

This section details the data collection methods we used to answer this question at the service, individual and cultural levels. It introduces all the different methods separately for the purposes of understanding the detail of each.

Method

This evaluation uses a longitudinal mixed method design. This means there are two broad methods used to capture a range of outcomes relating to the programme over time. Quantitative methods seek to understand behaviour through descriptive interpretation and statistics. Qualitative methods facilitate an in-depth understanding into experiences and behaviours. These methods will be used sequentially throughout the course of the evaluation.

Quantitative		Qualitative	
<i>Measure</i>	<i>Rationale</i>	<i>Measure</i>	<i>Rationale</i>
Routine data	Description of clientele	Interview ICJ clients	Analyse benefit
PAM-13	Patient activity level	Interview ICJ stakeholders	Joint working analysis
FACT-G EQ5D-3L	Quality of life Health status		
MOS-SSS	Social support		

Table 3.1. Key measures

Quantitative methods

Routine data

Since inception, the ICJ team has collected data on everyone who uses the ICJ service. The aim is to use this data to generate a profile of service use and to see if there have been any changes since our last report in 2016. There is demographic data on age, gender, marital status, ethnicity and socio-demographic status. Clinical

data relating to cancer type and stage and data relating to the HNA process such as HNA score, range and number of concerns identified, actions taken as a consequence, number of visits and length of time in the service is also collected. All these variables have been analysed to better understand the range of people who use the service.

Questionnaire measures

Questionnaires have been sent to people who have used ICJ and to those who have not to compare and contrast the responses (Appendix 4). Details of participants are given later. This section describes the measures used to obtain information on patient activation, quality of life and social support. We chose these measures because they are widely used and validated tools relating to both health and behavioural concepts. They align with wider service and political aspirations around improving the quality of life for people affected by cancer.

Patient activation

Patient activation is a behavioural concept relating to an individual's self-management needs, abilities and priorities. The patient activation measure is constructed to identify different levels of patient activation. These levels have been used to estimate costs in relation to service use, such as hospital admissions and accident and emergency usage. A related benefit of this measure is that the levels are a useful indicator of the types of support individuals may require from professionals to engage in self-management. Consequently, if there are patterns of activation observed in clients who engage with ICJ this may be useful to know. Level 1, the lowest group suggests that people may be passive and overwhelmed by managing their own health. Level 4, the highest group suggests that people may have adopted many of the behaviours needed to support their own health.

Quality of life

Participants complete two measures of quality of life. The Functional Assessment of Cancer Therapy-General (FACT-G) is a validated measure of quality of life for specific use in a general cancer population. It is one of the most widely used measures of quality of life worldwide. FACT-G encourages the respondent to reflect on their thoughts and feelings relating to physical, emotional, social and functional quality of life. EuroQol Five Dimensions Questionnaire (EQ-5D) is a standardised instrument for measuring economic preferences for health states. It is in widespread use in many countries and provides a simple descriptive profile and index value for health status. Using this measure a quality-adjusted life year (QALY) can be computed. QALYs gained will be used as an outcome in the cost-utility analysis. This is a type of economic evaluation that compares the benefit and cost of health care programs or interventions.

Social Support

The Medical Outcomes Study Social Support Survey (MOS-SSS) is a validated measure of perceived social support that was developed for patients with chronic conditions. It encompasses several domains of support including tangible support, emotional support and positive support. Social support drawn from a number of sources has been associated with better outlook and better emotional health, especially with older adults experiencing a stressful life event such as cancer. Further, a lack of support is potentially modifiable if it is reliably measured.

Qualitative Methods

Interviews (ICJ clients)

Consenting participants who have used ICJ. Interviews provide insight into the perceived benefits of using ICJ, the HNA process and wider service utility.

Interviews: other stakeholders

Key stakeholders from relevant health, social care and third sector organisations. The purpose of these interviews is to explore how ICJ has impacted on attitudes and actions in relation to joint working initiatives and health and social care integration.

Summary

We will use a combination of routine service data, questionnaires and interviews to explore the impact of ICJ from the perspective of those who have used the service and from the perspective of wider stakeholders. For full description of the method please see our published protocol⁹.

⁹ Snowden, A., Young, J., & Fleming, M. (2016). Protocol for a mixed methods longitudinal enquiry into the impact of a community based supportive service for people affected by cancer. *BMC cancer*, 16(1), 720.

SECTION FOUR: The Service Level

Overview

ICJ routinely collects data on ICJ service users with their consent. These data can be analysed to develop understanding of who engages with the service over time, their interaction with other services and to highlight any patterns to better understand the client journey.

AIM

To present a demographic profile of ICJ service users, summary of concerns and actions taken.

Profile of ICJ service users

From its inception in 2014 until end of August 2017 ICJ has seen a total of 2413 individuals with average age 63.5 years, 53% of whom were women. Figure 4.1 shows a breakdown of all patients by age and gender.

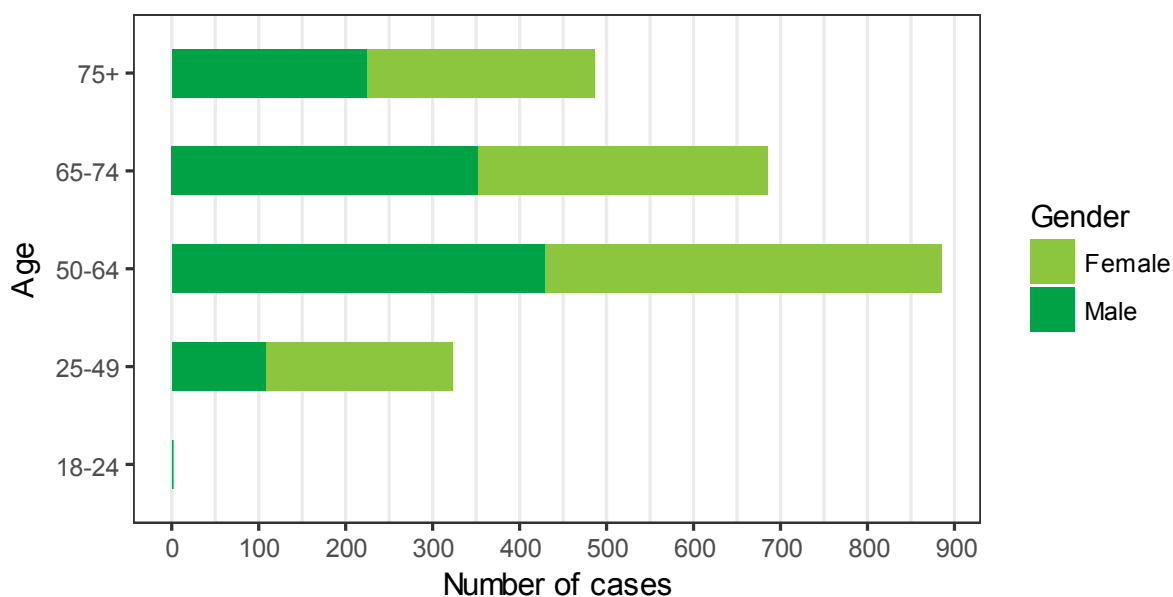


Figure 4.1. ICJ participants by age band and gender

Figure 4.2 shows the top four cancers by gender. These four cancers -bowel, prostate, breast and lung account for 53.5% of all cases seen by ICJ. There were approximately 140 different cancer diagnoses in total.

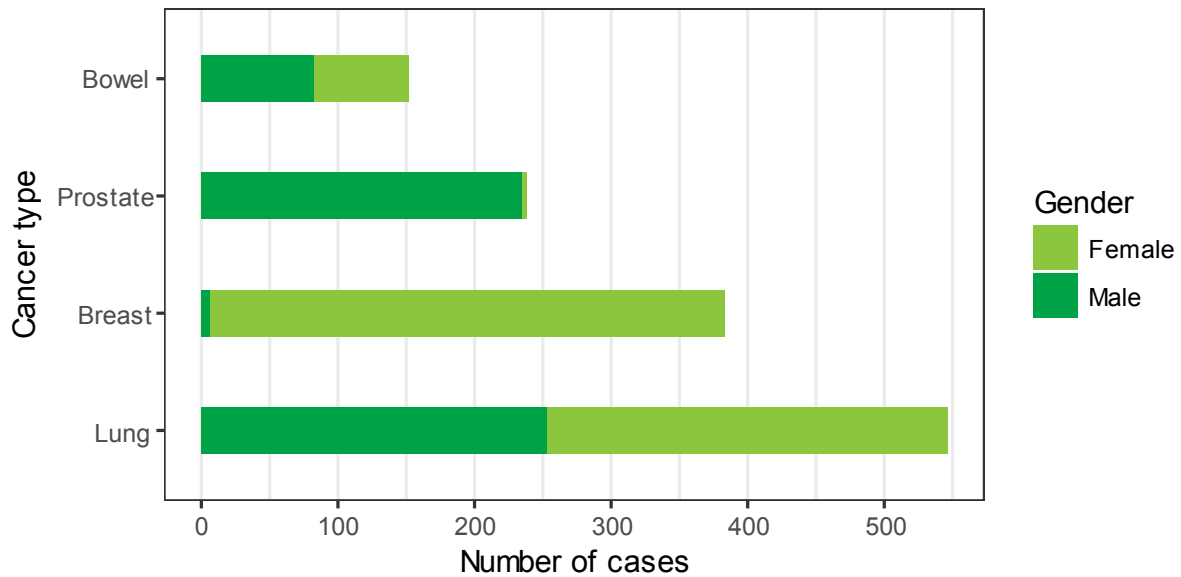


Figure 4.2 Top four cancers by gender.

Thirty eight per cent of ICJ users were married (n=941) with 520 being single, 408 widowed, 315 divorced or separated, and 156 living with a partner. The majority (82%) described themselves as ethnicity 'white'.

The majority were from the most deprived areas of Glasgow. Figure 4.3 breaks down the SIMD profile of service users by quintiles and vigintiles. Quintiles splits the area deprivation categories into five, representing 20% of Scotland's datazones¹⁰. Vigintiles split areas into 20 representing 5%. The lower the quintile or vigintile, the greater the deprivation.

61% of ICJ service users are in the bottom SIMD 1 (SIMD 2016, quintiles) reflecting high levels of deprivation. For comparison Glasgow City has 48% its population in the bottom 20%. Glasgow has more people in the bottom 20% than any other area in Scotland; the cohort using ICJ are proportionally worse off than the norm.

¹⁰ Datazones are groups of areas that have on average, populations of between 500 and 1,000 household residents. They nest within local authority boundaries. As far as possible, they have a regular shape and contain households with similar social characteristics.

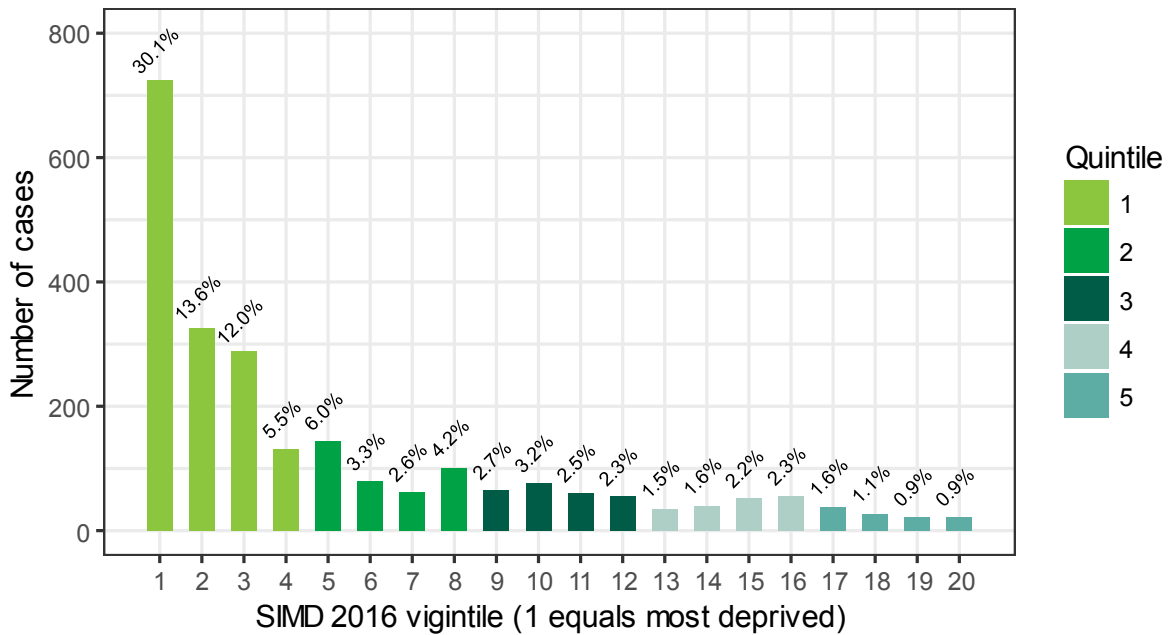


Figure 4.3. SIMD categories of ICJ patients. 61% of ICJ clients come from lowest quintile areas, and 77% come from the bottom two quintile areas.

