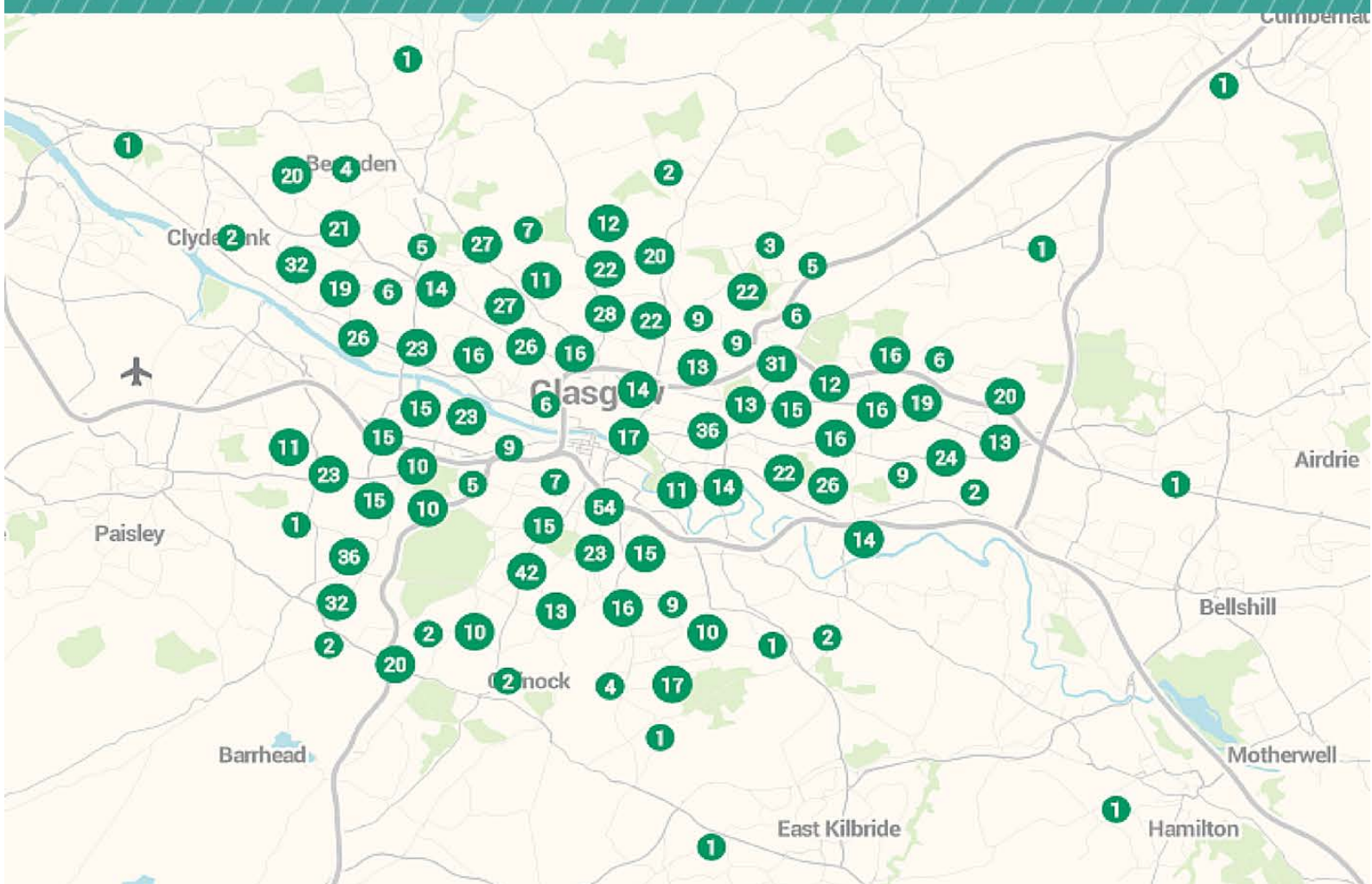


# Evaluation of Glasgow Improving the Cancer Journey Programme



Edinburgh Napier  
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**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

Improving  
Your Cancer  
Journey

## Executive Summary

### Background

This is the first report from a five-year evaluation of Glasgow's 'Improving the Cancer Journey' programme. Improving the Cancer Journey (hereafter referred to as ICJ) was launched in 2014. ICJ is a community-based service supporting people affected by cancer in Glasgow, Scotland. It supports people by providing structured individualised assessment and care to all local people diagnosed with cancer. In brief, ICJ writes to all people newly diagnosed with any type of cancer within the Glasgow City Council area to offer holistic needs assessment. Holistic needs assessment (HNA) is a structured method of discussing someone's physical, emotional, family, practical, lifestyle and spiritual needs. If people contact ICJ to accept the offer of assessment, a 'link officer' from Glasgow City Council then arranges to see them in a convenient location. At the visit the link officer conducts the assessment and then helps address any identified concerns by signposting or referring the person to relevant services.

This proactive service is a UK first. It is led by Glasgow City Council (GCC) and the main partner in delivery and investment is Macmillan Cancer Support. Further partners include: NHS Greater Glasgow & Clyde, Cordia Services, Glasgow Life, The Wheatley Housing Group, The Beatson Cancer charity and Boots Chemist Ltd. There is considerable interest internationally in the project and it has already won awards for its innovative and inclusive approach, most recently the MJ award, a UK wide award designed to celebrate excellent practice from the best local authorities. ICJ won the award in the category of 'delivering better outcomes'<sup>1</sup>.

From a policy context there is a clear clinical and social recognition of the need to ensure that people affected by cancer receive personalised, coordinated and timely support across health and social care services. ICJ is designed to provide exactly this support: a multi-agency approach to care, aiming to improve the outcomes of people affected by cancer in Glasgow. There is high-level evidence it is already achieving this. As well as the awards it has won, 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)

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<sup>1</sup> <http://awards.themj.co.uk/winners>

In order to provide a deeper understanding of the impact of ICJ, and provide evidence for future planners and commissioners of comparable services, an independent five-year evaluation of the programme began in 2015. This is its first report.

## **Aim**

The purpose of this evaluation is to provide independent evidence for the impact of ICJ. In brief it addresses the following overarching question:

***How does ICJ improve outcomes for people living with and affected by cancer?***

## **Method**

This question is considered from three different perspectives, the:

- a) individual level (eg people affected by cancer),
- b) the service level (ICJ), and
- c) the cultural level (health and social care agenda).

The outcomes ICJ needs to achieve are specified in goals described in Macmillan’s ‘logic model’. The logic model goals pinpoint aspirations for ICJ. For example, it contains the following statement:

*Individuals, families/carers and communities and professionals are aware of the support available and how to access it*

Success of ICJ is therefore measured against the degree to which this and the other goals have been met. There are 29 logic model goals in all. They are categorised by Macmillan in the model as short, medium and long-term. This allowed the evaluation to map the specific individual, service and cultural findings against specific short, medium and long term outcomes. In summary, this is the framework for evaluation:

		<b>Logic model outcomes</b>		
		<i>Short Term</i>	<i>Medium Term</i>	<i>Long Term</i>
<b>Perspective</b>	<i>Individual</i>	?	?	?
	<i>Service</i>	?	?	?
	<i>Culture</i>	?	?	?

In order to measure the individual level outcomes a range of methods were used including analysis of routine data, validated questionnaires and interviews. To measure the service level outcomes, client feedback was used alongside observations of visits and reflective diary entries from the link officers. To measure the cultural perspective the same data were analysed from the perspective of the wider health and social care agenda. Each section of the analysis begins with the relevant logic model outcomes, specifies the method by which they will be evaluated

and ends by mapping the evidence gathered back to those same logic model items. It also specifies the strength of a particular piece of evidence.

## Results

Perspective		Logic model outcomes		
		Short Term	Medium Term	Long Term
Individual	Individual	Strong evidence	Strong evidence	Strong evidence
	Service	Strong evidence	Strong evidence	Strong evidence
	Culture	Strong evidence	Strong evidence	Strong evidence

The overall results are extremely encouraging. There is strong evidence that the vast majority of logic model outcomes are being met. Some key results are highlighted below.

### Individual level

At the time of receiving the dataset ICJ had helped around **1300** people. The front cover shows the amount of people in a particular postcode area who have used ICJ. Median age was **50-64** with **52% female 48% male**. There were **83 different cancer diagnoses**. The top four (**lung, breast, prostate and bowel**) accounted for the majority of all diagnoses. The majority of people had **at least one comorbidity**, with just under **4% stating they also had mental health problems**. **Forty per cent were married** and **92%** described themselves as **white Scottish**. **43%** had **financial issues**, **18%** were **carers** and **7%** had **housing** issues.

In terms of deprivation, **61% were from the most deprived category (SIMD 1)**, suggesting that those in most need were accessing the service. Whilst the levels of deprivation are high in Glasgow, there are still *more* people proportionately in the first two quintiles of the ICJ cohort than the wider population in general.

On average, people identified just over **6 concerns** each, although the **range went from zero to 47**. Those with **cervical cancer** had the most concerns, with an average of **21 concerns per person**. The **top three concerns were money and housing, fatigue/tired/exhausted, and getting around**.

These top concerns are different from a comparable study of 5000 assessments where a nurse carried out the holistic needs assessment.<sup>2</sup> The major concern for ICJ

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<sup>2</sup> Snowden, A., and Fleming, M. P. (2015). Validation of the electronic Holistic Needs Assessment. *SpringerPlus*, 4(623). doi:10.1186/s40064-015-1401-0

was money or housing, representing 8.15% of all concerns identified. This is compared to 2.46% people in the NHS sample, a threefold difference. Also, even though the ICJ cohort averaged slightly lower mean number of concerns, they averaged slightly higher total scores, which take into account *severity* of concerns identified. This suggests that ICJ may be dealing with a higher average level of distress overall.