The majority of service users (54%) had at least one comorbidity (Figure 4.4), with the five most common comorbidities reported being Arthritis (25.9%), Diabetes (17.6%), Chronic Obstructive Pulmonary Disease (17.5%), Hypertension (17.5%), & Mental Health (15.3%).

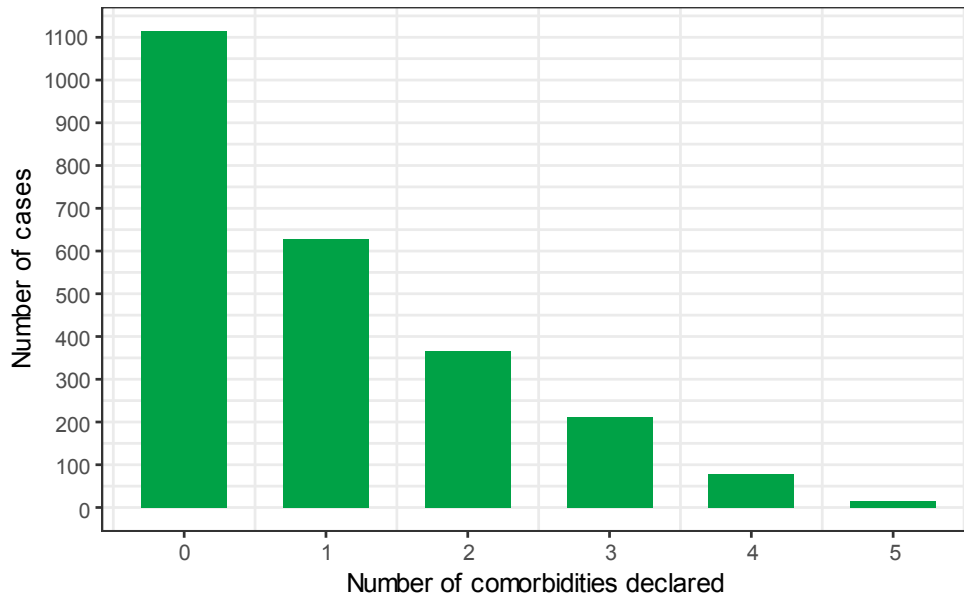


Figure 4.4. Number of comorbidities reported by clients

At the time of their first visit by the link officer, the largest proportion of people (38.4%) were undergoing treatment, with 17.3% palliative, 16.9% living with condition and 13.8% recently diagnosed (figure 4.5).

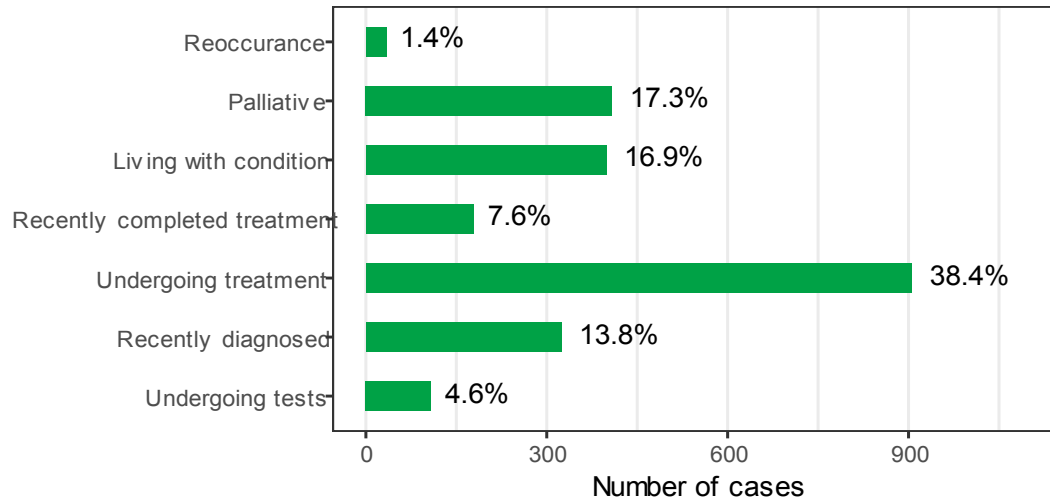


Figure 4.5. Cancer treatment stage.

First visits by the link officer mainly took 60 or 90 minutes; the average was 68.6 minutes, with a range of 10 minutes to 3 hours (figure 4.6).

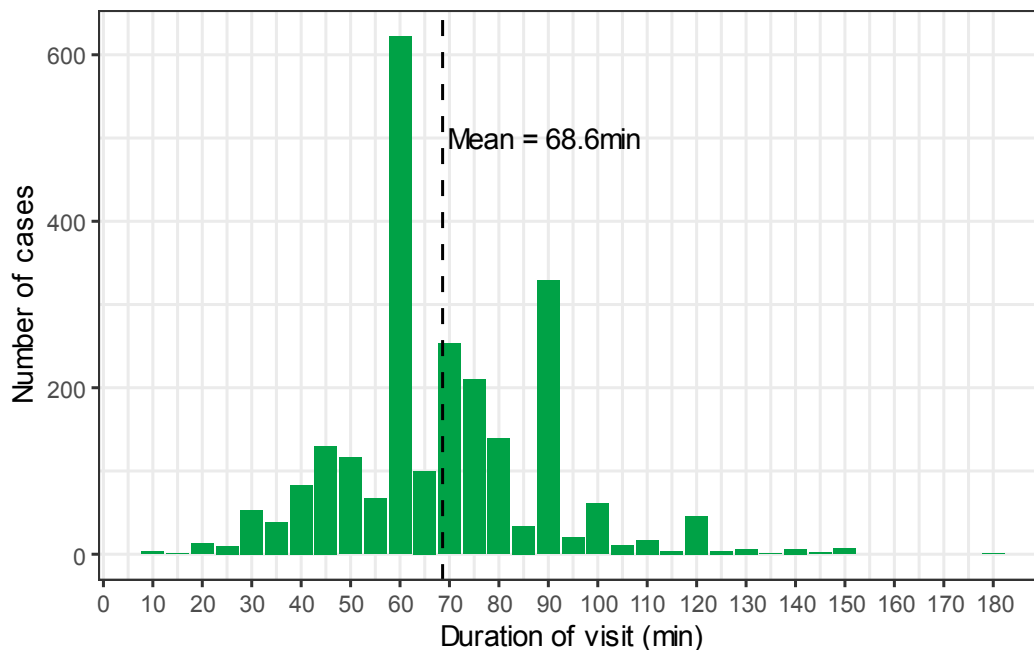


Figure 4.6. Duration of link officer visit.

Identified Needs

In total, 13,168 needs have been identified. The top three concerns remain: money and housing, fatigue/tired/exhausted and getting around. 1039 people declared they experienced financial difficulties and 209 had explicit housing issues. Figure 4.8

shows all needs identified, ranked by frequency. Average severity of concerns identified at the first visit was 6.5 out of 10.

Changes in severity of concern

As would be hoped, severity of concerns was substantially reduced on return visit (figure 4.7). On review, average scores had reduced from 7.15¹¹ to 3.82, a highly significant reduction of 3.33 points on the 10-point scale. The predecessor of the HNA instrument, the Distress Thermometer (DT), classifies scores above 7 as clinically relevant distress, and scores below 4 as clinically insignificant¹². If we assume that the results of both instruments are compatible, we can conclude that at review, ICJ individuals' scores dropped to a sub-clinical level.

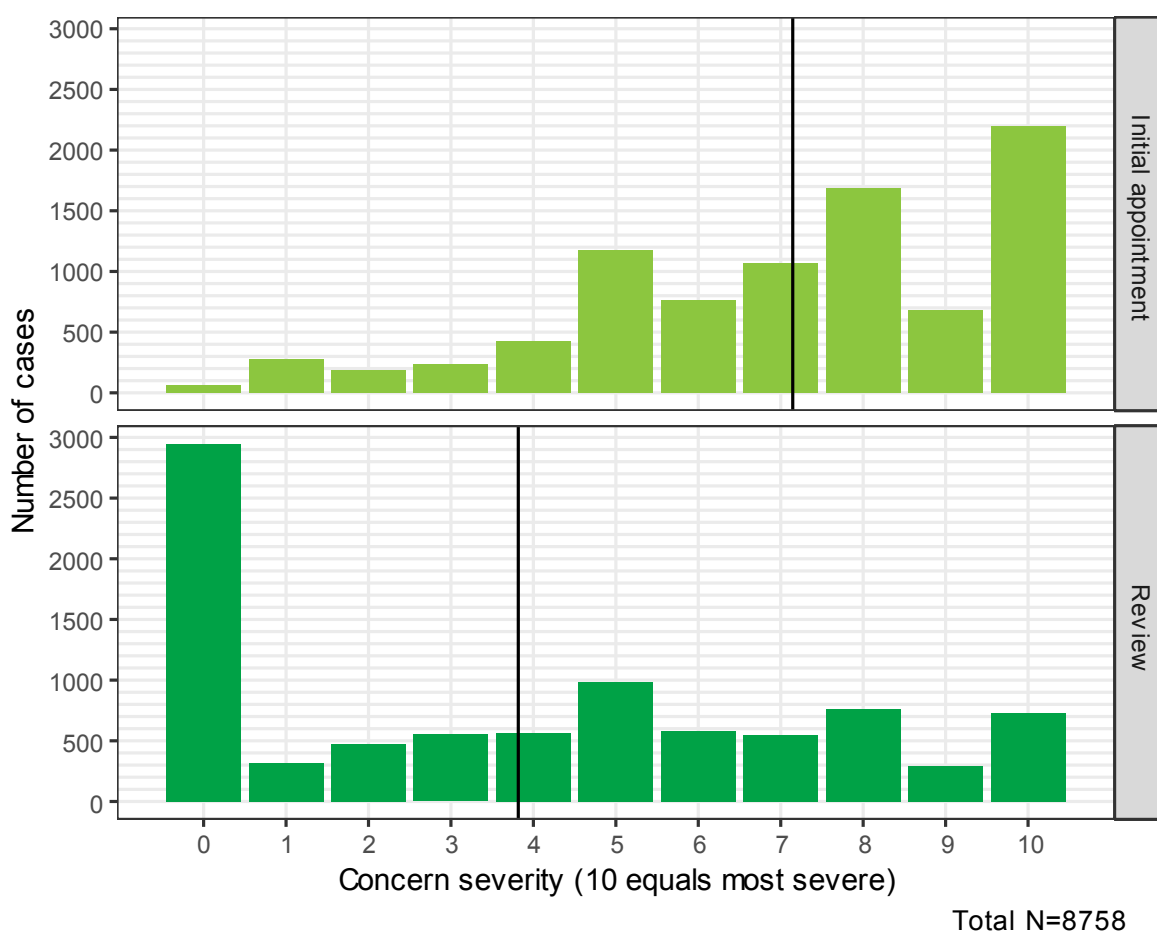


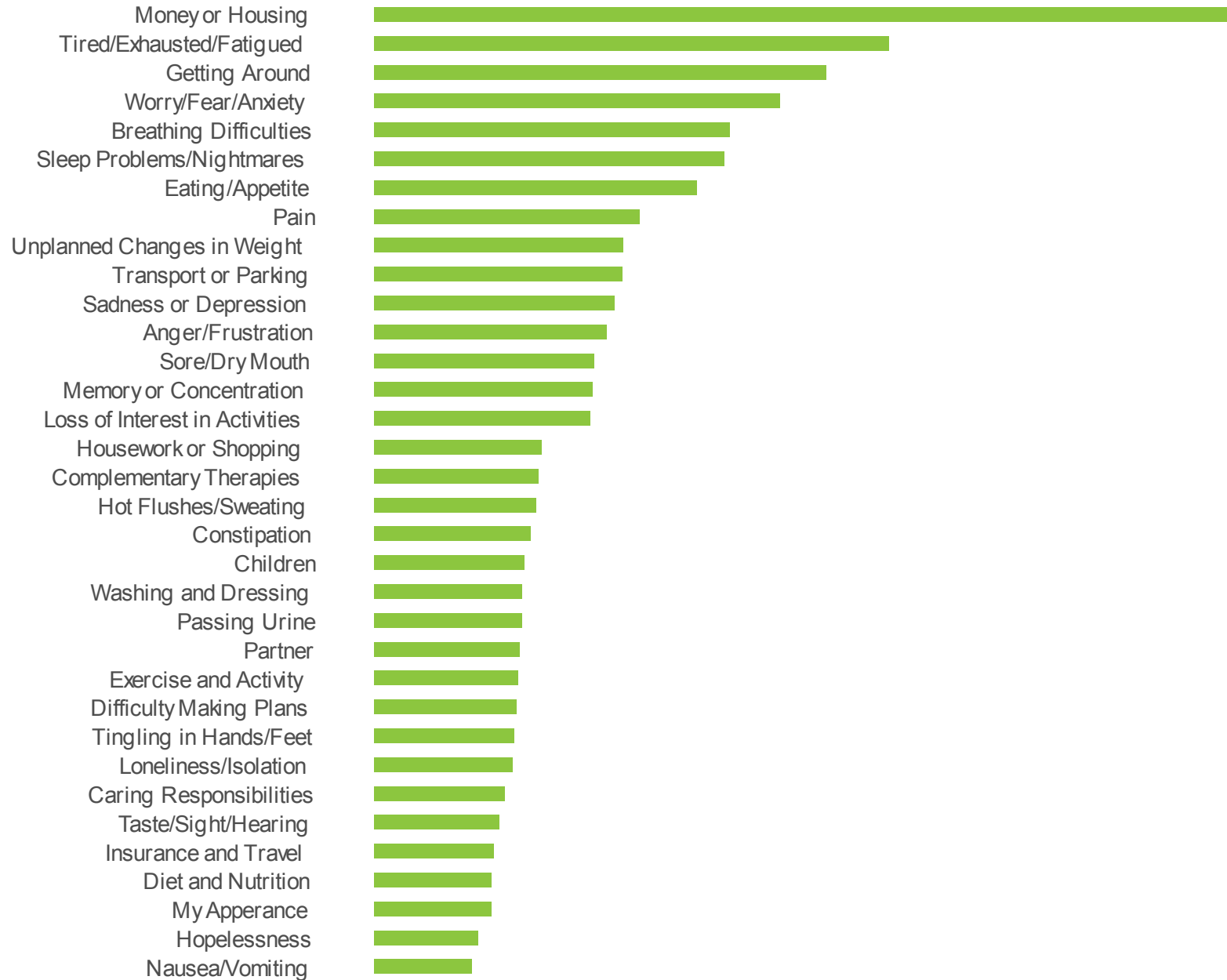
Figure 4.7 Change in overall level of concern between initial assessment and review. Vertical line denotes average concern severity at the two times.

¹¹ Note: the average concern severity here was calculated from those who had completed both the initial and review assessments which is why it is 7.15

¹² In clinical use, scores above four on the distress thermometer are used for referral to psychologist. Scores above seven represent severe distress Lynch, J., Goodhart, F., Saunders, Y., & O'Connor, S. J. (2010). Screening for psychological distress in patients with lung cancer: results of a clinical audit evaluating the use of the patient Distress Thermometer. *Support Care Cancer*. <http://doi.org/10.1007/s00520-009-0799-8> [doi]

Needs identified

Total N=13168



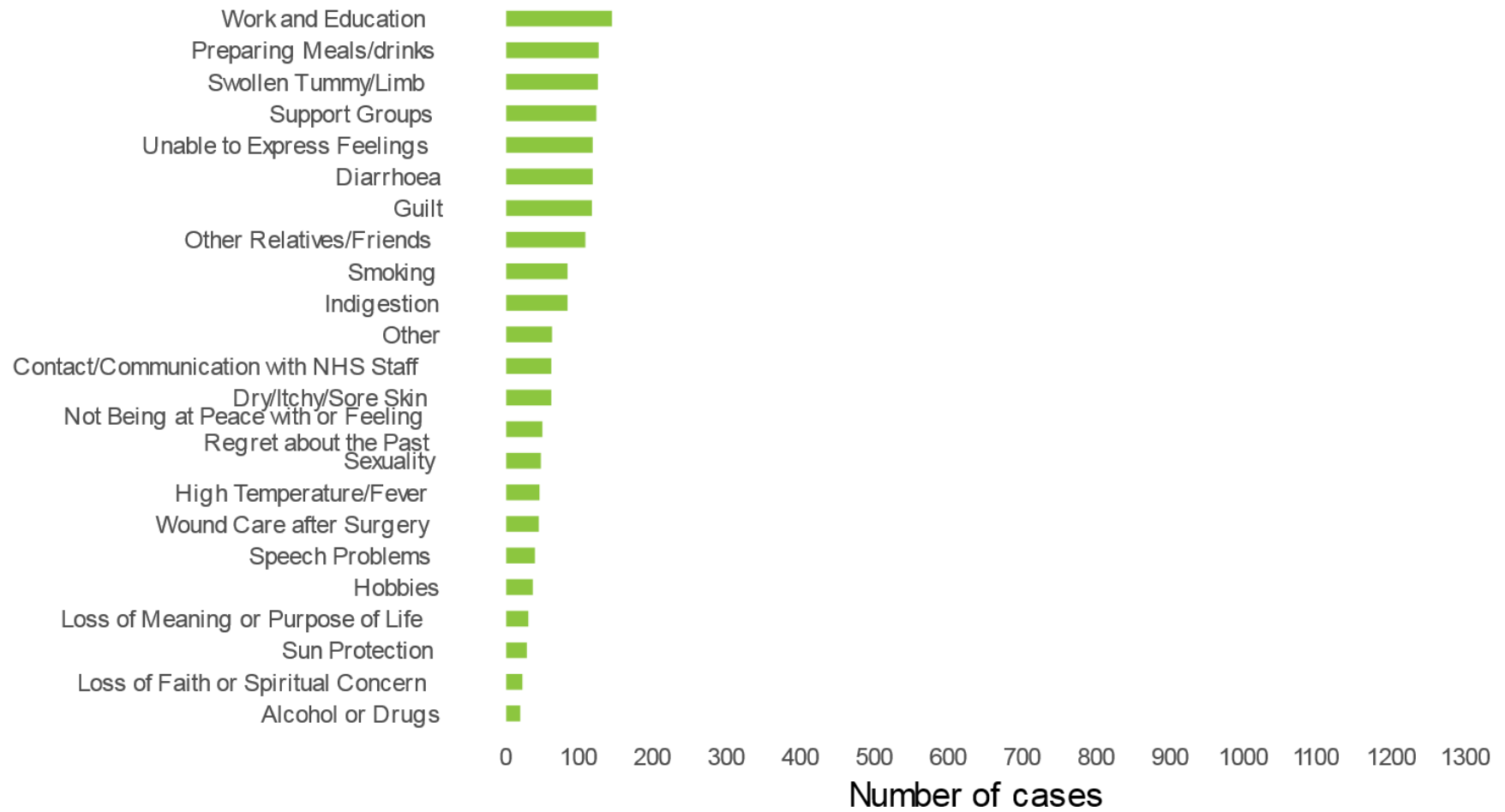


Figure 4.8. All needs identified by ICJ ranked by frequency

Referrals

Between March 2014 and July 2016 inclusive, a total of 8117 referrals were made, of which 1070 (13%) were for Self-management. Most people were referred to Macmillan, self-management, the NHS, Glasgow City Council or ICJ. People were referred to a total of 220 different agencies.

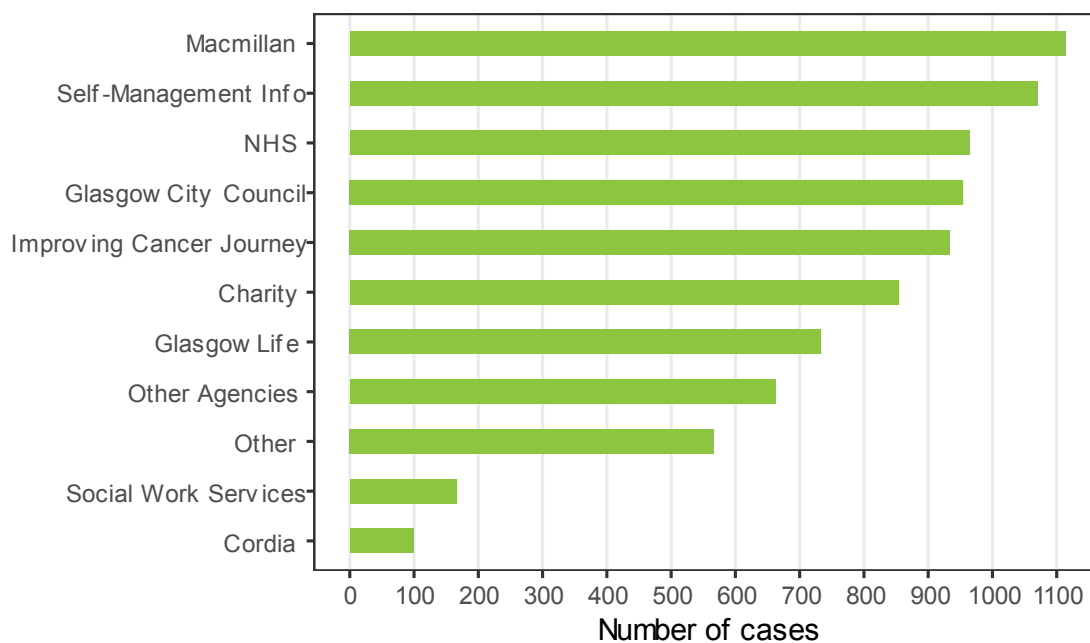
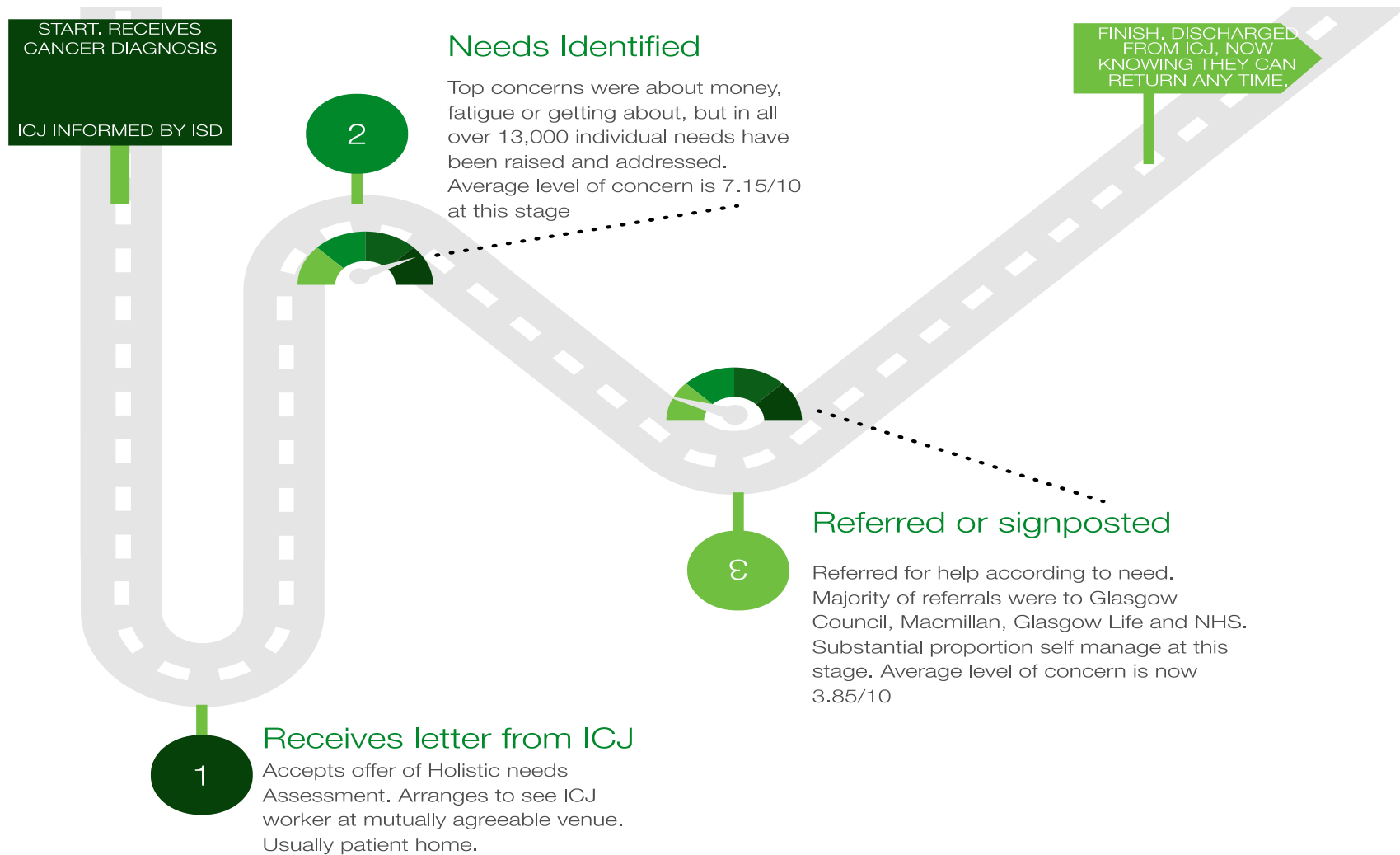