So far in ICJ **£1,667,820** has been generated in additional financial gains and welfare benefits for clients and **£107,684** debt written off. These figures suggest that the priorities of the ICJ clients are being addressed.

The average time for the visit to complete was **69 minutes**. People with **housing issues** spent **significantly longer (78 minutes)**, as did people with **mental health issues (74 minutes)**, **caring responsibilities (72 minutes)**, and **financial difficulties (73 minutes)**. There were no differences according to age or gender. **The best predictor of time spent in consultation was number and severity of concerns**. The more numerous and serious concerns were, the more time was spent with those people. This suggests again that the service is targeting resources to those most in need.

**Further, the service has a 36% completion rate for carers assessment which is over seven times higher than the average rate of 5%.**

Onward referrals were made to over **220 different agencies**. The most frequent referrals by organisation were to **Glasgow City Council (27%)**, **Macmillan (14%)**, **Other Charities (14%)**, **NHS (10%)** and **self-management (9%)**. **This indicates that a large number of concerns can be appropriately addressed within the community.**

In relation to health and social outcomes, the results of a **pilot survey returned by 64 people** showed that those who had chosen to take up ICJ had **less social support, less friends and reported lower levels of health related quality of life** than a sample of people who had been offered ICJ but did not take it up. With the caveat that this is a very small sample, it seems that those people experiencing higher levels of need are more likely to seek support. In terms of satisfaction with the service, feedback is almost entirely positive. For example:

- **93%** agreed that the assistance from their link officer ensured they felt supported through their cancer journey
- **81%** agreed the service had improved their quality of life
- **90%** agreed their concerns had been reduced
- **93%** agreed that support from their link officer had reduced their feelings of isolation
- **86%** agreed that their link officer had encouraged them to raise physical issues with their medical professionals
- **88%** agreed that they felt better informed about their diagnosis

Taking these two aspects together shows that those in greatest need are extremely satisfied with the care they receive from ICJ and report improvements in key target areas such as isolation, quality of life and capacity to take control of their care where necessary. The nature and range of the referrals illustrate extensive networks and effective joint working. Integrating these results into the logic model shows that the following goals are already being met:

- Gaps in support are addressed and unnecessary barriers and difficulties (and associated stress) minimised
- Enhanced wellbeing for those living with, recovering or dying from cancer and their families/carers
- The current and future needs of those with cancer and their families are identified
- Individuals, families and carers are better prepared and supported throughout their cancer journey
- Individuals, families/carers are aware of the support available and how to access it
- Individuals, families and carers are informed and engaged in the decision making about their care and support
- Areas of concerns identified are improved from HNA activity with increased patient empowerment
- Increased resilience and sense of control amongst those with cancer and their families/communities
- Negative financial consequences of living with cancer are minimised, financial needs supported, income sustained
- Social and psychological needs of all those diagnosed with cancer (and their families) are addressed and feelings of isolation reduced

### *Service level*

This element of the evaluation focused on the capacity of the ICJ service to deliver successful outcomes. It showed, through observations, interviews and reflective diaries that the link officers are highly skilled professionals delivering an individualised service. Although every person was treated uniquely there were parallels that could be drawn. The observations showed that every visit began with expert introduction and the link officer clearly articulating their role. The assessment was then undertaken in a systematic and consistent manner but contextualised to every different scenario. The outcome was a range of **signposting and referrals coherent with the needs of the individual**.

The diary entries allowed for unique insight into the role of the link officer, showing how important they are to the successful delivery of ICJ. The formal support structures they have in place such as **action learning** are highly valued, as are the informal support they offer each other. They all report professional satisfaction from this challenging role. They struggle as many do to balance administrative tasks with patient visits, but this risk is known to ICJ management and solution focused discussions are ongoing.

As well as the goals discussed in the individual section, this section showed that these additional logic model outcomes are also being met:

- All aspects of service delivery through the cancer journey are evidenced, informed and improved
- GCC cancer support pathways and services are patient centred, integrated, high quality, visible, easily negotiated, responsive to emergent needs and continuously improving
- Areas of concerns identified are improved from HNA activity with increased patient empowerment
- Professionals and volunteers have the necessary knowledge, skills to provide high quality support and services throughout the cancer journey
- Personalised, holistic, integrated evidence informed support packages are jointly developed and put in place
- Services are monitored and evaluated and learning used for service improvement, with robust equalities data
- ICJ impacted across all cancer types and reduced inequalities in relation to access to support services

#### *Cultural level*

ICJ has made partnerships with many organisations to provide new and existing services more efficiently than would otherwise be the case. It has achieved this through **actively networking with relevant partners** and creating **innovative solutions** where necessary to **better support people**. For example, it has formed a partnership with **Boots** the chemist to jointly create new posts to help with **medication management issues**. Through a partnership with **ISD**, ICJ has access to the NHS database in order to **identify all newly diagnosed people**. They are working with **GPs** to integrate the **HNA into people's annual cancer care review**, thus making HNAs more useful to a wider group of professionals.