Figure 4.9. Number of referrals by destination. Total N=8117, of which N=1070 were referrals for self-management.

Typical client pathway



Focus on money: Housing

Overview

Research indicates that the average 'cost' of cancer per month has been estimated at £570. Patients may experience increased costs due to the cost of travel to outpatient appointments, higher day to day living costs, for example, due to higher fuel bills and a loss of income after being moved onto sick pay (Macmillan, 2013). Consequently, the negative financial impact of cancer can also impact on housing security. For example, 6% of those affected by cancer may lose their home as a result of their diagnosis and 18% will have difficulties keeping up their rent or mortgage payments¹³. Therefore, it was recognised by ICJ that individuals accessing the service may require specialist advice and financial help with housing issues.

To meet that need, in 2015 a housing professional from The Wheatley Housing Group was seconded into the service. The aim was to provide advice and support to ensure no one loses their home, to support people to sustain their tenancy and remain in their home and to support individuals, if required due to medical reasons, through a move to new housing. This has been achieved by working in partnership across organizational and professional boundaries as will be evidenced through the case studies below. Expertise and knowledge has been shared through coaching and mentoring with the ICJ team members as well as Glasgow city wide Housing Options link workers.

Since September 2015 the housing professional has supported 209 individuals affected by cancer in the ICJ service reflecting the relatively high number of individuals who require practical assistance with their housing needs.

Impact of Housing Support

To identify the impact of this housing support the ICJ service managers drew on the knowledge gained from the evaluation of the Glasgow Housing Options programme¹⁴. 'Housing Options' was developed by Glasgow Housing Association and Glasgow City Council with other Housing Associations, NHS Greater Glasgow & Clyde and the voluntary sector. The Housing Options model began in June 2012. It has similarities to the ICJ approach in that it offers personal advice to anyone who may need housing advice or assistance. It aims to support individuals if they feel they are struggling to stay in their current home, to help them make informed choices about their housing options and to prevent them from becoming homeless. Project evaluators noted that people successfully avoid crisis as a result of engaging with the housing options model. They estimated typical savings to the city of Glasgow associated with homelessness prevention at over £10,000 per case.

¹³Macmillan Cancer Hitting Home Campaign December 2006.

¹⁴ Arneil Johnston (2017) Glasgow Housing Options Model: 2016 Evaluation Study.

ICJ clients

The support the ICJ service users required can be generally grouped into four areas of need:

1. General advice and information (n=49)
2. Support to move to more suitable housing (n=102)
3. Support to move into sheltered housing (n=22)
4. Support with prevention from homelessness (n=26)

As discussed above, according to external evaluators an average £10,000 per case¹⁵ is saved where homelessness has been prevented. Given that the housing officer prevented homelessness in 26 ICJ cases, the estimated saving/cost avoidance for the public sector can be calculated at £260, 000.

Evidenced through the figures above ICJ workers deal with a wide range of housing needs. For example, a number of ICJ service users have been helped to move to ground floor housing as a consequence of lung cancer or other comorbidities rendering stairs impossible. General advice and information offered to the clients covered topics such as housing support for family members, advice on dealing with rent arrears, assistance with furniture and assistance with succession tenancy following a family member's death. Where clients required assistance with finding sheltered housing they were helped to do so. The following case studies are typical of the support offered by ICJ.¹⁶

¹⁵ There have been a number of studies which attempt to quantify the costs to government and society of homelessness (Department for Communities and Local Government, 2013). While it is very difficult to pinpoint the exact cost, it has been estimated here at £10,000 by evaluators of the housing option model.

¹⁶ Clients have provided permission

CLIENT D: White Scottish, Female; age band 50 - 60
Cervical Cancer: unsure of date of diagnosis

- Client D is a female who has been diagnosed with Cervical Cancer.
- Client D is a tenant of GHA and has substantial rent arrears and not maintaining arrangement to pay. She is due to call at court as landlord has requested a decree for her eviction.

CLIENTS MAIN CONCERNS:

Client D had stopped engaging with her Housing Officer and was not responding to any home visits/telephone calls etc and had not maintained an arrangement to clear rent arrears. Client D had partial Housing Benefit in place, she had a non-dependent child living with her and had failed to pay the shortfall on her rent for a considerable time. As a result of this, the landlord had no alternative but to instigate court action to recover the property.

OUTCOME:

Area Housing Manager contacted the Housing Project Officer for assistance with Client D. Client D was already a client with LTC officer, who had assisted Client D in applying for PIP. LTC officer contacted Client D and confirmed that PIP was now in place. Change in circumstances was then completed and Client D is now in receipt of full Housing Benefit and has made an arrangement to pay the arrears, therefore preventing court action which could have resulted in homelessness.

CLIENT C: White Scottish Male, Age band 50-60
Cancer Type: Hodgkin's Lymphoma

Client was first diagnosed with Hodgkin's Lymphoma in 2004, chemotherapy was successful and client returned to work full time. A recurrence of Hodgkin's Lymphoma was diagnosed in March 2016 and client's treatment plan was radiotherapy and chemotherapy. As a result of client being unfit for work, his income reduced significantly with Statutory Sick Pay being his only source of income. Client was living in a shared house with others. He shared kitchen and toilet facilities. The property was in very poor condition – no heating and cooking facilities in very poor condition. Client was also sleeping on the sofa.

CLIENT'S MAIN CONCERNS:

Concern 1:

Breathing, Fatigue, Walking and Weight Loss. Client understood the concerns raised were directly related to his cancer illness.

Concern 2:

Client was concerned about his financial position as his only income now was from Statutory Sick Pay. Client had lost weight and his clothes no longer fitted him and he couldn't afford to buy new ones. Also, he was struggling with transport costs to attend hospital appointments.

Concern 3:

Client also stated that his present flat was no longer suitable for him. As he was receiving radiotherapy and chemotherapy, he needed a clean environment to live in and also needed someone to care for him. Client was estranged from his wife and had very little contact with his son in recent years, however recognising how poorly he was, his son offered to allow client to stay with him on a temporary basis whilst his estranged wife would visit and care for him on a daily basis. This was only a temporary measure as his current home was not suitable for him to return to and this would prevent the client from becoming homeless.

ICJ ACTIONS:

Concern 1:

Client has frequent contact with his oncology team and was advised to discuss his physical concerns with the clinician he would be meeting the following week to discuss the results of his CAT scan.

Concern 2:

PIP form ordered and referral made to LTC to support client to complete PIP when Part 2 of the claim form received and for full benefit maximisation.

Macmillan Grant applied for.

Concern 3:

Referral made to Housing Professional to assist with housing situation. Client was focused on returning to his employment and therefore wanted to live in the Ibrox/Govan Area. He did not wish another private let and he was keen to be allocated a social tenancy.

Update:

Client was awarded Macmillan Grant of £440.00 to assist with fuel costs, clothing/bedding and assistance with travel costs to attend treatment. PIP applied for and is now in place. Housing Professional met with client to discuss his housing situation. Client was living in a private let for the last 12 years and was sleeping on the couch. As a result of his illness, this was no longer suitable for him and he was now looking for his own accommodation. Client's son had agreed that client could stay there for a short period of time, however client was concerned that this was not a long term solution and that he may become homeless.

Application completed for Wheatley Group and medical form also completed. Client is keen to remain within the Ibrox/Govan area as he has a good network of friends within this area, who will provide support. Gave list of other Housing Association's to consider applying to. Client was able to secure a GHA tenancy within Ibrox within a few weeks of making an application, therefore preventing him from becoming homeless. Client is also hoping to return to work in the near future.

Interpretation

Without ICJ, 26 people may have lost their homes. This alone highlights the benefit of having dedicated expertise at hand. A cancer diagnosis can cause financial difficulties. The two major components of this financial impact work against each other: reduced income due to inability to work, and increased costs, such as expenditure on travel to treatment, parking or increased heating bills. Yet, results from the Scottish Cancer Patient Experience survey (2016) revealed that 48% of people who said they wanted financial support did not get any¹⁷. Research by Macmillan found that a major barrier to obtaining benefits was a poor understanding of the system among patients and health professionals (Macmillan, 2017).

Our recent findings are showing that different professionals elicit different needs from people even when using the same HNA (figure 4.10)¹⁸. People likely tailor their needs to the perceived skills of the professional in front of them. Further, as was explored in the client interviews, individuals don't always feel it is appropriate to raise practical concerns in a health setting. Financial concerns are significant for the majority of ICJ service users. ICJ link officers are the best qualified people to deal with these issues, far better than health professionals for example. This means that the right people are in the right place to deliver the right support to the right people.

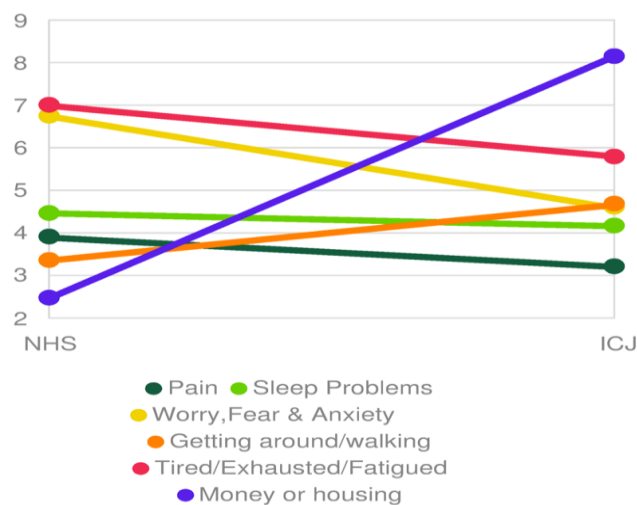


Figure 4.10. Percentage of top concerns elicited by people seeing a health worker (left) or ICJ (right). Note difference in 'money and housing'.

¹⁷ Scottish Government (2015) <http://www.gov.scot/Resource/0050/00501127.pdf>

¹⁸ Snowden, A., & Young, J. (2017). When are Holistic Needs not Holistic Needs? In *RCN International Nursing Research conference and exhibition 2017*. Oxford: RCN.