These examples of joined up working feed in to the cultural impact of ICJ. Many of the solutions are practically focused and straightforward, but have significant impact. For example, referral to **volunteer led** information and support services within the cities libraries has strengthened third sector partnerships and sustained the volunteering workforce in Glasgow. Further, the development of an **online cancer service directory** allows link officers to easily access **all support services available in the city**.

All of this activity is recognized at national level as **excellent practice**<sup>3</sup>.

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<sup>3</sup> The Scottish Government. (2016). *Beating cancer. Ambition and Action. Cancer Strategy*. Edinburgh. doi:10.1001/jama.280.17.1548

As well as the goals discussed in the previous sections this section showed that these additional logic model outcomes are also being met:

- Relevant agencies agree and accept collective responsibility for delivering the actions within the plan
- Agencies bring about change in practice reflecting the holistic needs approach reflecting common goal with organisational learning
- Multi-agency approach taken to gather/ share data on uptake across equalities and all cancer types
- Reflective practice through holistic approach has enabled greater organisational learning, ability to enable greater empowerment for patients

## Discussion

The results show clear progress against all the goals in the logic model. They have been presented at the individual, service and cultural level for ease of separating out specific achievements but the main accomplishment of ICJ is that it **cuts across these levels**. The cultural level influences the service and the individual level. Subsequently, the sustained achievements evidenced at these levels have fed back into the cultural level, such that **ICJ is now a part of national policy**. In other words, these levels are completely integrated within ICJ. **It acted on policy aspirations for person-centred, proactive, interagency care and created a leading example of integrated health and social care**. This has been its most significant achievement and all its success flows from there.

The purpose of this evaluation is to explain how and why this has happened. For nearly every outcome the evidence is strong. The reason the evidence is strong is *because* of the level of integration between ICJ and the wider culture. The question therefore becomes: how did this happen? Interagency proactive person-centred care has been aspirational policy for decades, yet it rarely materialises to the level and extent seen here. This report suggests four key reasons:

### *1. Strong leadership*

The driving force behind ICJ is its manager. Her energy and passion for the programme are outstanding. Her previous experience in successfully addressing inequalities has been invaluable and entirely transferable to this programme. She is respected both within and outwith the programme for her integrity. Her clarity of vision makes it easy for her colleagues to understand exactly what is expected of them. Her ability to disseminate ICJ success and therefore to not just implement policy but **influence it**, has been instrumental. This dissemination project was facilitated by her recognition that evaluation metrics needed to be embedded in the delivery of the service, so that key achievements could be articulated easily.

### *2. Strong buy in*

ICJ has 'buy in' from the leadership of all partner agencies. The ICJ board is constructed from several organisations across health, social care and the third



sector. All the partner agencies are strongly invested in the success of ICJ. This has resulted in the breaking down of traditional organisational barriers that have historically hampered numerous previous attempts to bridge cultures of care.

### *3. Highly skilled workforce*

Even with the best leadership and inter-organisational partnership, operationalization can stall at the delivery level. The delivery of ICJ by highly skilled practitioners has ensured that the third piece of the jigsaw is in place. The link officers have translated the principles of ICJ into practice by systematically and professionally supporting those in most need. The ICJ workforce also includes the administrative support who, as well as the link officers, all display high levels of professionalism, competence and commitment.

### *4. A workable process.*

In order to translate this vision, skill and energy into practice, the operational process needs to be clear, manageable, and efficient whilst simultaneously being capable of dealing with diverse individual needs. Macmillan's holistic needs assessment is at the heart of this and has proved to be up to the challenge.

## **Conclusion**

ICJ is helping those most in need when they need it most. It has transformed cancer care in Glasgow, and become a beacon of excellent inter organisational practice for others to follow. The key conclusion from this evaluation is that the components of its success are reasonably straightforward to identify: strong leadership, strong buy in from partners, and a highly skilled workforce practising within a clear process. So, whilst ICJ has set the bar extremely high, the components of success are there for others to follow.

## **Recommendations**

*ICJ leaders should:*

- Maintain current steer in terms of clarity, vision and strategy.
- Continue to take opportunities to engage external partners to further grow ICJ.
- Use their current platform of being UK leaders to translate the key elements of success to similar projects.