SECTION FIVE: The Individual Level

Overview

ICJ aims to improve outcomes for people affected by cancer. In order to evaluate the impact of ICJ we used two approaches:

1. We compared various outcomes between people who have used ICJ and a sample of people who have not
2. To understand the experience of using ICJ we interviewed a sample of ICJ clients.

Comparison between those who have used ICJ and those who have not

A questionnaire was constructed including all the measures detailed in section three.

AIM

To determine if there was a significant difference in quality of life, health status, patient activation and social support between people who have received ICJ and eligible people in Glasgow who did not.

Results

PROCESS

The questionnaire was posted to 500 individuals who had used ICJ and 500 individuals who were offered the service but did not take it up.

As of February 2017, from the 1000 questionnaires sent 354 questionnaires were returned: 186 ICJ and 168 non-ICJ service users, a return rate of 37% and 33% respectively. These response rates are fairly typical for postal surveys in healthcare.

Demographics

The demographic and clinical profile of those who returned the questionnaire is in table 5.1.

	ICJ sample		Non-ICJ sample			
Average age	61 years		64 years			
Females	n=101 (54% ¹⁹)		n=88 (52%)			
Males	n=85 (45%)		n=80 (47%)			
SIMD						
Vigintiles (deprivation measure) ²⁰	Median=4		Median=6			
Cancer type	Breast	38	20%	Breast	43	25%
	Lung	22	12%	Lung	16	9%
	Prostate	28	15%	Prostate	20	12%
	Bowel	27	14%	Bowel	17	10%
	Other	73	39%	Other	74	43%
Time since diagnosis	686 days ²¹					

Table 5.1 Demographic profile of questionnaire respondents

Interpretation

- Those who use ICJ are slightly younger (61 years old versus 64 years old)
- Those who use ICJ are from more deprived areas (vigintile 4 versus 6)
- There are proportionally more people with a diagnosis of lung, prostate or bowel cancer in the ICJ sample and more breast and 'other' in the non-ICJ sample

It is important to keep these differences in mind when interpreting results. For example, there is a long-established link between deprivation and quality of life (Chen, 2015) and so any difference noted between the groups could be a function of deprivation rather than anything else.

Questionnaire Measures (ICJ v non-ICJ)

In order to compare questionnaire responses from the two groups (those who used ICJ and those who didn't) the mean value for each measure - quality of life, health status, social support and patient activation was calculated (see method chapter for description of questionnaire measures). For each measure, higher numbers indicate a more positive state.

¹⁹ Figures have been rounded up or down so may not always total 100

²⁰ Vigintile is the most detailed SIMD deprivation measure -1 most deprived to 20 least deprived

²¹ There was no data on this for the 'non-ICJ' sample

Measure	ICJ Sample (M=mean)		Non-ICJ sample (M=mean)	
Quality of Life (FACT-G)	M=62.58		M=73.13	
Health Status (EQ-5D)	M=0.48		M=0.66	
Health state today (0-100)	M=51		M=63	
Social Support (MOS-SSS)	M=2.62		M=3.13	
Patient Activation (PAM-13)	M=55.24		M=62.98	
PAM Level (1-4)	1	30%	1	17%
	2	14%	2	13%
	3	39%	3	40%
	4	15%	4	28%

Table 5.2 Mean values for each measure

Interpretation

- Individuals who had used ICJ scored significantly²² lower across every measure.
- People who used ICJ had self-reported lower levels of quality of life, lower levels of social support and lower patient activation than people who have not used ICJ.

Results show that those people who require the support from ICJ have higher levels of need. It also gives us some insight into why people may choose not to use the service. They appear to have a better quality of life, greater support networks and have greater confidence in managing their own health. However, it is important to highlight that while we can speculate over the interpretation of these results we do not know the precise reasons why the ‘non-ICJ’ individuals did not use the service.

A further caveat with the interpretation of these differences is that the two groups (ICJ and non-ICJ service users) were not matched for factors that can influence how someone may score on these measures. As highlighted in table 5.1 they differ in terms of their average age, gender and deprivation category. This makes ‘like for

²² Significance is a statistical term that tells us how sure we are that a difference exists and that the difference between the two groups wasn’t a fluke.

like' comparisons difficult as characteristics like these can affect quality of life, social support and patient activation (Chen, 2015).

Summary

The aim of comparing those who had received ICJ with those that had not was to explore the impact of ICJ. On the surface, the results show that people who have used ICJ have worse outcomes across these measures than a sample of people who have not used ICJ. However, a major caveat here is that we did not obtain a matched sample. This makes any form of comparison between the samples meaningless as we do not know if we are measuring the impact of the intervention (ICJ) or if we are picking up the influence of other variables, such as diagnosis stage and deprivation.

Another explanation for these findings is the possibility that we did not measure the best outcomes. For example, from the routine data and in the interviews we see that a significant area of support for people receiving ICJ is financial and housing support. In our questionnaire we focused on proxy measures of these such as quality of life, social support, and well-being, rather than a direct measure of financial support. Consequently, we propose in future evaluations to include measures of financial wellbeing.

The experience of using ICJ

AIM

To gain an in-depth understanding of the individual experience of ICJ.

The final item on our questionnaire asked if individuals would like to take part in an interview with a researcher. Of 185 total responses, 45 people gave consent. From these, we purposively sampled 22 people. Sampling was based on gender, diagnosis and questionnaire responses in order to obtain a broad sample.

Participants- 20 individuals were interviewed (table 5.3).

Age	Mean- 58 years
Gender	Male n=7
	Female n= 13
Cancer type	Breast n=6
	Prostate n= 2
	Colorectal= 5
	Cervical n=1
	Lung=2
	Head and neck n=2
	Blood n=1
	Thyroid n=1

Table 5.3 Participant characteristics

Interviews were conducted with 7 males and 13 females. Their ages ranged from 38 to 74 years old. They had been diagnosed with a variety of cancer types. All had used the service within the last 12 months. Interviews were arranged at a time and in a location that was suitable for the participant. In most cases this was the participant's home (n=16).

Broad open questions were used to allow the participants to describe their experiences and a semi-structured interview schedule covered routes into the service, motivations for using the service, support needs, sources of support and thoughts around what other support routes they may have used if the service hadn't been there. Interviews ranged from 25 minutes to 50 minutes.

Data analysis

All interviews were recorded and transcribed. The data was analysed following Braun & Clarke's thematic analysis (Braun & Clarke, 2006). In summary, this involved reading and re-reading the transcripts then forming codes, sub-themes and themes that represented repeated patterns of meaning across the data.

Figure 5.1 presents the themes and sub-themes that were generated from the interviews. The three themes were: 'one person, one place' 'routes to unexpected support' and 'safety net'. In summary, these themes highlighted the perceived benefits of using this service.

Theme one: One person, one place

Participants valued having one point of contact to help them navigate through the cancer system. The link officer liaised with other professionals and assisted with tasks such as completing paperwork and making phone calls. This was valuable

particularly within the diagnosis and treatment phase of their cancer journey when they were too ill to do this themselves:

“At the time, I was struggling and everyone came out here. They filled out all the forms, they arranged everything, dealt with everything” [Interview 8, female]

That the support came to them in ‘one place’ rather than having to seek it out was a defining feature of their experience:

“When you’re in that place you don’t have the energy either to think but it was just one place you had to go and they accessed everything for you, they accessed after chatting to you what they thought you needed rather than going to half a dozen different places which you don’t really have the energy for” [Interview 13, female]

“I had a place to ask people. I could phone them up and say how do I deal with this concern. So, there’s a contact, there’s a place to go. To have that support is wonderful.” [Interview 7, male]

The health and social care systems can be difficult to navigate, hence the need for the service. These interviewees describe ICJ simplifying their lives by reducing many incomprehensible contacts down to an understandable and accessible one:

“I think it’s great how everyone is tied in with everyone else doing referrals. It saves you looking yourself and going online” [Interview 18, female]

For those that lacked confidence the service enabled them to seek the help that they required. The following quote suggests the interviewee may have not attended subsequent appointments without the support of ICJ:

“I don’t like approaching places. I would never have gone and got help myself, I never would’ve done that. So, I don’t know what I would’ve done actually if the service hadn’t been there” [Interview 8, female]

The participants describe their positive experiences as they were guided through the cancer system. However, in the next theme it becomes apparent that they didn’t even know what the system entailed until meeting with the ICJ link officer.

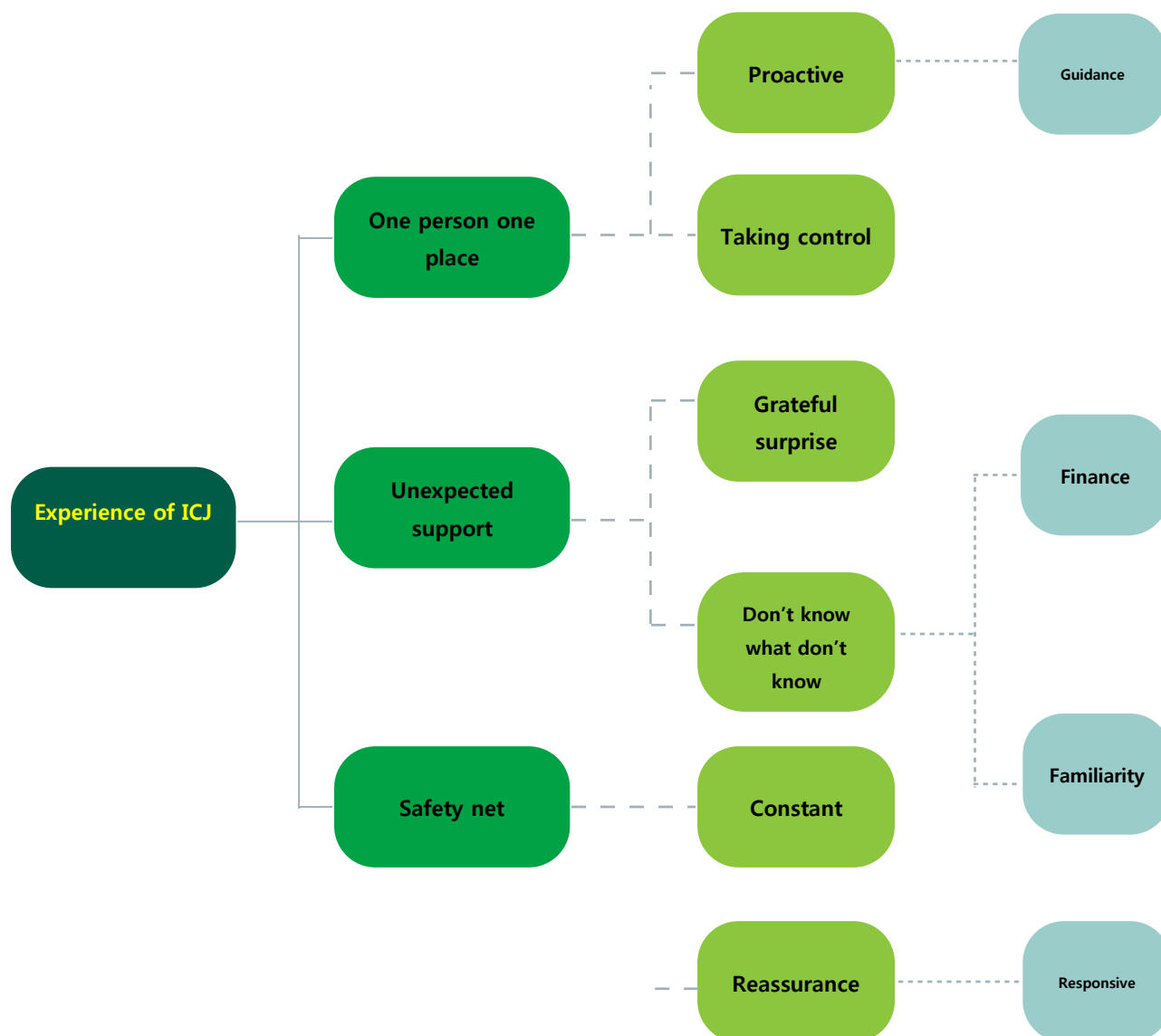


Figure 5.1 Themes and Sub-themes

Theme two: Routes to unexpected support

Being newly diagnosed, the participants were unaware of the wider support available to them until ICJ informed them of it. With this new knowledge and guidance, they could see the links between the information and their care. Directed by the HNA, the support offered by the link officers covered a range of needs to promote their wellbeing:

“You’ve never been in that situation so you don’t know what’s available so it’s good to have someone to guide you. They asked lots of questions would you benefit from massages, walking groups, talking groups that kind of thing”
 [Interview 13, female]

Almost every participant interviewed stated they needed support with financial difficulties. Yet, they didn't realise they were eligible for any support until they accessed the service and were informed. The participants describe crucial financial requirements in order get to their treatment sessions and fundamentally to keep their home:

"They [ICJ] came out and she asked me about any financial concerns. I didn't think I would qualify, I've never had a benefit in my life. But she was very good she asked me lots of different questions and I ended up getting £55 a week. It really does help me in the bad weather as anywhere I go it's got to be a taxi".
[Interview 11, male]

"I was worried about money, I was worried about losing my home. I didn't know there was so much help available. So that was a relief because there was benefits I was entitled to and I didn't realise" [Interview 9, male]

The root of these financial difficulties stemmed from changes in income and out-of-pocket expenses due to lifestyle adjustments, such as using taxis more frequently. The psychological impact of this was described by a number of the participants:

"I was on no pay and I had a mortgage to pay. I think it can become a crisis when you're ill and it can become a crisis not just because of your physical difficulties". [Interview 10, Female]

These people had not discussed their financial concerns before because they felt the health setting was not an appropriate environment to raise non-medical concerns:

"There is no scope in my treatment to engage with the medical professionals about that kind of thing. That's maybe a good thing as they have their role. It's not the right format for that kind of thing" [Interview 19, female]

"My oncologist was very good and my surgeon was amazing but you're only one of god knows how many people. So, I think it was good to have another outlet to ask questions and practical things too, you know" [Interview 13, female]

ICJ provides routes to support based on need. Here the participants benefited from having an outlet to discuss practical and lifestyle concerns. Once guided to this support the next theme highlights how they perceive that support.

Theme three: Safety net

A perceived benefit of this service was knowing exactly where they could access the support again should they ever need it in the future:

“I have the phone numbers and I sometimes check the website and pop in so it’s not cut off completely” [Interview 6, female]

ICJ is experienced by the participants as a constant source of support. This was described by one participant as a ‘safety net’:

“It’s a safety net that’s there; if it’s taken away, don’t ever get it taken away” [Interview 1, male]

Having this in place provided reassurance that should their situation change ICJ would still be available:

“I really count on them I know anytime if I need to share something I know they will listen” [Interview 3, female]

The participants’ language infers they feel a familiarity and deep connection with the service. That the service will ‘listen’ and can be accessed easily is more characteristic of say a friend than a cancer service. Knowing the service is there, ready to respond with support should it be needed, appears to provide comfort and strength:

“I’m going for major surgery soon but it’s ok I know I’ve got the help there if I need it. If anything crops up I can pick up the phone” [Interview 9, male]

Consequently, this reassurance has been created through the manner in which an individual’s case is closed. There is still contact:

“They keep me posted with everything that I can do” [Interview 2, female]

Knowing ICJ was there as a safety net brings a sense of ease and for this particular participant it encouraged self-management of their problems:

“Having the service there I knew there was someone just a phone call away that makes a big difference. Then it encouraged me to do more research on my own. I was looking at the work situation it encouraged me to do a lot of things on my own” [Interview 19, female]

In summary, recipients of ICJ valued the consistency of having one person to help them with everything. As they hadn’t been in that situation before they appreciated the expert navigator. Further, they perceived the informality, perceived lack of rush, and the security ICJ brings as beneficial.

Conclusion

This section of the report focused on individuals who have used ICJ. To understand the impact of the service at an individual level we measured a number of key factors that the literature recognises are important for people affected by cancer, such as quality of life, social support and patient activation. We compared these outcomes in sample of people who have used ICJ with a sample of people who were offered ICJ but did not take it up. We found that the people who were offered but did not use ICJ (for whatever reason) had higher scores across the measures. That is, a higher quality of life, greater levels of support and higher confidence and greater likelihood that they would engage in self-management. However, a major limitation with this is that the samples were not matched on all the key variables that can affect these outcomes.

In addition, these measures may not be the ones to pick up the benefit of ICJ. For example, the interviews highlight ICJ is clearly beneficial to those who use it. ICJ is being accessed by people who need it the most and the HNA indicators show that levels of concern are falling by a significant margin. The main problem for the ICJ cohort, by a considerable margin, is housing/finance. Future evaluations will therefore focus on measuring financial well-being to see if this benefit can be better quantified.

To understand what it is like to use the service a sample of individuals were interviewed. Analysis of the interviews highlighted a number of positive features in the support offered by ICJ. Proactive, personalized and constant support underpinned by HNA were the defining features of the participant's experience. Participants described the benefit of a service that makes referrals across health, social care and the 3rd sector to ensure that they are well supported. What is more, individuals described a reassurance that they knew where to go should they require the support again.

SECTION SIX: The Culture

Overview

There is a legislative requirement to integrate health and social care services to improve the experience and quality of care for people in Scotland. It is within this cultural context that ICJ currently operates. ICJ is led by Glasgow City Council and has partnerships with a range of organisations across health, social care and the third sector to enable this integrated approach.

To understand more about these partnerships and their role in the development and provision of ICJ we wanted to hear from wider stakeholders working across health, social care and the third sector. To interview people with relevant expert knowledge and experience individuals involved in the implementation and governance of ICJ were approached.

AIM

To explore key successes from stakeholder perspective

**WE ARE
MACMILLAN.
CANCER SUPPORT**

NHS
Greater Glasgow
and Clyde

 **Wheatley
Group**

cordia
DELIVERING FOR GLASGOW



Glasgowlife™



Method

The interviews were conducted between April and August 2017. Interviews ranged from 25 minutes to 40 minutes. A semi-structured interview schedule was used (appendix 5). However, it was used flexibly to allow participants to focus on topics that were important to them. Interviews were recorded and transcribed verbatim. Ten individuals were interviewed representing the following organisations; Glasgow Social Work Services (SWS) (n=2), Glasgow City Council (n=2), Cordia (n=1), The Wheatley Housing Group (n=2), Glasgow Life (n=1), NHS Greater Glasgow & Clyde (n=1) and Macmillan Cancer Support (n=1).

The data was analysed using thematic analysis with a focus on coding process related themes. This involved examining individual responses for each discussion area and then a comparison of themes within and across the organisations. We sought to identify both similar and varying views. The findings are presented next with interview extracts referenced by organisation and participant number.

Results

The participant's (stakeholders) roles and their degree of seniority and involvement with the ICJ board was varied. Yet, on the whole their views were similar. Overall, the service and its impact on improving outcomes for people affected by cancer was described extremely positively. The model of integration was hailed as a key success. The three themes were: a 'model of integration', 'working together for the individual' and 'strategic alliances'

A model of Integration

The 'integrated model' within ICJ was viewed a success:

"For us undoubtedly one of the successes of ICJ is the integrated model itself. That doesn't come easy" (Participant 7, Wheatley)

"I think it's an outstanding model of integration. In relation to strategic planning, in relation to governance, in relation to delivery, in relation to realising its not exclusively the remit of specialist organisations to deliver a wider well-being outcome" (Participant 1, SWS)



Figure 6.1. ICJ has grown from and is more than the sum of its parts

Considering first what is meant by this ‘integrated model’ the participants broadly described two features; partnership building across organisational and professional

boundaries and a common goal: the delivery of improved outcomes for people affected by cancer:

“I think the service has been very good for developing integration. Partnership has been a good thing” (Participant 9, NHS)

“You could put a great project plan together on how to integrate a service and it might take 5 years. But here we’re getting partners to work together on a common goal. That’s what’s moving minds” (Participant 10, Macmillan)

“I think the key success is that people are actually working together to focus on people who are probably at their most vulnerable. I think everyone should be applauded for the collaborative leadership that has developed” (Participant 2, Glasgow Life)

Integration as described by participant 7 'doesn't come easy'. Participant 10 referred to the partnership working in ICJ 'moving minds'. Consequently, it appears one of the reasons the integrated model within ICJ has been labelled a success is that despite the challenges of delivering integrated care it has been implemented. This *activity* then led to a positive shift in thinking and working.



Figure 6.2. The partners got on with it. That in turn helped them get on with it.

Exploring why integrated care may pose a challenge, participants discussed the complexity of bringing together different cultures:

“It was challenging in the beginning because I think as people, it was about how do we make this work. The cultures had to mesh a bit because we didn't have a blueprint and it was different engagement, not the normal engagement we would have” (Participant 8, Wheatley)

“There are challenges possibly because of the cultures but also different ways of working, different expertise.” (Participant 9, NHS)

“It's about culture, it is about the way we are with each other, it is about being different and now that is enormously difficult” (Participant 1, SWS)

Culture through these quotes is described in terms of people and working relationships. The participants associate their organisation with a particular culture and working practice and this is what differentiates them from the other partners. A challenge therefore is how these differences can engender positive change and improved outcomes for the individual. This requires a genuine collaboration between the organisations rather than a certain culture dominating:

“I think there's a broader agenda in and around how do you bring the partners together on an equal footing in terms of the voices round the table” (Participant 7, Wheatley)

“I think what can be difficult is ICJ cuts across different sectors so what can be difficult sometimes is the boundaries” (Participant 9, NHS).

There is a repeated emphasis through these quotes on partnership working. However, while bringing different cultures together was recognised as a challenge, it was not an immovable barrier. In fact, lowering barriers played a significant part in delivering and maintaining the ICJ model of integration.

“I think we’ve put down barriers and worked to a common cause. We’re all slightly working differently and being different with each other as organisations and this is providing focus. It’s a change to the way organisations generally have historically worked” (Participant 1, SWS)

“You take people out of their respective cultures and bring them together into a single environment, you know, and the culture in there is properly focused with all of the barriers to people doing things out of the way” (Participant 7, Wheatley)

“It’s difficult to manage relationships when everybody has a different focus but everybody really has got the same ambition for it to be a success which is good and quite unusual” (Participant 5, Cordia)

The organisations each approach the support of people affected by cancer in a different way. Nevertheless, they are effectively working together as they share a common focus. What has united the organisations to deliver this integrated care will be explored next.

Working together for the individual

The participants and their representative organisations have been motivated to work together with the common goal of helping those that require support:

“The issue is around the people who need support. I think that’s what public service is. You can lose sight of that. Organisations have lost sight of that in the past. We are public servants we are here to service the public and I think ICJ has broken that down” (Participant 1, SWS)

“What’s been really strong has been the will across the organisations to improve things for people affected by cancer. To listen to what their needs are” (Participant 10, Macmillan)

This person-centred approach was influential in bringing the services together. As suggested by participant 1 this has not always been the case making the approach here innovative. The participants describe a commitment to working collaboratively to meet shared goals again with the driver of improving care for the individual:

“It’s a shared service commitment you know. You realise your day job is your own service approach but actually you’re coming from a multi-service and delivering it in a multidisciplinary team and seeing fantastic outcomes. So you’re really appreciating not just the difference you’re making but also your colleagues, which is really powerful” (Participant 8, Wheatley)

“People are really committed to not just looking at the bit of work they’re responsible for but to look at what else could be done to make this experience more positive” (Participant 2, Glasgow Life)

Considering further why this commitment has been sustained, the participants describe instances where ICJ has had a positive impact on the delivery of care within their own service:

“So, other services that can improve the pathway and improve the anxiety of the person and their family, or can deal with other services and signpost to other supports, that takes some pressure off us” (Participant 5, Cordia)

“What has been really important to us is being able to see all that information on the clinical portal” (Participant 9, NHS)

“The support plans that are put in place after the holistic needs assessment help within the workplace because otherwise HR would need to put together those plans. Whereas now we have experts putting them together, someone who is slightly removed from the situation but has a lot more experience. So these support plans now complement the HR activity that is going on” (Participant 3, Glasgow City Council)

“I like to look at the number of and places where the link workers refer on to, which obviously, as a collective supports people to remain well. Given that our resources are getting tighter that’s a good thing because we don’t want people coming to social work if they don’t need to” (Participant 6, SWS)

This joint working across the organisations has enabled a more appropriate and efficient use of staff resource and ultimately improved coordinated care and greater access to services for the individual:

“It frees up people to do the jobs they should be doing. It’s the idea that actually clinicians are getting freed up from some of the enquiries they have had to provide as they’re getting that from somewhere else” (Participant 4, Glasgow City Council)

“If you are a patient going through that cancer journey then all your needs are wrapped up into one. You don’t need to tell your story many times to different

professionals. So for us that's night and day to how patients used to be supported" (Participant 8, Wheatley)

"I think the key successes are very much the wider scope that the service is able to have in referring people on. We've got services that patients would have not known about if they hadn't come to ICJ" (Participant 9, NHS)

Subsequently, integration has brought benefits to each person's organisation and improved the delivery of support. This has underpinned the commitment to the service at board level. The final theme shows how wider strategic alliances between the partners also helped to strengthen commitment to the service.