*ICJ link officers should:*

- Continue to participate in bespoke training and action learning as part of structured supervision.
- Be aware that those with cervical cancer were the most concerned of the cohort. These people and others identified in figure 5.3 may require more time, because severity of concerns was associated with time taken in consultation.
- Consider a mechanism to systematically contact and follow up people at the end of their treatment.

*ICJ partners should:*

- Identify methods of further improving joint working where possible, building on the outcomes already achieved.
- Construct a mechanism of reporting back to ICJ so outcomes of signposting and referrals can be assessed and client journeys fully traced.

*Evaluators should:*

- Advise relevant stakeholders on the type of data they should be collecting in order to further enhance the evidence base.
- Work with ICJ to identify best practice on managing large volumes of data.

*Macmillan should:*

- Celebrate the success of ICJ by disseminating the key findings of this evaluation.
- Support the evaluators in obtaining relevant data and resources to generate economic evaluation for the next report.
- Reduce risk when attempting to replicate ICJ elsewhere by using the key findings of this report to identify the requisite building blocks to success. Use figure 8.1. from the full report to introduce these.

## Acknowledgements

We would like to acknowledge in particular the contributions of the following people:

- Zohaib Zahid, for his excellent work coding and formatting datasets and for creating many of the diagrams and charts in this report.
- The anonymous patient reference groups who commented on earlier drafts of the questionnaires.
- Workshop participants who provided further feedback on the research methodology.
- The ICJ evaluation group for their critical feedback on earlier drafts of this report.
- All the people who took the time to complete and return questionnaires.
- All the people who volunteered to be interviewed.
- The ICJ link officers for allowing the evaluation team to work so closely with them
- ICJ team for inputting, anonymising and making available relevant datasets.

Thank you

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Date: 28<sup>th</sup> July 2016

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## **List of abbreviations**

ICJ – Improving the Cancer Journey

HNA – Holistic Needs Assessment

GCC- Glasgow City Council

NHS – National Health Service

SIMD - Scottish Index of Multiple Deprivation

ISD – Information Services Division

Self Mgt- Self Management

MAC- Macmillan

OC- Other Charity

SWS- Social Work Services

GL – Glasgow Life

OA- Other Agency

FACT-G- Functional Assessment of Cancer Therapy-General

EQ-5D- EuroQol Five Dimensions Questionnaire

QALY- Quality-adjusted life year

MOS-SSS - Medical Outcomes Study Social Support Survey

PAM-13 Patient Activation Measure-13 item

## **SECTION ONE: Overview**

### **1.1 Introduction**

Improving the Cancer Journey (hereafter referred to as ICJ) was launched in 2014. ICJ is a community based cancer service supporting people affected by cancer in Glasgow, Scotland. It does this by providing structured individualised support to *all* local people diagnosed with cancer. This service is a UK first. It is led by Glasgow City Council and mainly funded by Macmillan Cancer Support. However, the aim over time is that the service will become sustainable through multiple partner investments and become embedded within Glasgow City Council. Currently, other partners include NHS Greater Glasgow & Clyde and a range of organisations operating within health and social care across the city. There is considerable interest internationally in the project and it has already won many awards for its innovative and inclusive approach, most recently the MJ award for delivering better outcomes<sup>4</sup>.

There is a clear clinical, political and social recognition of the need to ensure that people affected by cancer receive personalised, coordinated and well-timed support across health and social care services. ICJ is designed to provide exactly this support: a multi-agency approach to care aiming to improve the outcomes of people affected by cancer in Glasgow. There is high-level evidence it is achieving this, as it is named in the Scottish Government's 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*)

### **1.2 National socio-political backdrop**

Health policy is driven by a commitment to improve quality of care. In Scotland the emphasis has moved from disease based models to a person centred approach [1]. Policy recommendations centre on supporting individual needs with the aim of acknowledging not only physical but also the social and emotional needs of those affected by cancer. A number of key values are promoted within these policies including empowerment, inclusion, joint decision-making and holistic needs assessment.

In Scotland the Public Bodies (Joint Working) (Scotland) Act 2014 has been introduced. This means there is now a legislative requirement to integrate adult health and social care services. The aim is that those with care requirements will

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<sup>4</sup> <http://awards.themj.co.uk/winners>



benefit from improved joined up working with a greater emphasis on community-based care. NHS Boards and local authorities are required to integrate health and social care budgets to establish integrated partnership arrangements to strengthen the role of clinicians and care professionals, along with the third and independent sectors, in the planning and delivery of services.

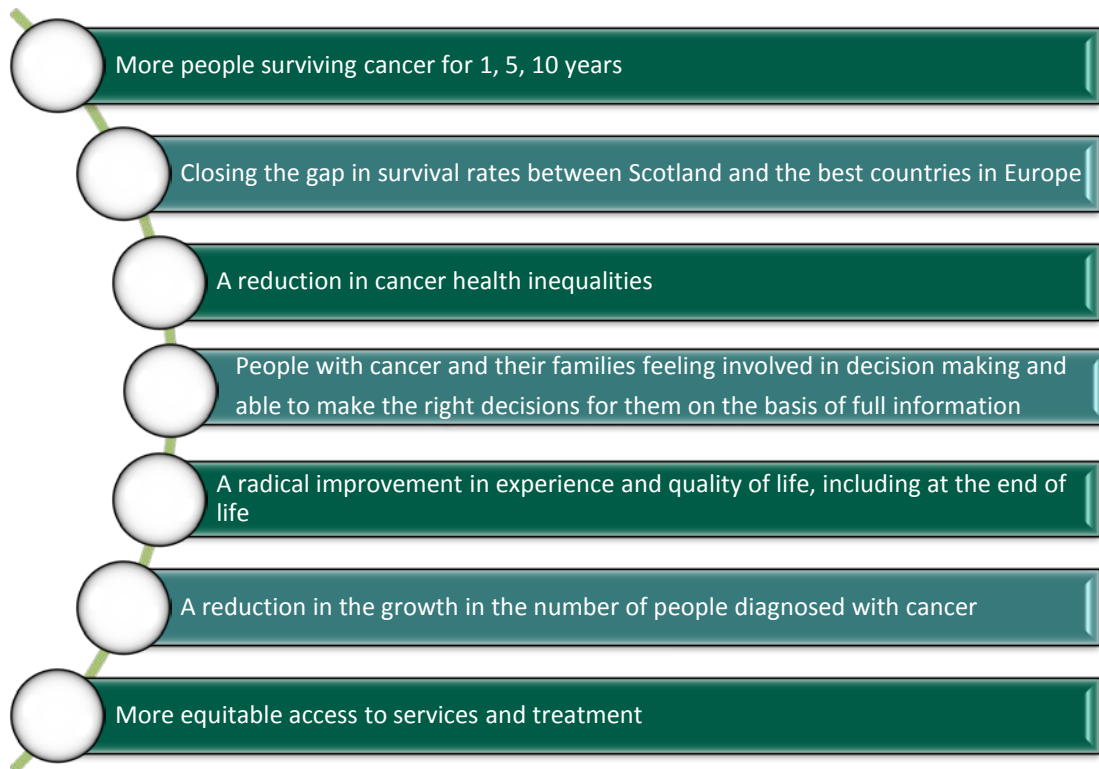
Scotland's 2020 Vision, the Healthcare Quality Strategy for NHS Scotland and accompanying Route Map represent a detailed agenda to provide care that is safe, effective and person centred. This agenda states that *by 2020, everyone will live longer, healthier lives at home or in a homely setting*. The accompanying Route Map to the 2020 Vision identifies focus areas for delivering health and social care. In particular the vision sets out to build up the assets of individuals and communities through supporting social change by encouraging self-management and working with community planning partnerships.

The Scottish Government's new cancer strategy published in March 2016 contains over 50 actions to improve cancer services across Scotland. The strategy aims to ensure that people affected by cancer have support to live well and, when the time comes, die well. It is proposed 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. 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. It is ICJ's model of support that is held up by this paper as a model of good practice for others to follow. The cancer strategy helpfully articulates what success would look like (figure 1). These objectives will be revisited at the end of this report to contextualise the evaluation.

### **1.3 The cancer context**

International and national figures show specific and consistent trends in terms of the increasing incidence, prevalence, and survival rates for people with cancer [2]. An ageing population, socio-economic factors and the adoption of lifestyle behaviours such as smoking, drinking alcohol, poor diet and physical inactivity all contribute to the increase of cancer cases [3].

In Scotland, cancer survival rates are low in comparison to the rest of Western Europe. This has been partly attributed to the late presentation of cancer and the high rates of lung cancer [4], [5]. Every year, approximately 30,000 people are told they have cancer in Scotland [6]. The predicted increase in the incidence of new cases of cancer in Scotland will be 33% over the next 15 years resulting in over 40,000 new cases per year between by the years 2023-2027 [7].



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

Within Scotland, Glasgow has poorer health and shorter life expectancy than other areas [8]. 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 49% of its total neighbourhoods categorised within the first and second most deprived socio-demographic bands.

There is a link between socio-economic factors, negative health related behaviours and incidences of cancer. In particular, deprivation is an important factor in outcomes from cancer and can be associated with increased levels of distress in cancer patients [9]. Nevertheless, it is acknowledged that while deprivation is a detriment to health it is just one part of a complex picture for people affected by cancer that may include psychosocial issues too [10].

Individuals with a cancer diagnosis commonly experience a range of physical, emotional and social concerns [11]. Furthermore, a diagnosis of cancer not only impacts the person who is diagnosed but those close to them too [12]. Recognition of the need to identify concerns and provide personalised support within oncology services has grown and is a feature of current policy and clinical practice guidelines [13], [14].