Strategic alliances

There are clear strategic alignments between ICJ, the partner organisations and wider policy. For example, around providing person-centred care:

"We are in a climate where our values are very similar and very overlapping. Everyone's strategies are the same, we're all wanting to be better person centred, better outcomes for people. More humanity and dignity" (Participant 5, Cordia)

"It sits really well in ensuring we have person centred care. So it also fits really well with the broader Scottish Government agenda of what matters to you on person centred care" (Participant 10, Macmillan)

ICJ provides support based on need which may be at any point in an individual's cancer 'journey'. For some participants, providing an immediate route to support fitted well with their organisations early intervention agenda. That is, providing support close to diagnosis to prevent concerns from escalating:

"I think part of the decision for us to invest is that we have a clear commitment to early intervention and prevention so when you have visions that align it made a lot of sense because that's the way we're always heading and investing our future strategies" (Participant 7, Wheatley)

"If you can prevent someone from getting to a crisis point then that will be saving money because they won't be approaching someone at crisis. Those things are getting dealt with and in any situation, that's always cheaper" (Participant 4, Glasgow City Council)

"It sits very positively from a strategic point of view because it's about keeping people well. Yes we need to be part of keeping people well and safe but other services are available that can support people without them having to unnecessarily come to social works door" (Participant 6, SWS)

Whereas, for other participants they saw alignment in the longer-term support needs of someone affected by cancer:

“For some it [ICJ] will be really good early on but for some patients the end of treatment is a crucial time. So it fits really well with all that’s going on there”
(Participant 9, NHS)

“We might not be providing frontline emergency need but we provide a sustainable bit in the longer term on the wider health and mental health side of things. So benefits and alignments there” (Participant 2, Glasgow Life)

Subsequently, these alignments represent shared values and aspirations for supporting people affected by cancer. The proactive nature of the service helps to prevent the escalation of cases and a more efficient use of resource. The impact of this is that the organisations became invested in the ICJ model. Different professional bodies may focus on certain components of that support and at certain time points. This develops the alliance by generating a new way of thinking how to deliver appropriate and well-timed support.

Conclusion

ICJ has created a collaboration between the sectors with the goal of improving well-being and system efficiency for people affected by cancer. Across the three themes we explored the reasons why the integration agenda has worked and what the challenges are. There was a motivation to provide person centred care that recognises the multifaceted consequences to living with a cancer diagnosis. This motivation was sustained through strategic alignment.

Integration is a complicated phenomenon meaning part of the analysis involved exploring what integration meant to these participants and why it was successful in ICJ. There was a repeated emphasis on people and working relationships highlighting the importance of getting that right. Historically attempts to integrate haven’t worked, which makes the success here unique and noteworthy. It is difficult to pin down why this has worked where others had failed, but one of the strongest themes throughout was *action*. People in all ‘cultures’ had just got on with it. Success bred success:

We are what we repeatedly do. Excellence is not an act but a habit.

Aristotle.

SECTION SEVEN: Bringing it all together

Since inception in 2014 ICJ have seen 2413 individuals. A total of 13,168 needs have been identified, an average of 6.3 problems per person. The top three concerns remain: money and housing, fatigue/tired/exhausted and getting around. 1039 people declared they experienced financial difficulties and 209 had explicit housing issues.

The majority of people were referred on to Glasgow City Council, Macmillan Cancer Support, Glasgow Life or the NHS, although the second largest category of referral (14.5%) was for 'self-management'. Patients have been referred to a total of 220 different agencies. Importantly, level of concern reduced significantly between assessment visit and final review. Scores went down from average 7.3 out of 10 to 3.7, a statistical and clinically significant drop. The vast majority rated the outcome of their referral as 'very helpful', giving it 9/10 on average. Individuals are highly satisfied with ICJ as a service. ICJ meets people with high levels of concern and by their final review this concern has reduced down to a manageable level.

We have so far been less successful demonstrating the impact of ICJ using proxy measures of wellbeing, patient activity and quality of life. This is likely to be an artefact of sampling. The people who responded to requests to complete questionnaires were from less deprived areas. There is also the possibility that the measures we have used so far may not be the right ones. This will be revisited. The biggest problem for users of ICJ is money and housing. The next evaluation will look further at the direct measurement of this and understand better the impact it has on the individual.

The client interviews revealed in detail the depth and breadth of the benefit of ICJ. Being able to deal with everything in one place was seen as extremely beneficial for clients, especially when they had little energy. The fact that ICJ could navigate the support systems for them was useful. Some individuals may not have had the confidence to attend appointments without ICJ. Nearly all were worried about money and did not know about any of the help available prior to meeting ICJ. In some cases, this prevented homelessness. Interviewees were unanimously grateful to ICJ.

In relation to stakeholders, ICJ was seen to be a model service, a working example of government aspirations to operationalize person centred care through closer joint working across services. This joint working was viewed as one of the drivers that enabled more efficient use of resources across the organisations. Historically, health and social services have been trying to work together since aspirations of a 'seamless service' first appeared over 40 years ago. The fact that ICJ is a working example makes it extremely important to understand.

The previous report had identified the key components: strong leader, strong buy-in from all partners, a skilled workforce using a workable system. This continues. What this evaluation has added is the background context within the individual cultures and their efforts to make this succeed. All stakeholder interviewees described the proactive person-centred vision of ICJ as key to buy-in in the first instance. They all described the need to knock down barriers from within and they all described the act of getting on with it as the reason for its success. In short, ICJ works because people made it work. The positive feedback from early success further enthused partners and so effort was redoubled and so on. As a model to follow the components remain very simple.

In relation to the key objectives for the service, ICJ continues to deliver. It adopts a personal outcomes approach providing tailored support based on need. It enhances the experience of services for people in their community. It impacts on survivorship by getting help to people proactively. It reduces health inequalities by predominantly helping people in the lowest SIMD categories (over 77% ICJ clients come from SIMD quintiles 1 & 2). This is notable as people from socioeconomically disadvantaged groups are generally less likely to make use of the care system demonstrating a more equitable access to services and treatment within ICJ. Individual cases show the life improving impact ICJ has had. For example, ICJ has so far prevented 26 people becoming homeless and supported over a 100 people to live safely in their own home. Accordingly, there is no doubt ICJ is having a significant positive impact across Glasgow and meeting the objectives of the Scottish Government.

SECTION EIGHT: Recommendations

Recommendations and Next Steps

1. Continue to fund ICJ

We recommend ICJ should continue to be funded. ICJ helps the most vulnerable people in society at a time when they need the help most. It does this proactively, systematically and (inter)professionally. It is a working model of integrated care at a time when most service providers are wondering how to operationalise the idea. For example, the Chief Medical Officer talks about the NHS delivering 'Realistic Medicine'. Realistic Medicine:

... puts the person receiving health and care at the centre of decision-making and encourages a personalised approach to their care.

ICJ is already doing this. The fact that it does it so comprehensively makes it a model to follow.

2. Further explore the clinical significance of the drop in 'level of concern'

This report is the first to show objective benefit of ICJ using the metrics available within the holistic needs assessment. It showed that average 'level of concern' reduced from nearly seven to below four. Given the HNA was developed from the distress thermometer (DT), and any such drop in DT is considered clinically significant, then this finding should be explored in more detail in the next report.

3. Create a matched sample to compare outcomes between ICJ and a non-ICJ cohort.

There is a small window of opportunity to create a matched cohort in other Scottish cities so that service usage could be meaningfully compared between an ICJ and non-ICJ sample²³. Permissions are in place to do this, and strict control should be placed on the parameters 'time since diagnosis' and deprivation category given these factors are so instrumental to quality of life.

4. Measure financial well-being

There is a possibility that the tools we chose to measure impact are not relevant to ICJ. We chose proxy measures 'well-being', 'general health' and 'quality of life',

²³ Previous attempts resulted in wide variation in deprivation categories and time since diagnosis, such that the 'control' group was considerably better off and further on with their recovery than the ICJ group.

partly because economic evaluations could be constructed from these measures. However, it is fair to say that so far, they have not been useful in articulating what is important to users of ICJ. The next evaluation will incorporate measures of financial well-being given this is such an issue for this cohort.

5. Understand the carer experience

The Scottish Government talks about people with cancer 'and their families' being cared for. The next report will focus on the carer experience to examine the degree to which ICJ helps them.

6. Understand the impact of outreach

ICJ now has outreach in acute care. The setting the HNA is delivered in may have an impact on concerns raised and user experience. We recommend this be evaluated from all perspectives.

7. Explore the prevalence and impact of signposting v's referral

In order to 'close the loop' we need to understand what happens to people who have used the service. For example, if someone actively engages with a service after being signposted or not. Evidence suggests that once people know about ICJ they will use it again if they need to. This will also be followed up.

8. Saving clinical time

This evaluation found anecdotal evidence for clinical time being utilized more productively. The next evaluation will gather empirical evidence.

9. Consistent data entry and reporting across all areas adopting the ICJ model to enable UK comparisons and service provision

Consistency of reporting will be key to understanding future changes. Data has not historically been consistent, both within ICJ and more widely, making reporting difficult. We recommend Macmillan Cancer Support and Glasgow City Council set up a short working group including evaluators from Edinburgh Napier University to ensure all data are consistently entered and recorded.

References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Calderwood, C. (2017). Realising Realistic Medicine. *Chief Medical Officer's Annual Report 2015-2016*. Retrieved from <http://www.gov.scot/Publications/2017/02/3336/downloads>
- Chen, X. (2015). Relative deprivation and individual well-being. *IZA World of Labor*, 1–10. <http://doi.org/10.15185/izawol.140>
- ISD (2017) Deprivation and Cancer Survival in Scotland: Technical Report
- Macmillan Cancer Support (2006) Hitting Home Campaign Report
- Macmillan Cancer Support (2013) No small change
<http://www.macmillan.org.uk/documents/policy/money-and-cancer-policy-report.pdf> [Accessed Sep 2017]
- NHS Health Scotland. (2017). *Screening and inequalities*. Retrieved from <http://www.healthscotland.scot/media/1342/finalconfbrochure.pdf>
- ScotPHO (2017) The Scottish Public Health Observatory
<http://www.scotpho.org.uk/health-wellbeing-and-disease/screening/data>
- The Scottish Government (2005) *Social Focus on Deprived Areas*. A Scottish Executive National Statistics Publication Edinburgh
- The Scottish Government (2015) *National Health and Well-being Outcomes*. Edinburgh
- The Scottish Government. (2016a). *A national clinical strategy for Scotland*. Edinburgh.
- The Scottish Government. (2016b). *Beating cancer. Ambition and Action. Cancer Strategy*. Edinburgh.
- Watt G.C.M. & R. Ecob, (2000) Analysis of falling mortality rates in Edinburgh and Glasgow. *J. Public Health Med.*, 22, (3), 330–336