However, despite these political drivers, there is a large body of evidence reporting unmet needs in those affected by cancer relating to physical, psychological, practical and/or social factors [18]–[20].

Key statistics produced by Macmillan Cancer Support suggest that 2 in 3 people living with cancer have practical or personal needs, 4 out of 5 have emotional needs, 83% of people living with cancer are impacted financially and 10,000 people are at risk of losing their home as a result of cancer<sup>5</sup>. What is more, it has been suggested that the majority of unmet needs are beyond the function of services that are primarily designed to focus on the medical aspects of care [21]. For example, '*Hidden at Home – the social care needs of people with cancer*'<sup>6</sup> revealed that 1 in 10 people with cancer in the UK (equivalent to about 160,000 people) say they are constantly or often left housebound due to a lack of support. Results from the 2016 Scottish Cancer Experience Survey revealed that nearly half of all the respondents (49%) who wanted it indicated that they received no information on financial assistance or benefits [22]. These figures highlight that people affected by cancer have widespread needs that cannot be met solely by a medical model of care.

It is against this background that ICJ was developed. Its development is detailed in section two. For the purpose of situating it within the cancer context here, it is important to know it was developed with the following stated aims:

*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.*

*The project aims to bring about a change in attitudes and behaviours of not only health care practitioners, but all other professionals who have a responsibility for treatment, support, information and advice to people with a cancer diagnosis, their families and carers. This will require in some instances a change in culture and practices to recognise the wider social issues facing those with a cancer diagnosis and an awareness of the frameworks being designed and developed to deliver this.*

#### **1.4 Overview and report structure**

The purpose of this report is to systematically evaluate ICJ and to provide a deeper understanding of how it has achieved its successes to date in order to provide recommendations and transferable evidence where possible. This is the first report from a five-year evaluation of the programme undertaken by Edinburgh Napier University that began in Feb 2015. It is presented in the following way.

This first section has summarised the social and political context to demonstrate how the principles of ICJ align with these current criteria. The second section describes the background and development of the service, introduces the key personnel and goes on to describe some basic demographics such as how many

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<sup>5</sup>[http://www.macmillan.org.uk/aboutus/news/latest\\_news/250,000%20people%20with%20cancer%20are%20unable%20to%20keep%20up%20with%20housing%20payments.aspx](http://www.macmillan.org.uk/aboutus/news/latest_news/250,000%20people%20with%20cancer%20are%20unable%20to%20keep%20up%20with%20housing%20payments.aspx)

<sup>6</sup> <http://www.macmillan.org.uk/documents/getinvolved/campaigns/carers/hidden-at-home.pdf>

people it has seen so far, the needs identified and the outcomes of interventions in terms of signposting, referrals or other actions.

The third section introduces the aims of the evaluation. The aims are grounded in Macmillan's 'logic model'. This model states the short, medium and long-term goals expected of the project and so this model is detailed in this section. It shows how these goals were turned into research questions. In brief, the individual goals specified within the logic model were grouped according to whether they related to individual level goals (eg patients and carers), service level goals (ICJ related) or cultural level goals (eg joint working between health and social care). These groupings allowed for a systematic method of structuring related goals and the construction of dedicated methods to understand them better.

The fourth section details the evaluation method. It takes the aims described in section three and turns them into research questions. The methods for answering these research questions are then detailed. For example, in order to understand whether ICJ improves individual quality of life a valid measure of quality of life is needed. In order to understand how the ICJ workers manage to succeed in the role we need to gather data that allows for a deep understanding of this. This chapter details these methods.

In order to maintain clear links to the programme's desired outcomes each subsequent section begins with the relevant logic model items to signpost the reader to the purpose of the particular section. In short, section five discusses findings at the individual level. Section six discussed findings at the service level and section seven the cultural level. Each section ends with a summary table of whether the logic model goals have been met, where the evidence is and an indicator of how strong that evidence is.

Section eight then discusses the key elements of all the results together to provide conclusions from the whole. It revisits the wider aims of ICJ and the cancer strategy to contextualise the findings. It concludes with recommendations for further action.

## SECTION 2: ICJ

### 2.1 Background to Improving the Cancer Journey

'Improving the Cancer Journey' (ICJ) is a health and social care community initiative designed to proactively support people affected by cancer. ICJ offers its services to everyone diagnosed with cancer in the Glasgow city council area. People who take up the offer complete an assessment with a dedicated link officer from the project and then a plan is put in place to best support the identified needs (Figure 2.1). 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, Boots Chemist Ltd and The Beatson Cancer charity. It has been commissioned for five years.

In more detail, 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 recurrence. The letter offers a Holistic Needs Assessment (HNA) with a named link officer from ICJ.