Appendices

Appendix 1- Alignment between ICJ and 9 National Health and Wellbeing Outcomes

Glasgow ICJ delivers across all 9 National Health & Wellbeing outcomes	
1. People are able to look after and improve their own health and wellbeing and live in good health for longer.	The focus of ICJ and support by link workers is to intervene early and build confidence in self-management in 95% of cases
2. People, including those with disabilities or long term conditions or who are frail are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	<p>ICJ has a dedicated housing professional within the team who ensures people are prevented from homelessness and receive the support they need to live in their own home independently and well for longer.</p> <p>ICJ Link officers and 3rd sector partners spread of low level volunteering services in the community, focus on connecting individuals up to support services already existing within their local context; building community capacity and maximising support closest to the individual and their home; many with cancer also have other long term conditions which are assessed alongside cancer, making it a model appropriate for all LTCs</p>
3. People who use health and social care services have positive experiences of those services and have their dignity respected.	ICJ has embraced Macmillan's value based standards and is a test site across the UK; dignity and respect is core to this programme and 93% said their link worker made them feel supported through their cancer journey
4. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.	Using HNA and care planning allows services to be focused on supporting an individual's needs; person centred care. Glasgow ICJ has developing relationships across primary (GP & community pharmacy joint working) and acute NHS and social care to ensure all services

<p>5. Health and social care services contribute to reducing health inequalities.</p>	<p>Interim evaluation demonstrates 77% access the service from the most deprived areas (self-selecting), implying those in more affluent areas tend not to access it for support, feeling able to manage their needs.</p>
<p>6. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing.</p>	<p>ICJ now has carer assessment uptake over 4 times the national average. In addition, a carers HNA is being tested for spread across the UK ensuring carers, and their role in supporting people with cancer, is valued and their needs supported.</p>
<p>7. People using health and social care services are safe from harm.</p>	<p>The link officers receive supervision from the NHS clinical psychologist in addition to having regular action learning sets provided by Macmillan. These 2 aspects help ensure the link officers themselves are in the best position to safely manage their clients; keeping the clients safe. There are also numerous examples of instances where the intervention of the link officers has been timely and important at minimising risks for the clients</p>
<p>8. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.</p>	<p>As above. In addition, the link officers have been supported with SVQ level 3 accredited training to support their work (newly developed by Glasgow City Council SWS and NHS accreditation)</p> <p>Link officers also receive one to one supervision from NHS clinical psychology quarterly and Macmillan Action Learning sets 6 weekly</p>
<p>9. Resources are used effectively and efficiently in the provision of health and social care services.</p>	<p>The service ensures people access the wide range of health and social care support that already exists – statutory, 3rd sector and community based volunteering or delivery models</p>

Appendix 2- The Concerns Checklist

National Cancer Survivorship Initiative – Your Holistic Needs Assessment

Concerns checklist
0001

Living with and beyond cancer – identifying your concerns

Patient's name or label

Completed by: _____

Date: _____

Designation: _____

Contact details: _____

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating or appetite
- Indigestion
- Sore or dry mouth
- Nausea or vomiting
- Sleep problems/nightmares
- Tired/exhausted or fatigued
- Swollen tummy or limb
- High temperature or fever
- Getting around (walking)
- Tingling in hands/feet
- Pain
- Hot flushes/sweating
- Dry, itchy or sore skin
- Wound care after surgery
- Memory or concentration
- Taste/sight/hearing
- Speech problems
- My appearance
- Sexuality

Practical concerns

- Caring responsibilities
- Work and education
- Money or housing
- Insurance and travel
- Transport or parking
- Contact/communication with NHS staff
- Housework or shopping
- Washing and dressing
- Preparing meals/drinks

Family/relationship concerns

- Partner
- Children
- Other relatives/friends

Emotional concerns

- Difficulty making plans
- Loss of interest/activities
- Unable to express feelings
- Anger or frustration
- Guilt
- Hopelessness
- Loneliness or isolation
- Sadness or depression
- Worry, fear or anxiety

Spiritual or religious concerns

- Loss of faith or other spiritual concern
- Loss of meaning or purpose of life
- Not being at peace with or feeling regret about the past

Lifestyle or information needs

- Support groups
- Complementary therapies
- Diet and nutrition
- Exercise and activity
- Smoking
- Alcohol or drugs
- Sun protection
- Hobbies
- Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



**WE ARE
MACMILLAN.
CANCER SUPPORT**

(DH) Department
of Health

NHS

NHS Improvement

This document is copyright NCSI © 2012. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC13689

**Workplace Induction Checklist
for Link Officers**

Name of

Employee.....

Date of

Appointment.....



The aim of this induction checklist is to help you settle into your new post. It provides you with the information, training and support to help you feel confident and competent in your new role.

To ensure that you are not overwhelmed by too much information at once the induction schedule will be spread out over the first 3 months of employment. Following the induction period your development needs will continue to be supported through regular one to ones and performance reviews with your line manager.

Week One	Arranged (Tick)	Completed (Date)
Introduced to all colleagues and be given an overview of their roles and responsibilities.		
Given the Holistic Care Needs Assessment Process document, Concerns Checklist Guidance and Care First Manual (paper or electronic)		
Introduced to common IT systems including EDRMS and Care First		

Within the First Month	Arranged (Tick)	Completed (Date)
Shadow ICJ Link officers on visits and paperwork days to become familiar with the visit and paperwork processes		
Attend Care First Training		
Attend in house teaching session on an introduction to cancer and common cancer treatments.		
Use a case study to complete a mock care plan and review with Clinical Advisor		
Start to carry out HNA's supported by the Clinical Advisor (Minimum of 6)		
Have a Care First support session with Development Officer		
Complete a Case Study		
Have a One to One with the Service Delivery Manager		

Within Three Months	Arranged (Tick)	Completed (Date)
Go out on visits independently (Min 6 per week)		
Weekly joint visits with clinical advisor (Min 1 per week)		

Within Three Months you should attend/visit the following	Arranged (Tick)	Completed Date)
Macmillan Cancer Awareness training		
Communication Skills training		
Recognition and Assessment of Common Psychological Issues in Cancer		
Adult Protection Training		
Child Protection Training		
Concerns Checklist Guidance overview (clinical advisor)		

Who's Who in Healthcare and overview of referral pathways (clinical advisor)		
Warning signs of oncology emergencies (clinical advisor)		
Visit the Calman Centre		
Visit the Maggie's Centre		
Visit the Libraries and Move More service		
Visit a Carers Centre		

Further learning and development needs required to reach competency

Employees comments:

Managers comments:

Declaration

I confirm that I have received information and instruction on the items contained in this induction checklist and have been given the relevant explanations and documentation.

I confirm that I feel confident and competent to carry out my role as a ICJ Link Officer

Employee

Signature:

Date:

Line Manager

Signature:

Date:

Appendix 4- The Questionnaire



TOGETHER WE'RE
IMPROVING YOUR
CANCER JOURNEY

WE ARE
MACMILLAN.
CANCER SUPPORT



Patient Questionnaire

Please read the enclosed letter for more information about this survey.

This questionnaire is about your experiences and quality of life. Its purpose is to provide information to help us evaluate the service - 'Improving the Cancer Journey'.

Who should complete the questionnaire?

The questions should be answered by the person named in the enclosed letter. If that person needs help to complete the questionnaire, the answers should be given from their point of view, not the point of view of the person who is helping.

Instructions

For each question, please put a tick in the box next to the answer that most closely matches your opinion.



Don't worry if you make a mistake. Simply cross it out and tick the correct answer.



Phone the research team on **0131 455 2943** if you have any questions.

Section 1	Quality of Life				
This section is about how you currently feel in relation to your quality of life.					
Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u> .					
PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box, and go to the next section.</i>					
I am satisfied with my sex life	0	1	2	3	4

Section 1 Quality of Life					
This section is about how you currently feel in relation to your quality of life.					
Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u> .					
EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry about dying	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
I am able to work (include work at home)	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4

Section 2 Health Status

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **today**

Mobility	Tick one box only
I have no problems walking about	<input type="checkbox"/>
I have some problems walking about	<input type="checkbox"/>
I am confined to bed	<input type="checkbox"/>

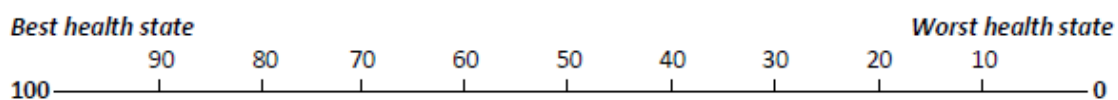
Self-Care	Tick one box only
I have no problems with self-care	<input type="checkbox"/>
I have some problems washing or dressing myself	<input type="checkbox"/>
I am unable to wash or dress myself	<input type="checkbox"/>

Usual Activities e.g. work, study, housework, family or leisure activities)	Tick one box only
I have no problems with performing my usual activities	<input type="checkbox"/>
I have some problems with performing my usual activities	<input type="checkbox"/>
I am unable to perform my usual activities	<input type="checkbox"/>

Pain/Discomfort	Tick one box only
I have no pain or discomfort	<input type="checkbox"/>
I have moderate pain or discomfort	<input type="checkbox"/>
I have extreme pain or discomfort	<input type="checkbox"/>

Anxiety/Depression	Tick one box only
I am not anxious or depressed	<input type="checkbox"/>
I am moderately anxious or depressed	<input type="checkbox"/>
I am extremely anxious or depressed	<input type="checkbox"/>

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by **drawing a circle around the number** that indicates how good or bad your health state is today:



Section 3		Social Support				
		Here are some questions about the support that is available to you				
<p>About how many close friends and relatives do you have? (people you feel at ease with and can talk to)</p>	Number:					
<p>How often is each of the following kinds of support available to YOU if you need it?</p>						
Please tick ONE box on each line.	None of the time	A little of the time	Some of the time	Most of the time	All of the time	
Someone to help you if you were confined to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone you can count on to listen to you when you need to talk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to give you good advice about a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to take you to the doctor if you needed it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone who shows you love and affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to have a good time with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to give you information to help you understand a situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to confide in or talk to about yourself or your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone who hugs you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to get together with for relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone to prepare your meals if you were unable to do it yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Someone whose advice you really want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Section 3	Social Support				
	Here are some questions about the support that is available to you				
	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to do things with to help you get your mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to help with daily chores if you were sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to share your most private worries and fears with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to turn to for suggestions about how to deal with a personal problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to do something enjoyable with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone who understands your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to love and make you feel wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 4	Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally. Your answers should be what is true for you and not just what you think others want you to say.			
	How much do you agree or disagree with the following statements?			
Please tick ONE box on each line.	Strongly Disagree	Disagree	Agree	Strongly Agree
When all is said and done, I am the person who is responsible for taking care of my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking an active role in my own health care is the most important thing that affects my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can help prevent or reduce problems associated with my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what each of my prescribed medications do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 4

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally. Your answers should be what is true for you and not just what you think others want you to say.

How much do you agree or disagree with the following statements?

Please tick ONE box on each line.	Strongly Disagree	Disagree	Agree	Strongly Agree
I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can tell a doctor concerns I have even when he or she does not ask	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can follow through on medical treatments I may need to do at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand my health problems and what causes them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what treatments are available for my health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have been able to maintain (keep up) lifestyle changes like eating right or exercising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to prevent problems with my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can figure out solutions when new problems arise with my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can maintain lifestyle changes, like eating right and exercising, even during times of stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Nearly finished!

Section 5 **About You**
This information will help us to identify if different groups of people have different experiences.

Do you look after, or give any **regular help or support to family members, friends, neighbours or others** because of long-term physical / mental ill-health / disability or problems related to old age?
(Exclude any caring that is done as part of any paid employment or formal volunteering)

No - please go to next question
 Yes up to 4 hours a week
 Yes, 5-19 hours a week
 Yes, 20-34 hours per week
 Yes, 35-49 hours per week
 Yes, 50 plus hours per week

**Is someone (other than a professional who is paid to) caring for you?
This may be emotional and/or physical support and care.**

Yes
 No

Which of the following best describes how you think about yourself?

Heterosexual (straight)
 Gay or lesbian
 Bisexual
 Other Prefer not to say

**Thank you for completing this survey.
Please post in the envelope provided. No
stamp is needed.**

Appendix 5 Stakeholder Interview Schedule

- Explore individuals background and involvement in ICJ
- Views on any key successes to date
- Views on alignment with the health and social care integration agenda
- Alignment with own organisations strategic aims
- Views on components of success- buy-in, leadership, HNA and link officers
- Is the model replicable
- Future of the service