Holistic Needs Assessment is an assessment that covers physical issues such as pain and fatigue but also asks about emotional, social, spiritual and financial needs such as housing, family and employment issues. The HNA is offered in a community setting, such as a local library or the individual's home if they prefer. Alternatively, individuals may be referred into the service by a health and social care professional or they may self-refer. ICJ was launched in February 2014 with a pilot phase focusing on five cancer groups. This service was then extended to all cancer types in 2015.



*Figure 2.1 How ICJ operates*

The ICJ service model is a 'hub and spoke' model with the client at the centre of the hub allowing links to be made with partner organisations. As far as we are aware it is the first cancer service in the UK to deliver HNA in a community setting. Traditionally HNAs have been conducted in a health setting, such as an oncology clinic, with a health practitioner. In ICJ, the HNA is delivered by a professional with a social and/or customer care background called a link officer. The HNA used is called The Concerns

Checklist (appendix 1). It is a valid and reliable client led assessment used routinely by Macmillan Cancer Support and the NHS.

## **2.2 The Link Officer**

The HNA is designed to generate a structured conversation around areas of need. Support structures, if needed, are then put into place through the care planning process. A trained link officer delivers this. The service currently has 7 full-time link officers all employed by Glasgow City council. 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 9 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. 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. In addition, link officers receive clinical supervision every quarter from a clinical psychologist who specialises in oncology.

## **2.3 The service users**

At time of writing ICJ had helped 1302 people<sup>7</sup>. Median age was 50-64 with 52% female 48% male (Figure 2.2). There were 83 different cancer diagnoses. The top four (lung, breast, prostate and bowel) accounted for the vast majority (85%) of all diagnoses (Figure 2.3). The majority had at least one comorbidity (Figure 2.4), with just under 4% stating they also had mental health problems. The majority were married (n=502), with 298 single, 234 widowed, 124 divorced, 84 living with partner and 47 separated. 1218 individuals described themselves as white Scottish, just over 91%. Full demographics are in table 2.1.

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<sup>7</sup> Full datasets were not available for every individual on every measure. This is why some sub categories may not add up to 1302.

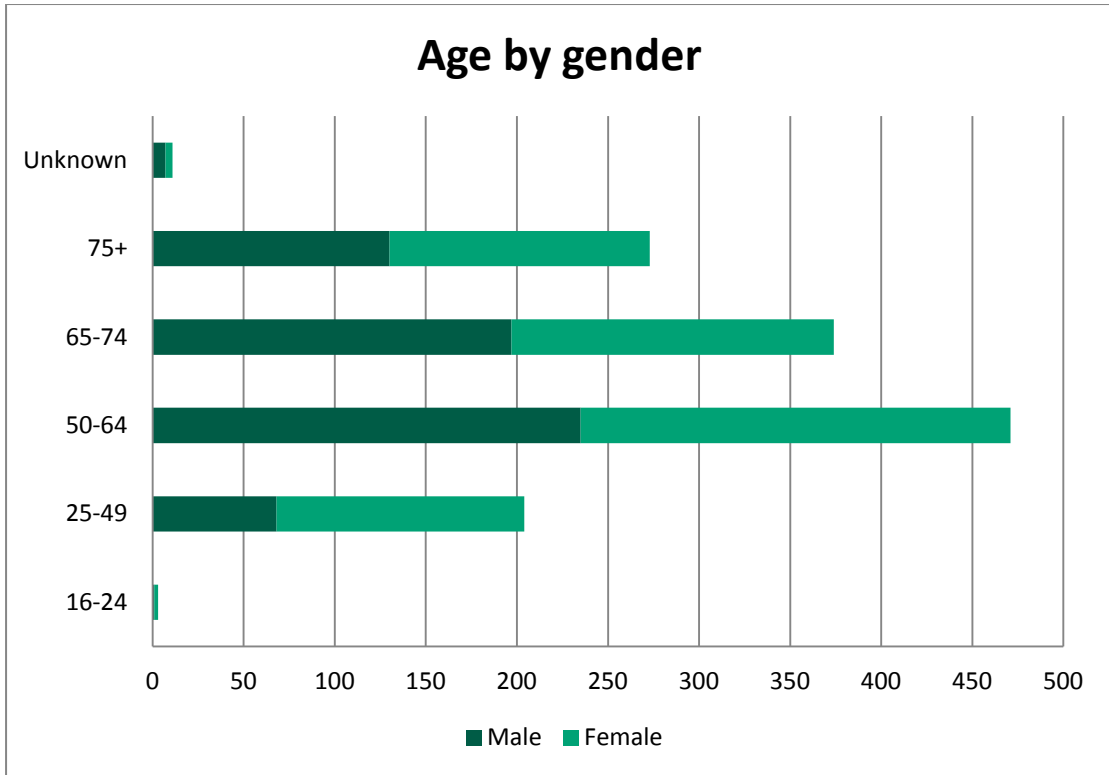


Figure 2.2 Age and gender of ICJ service users

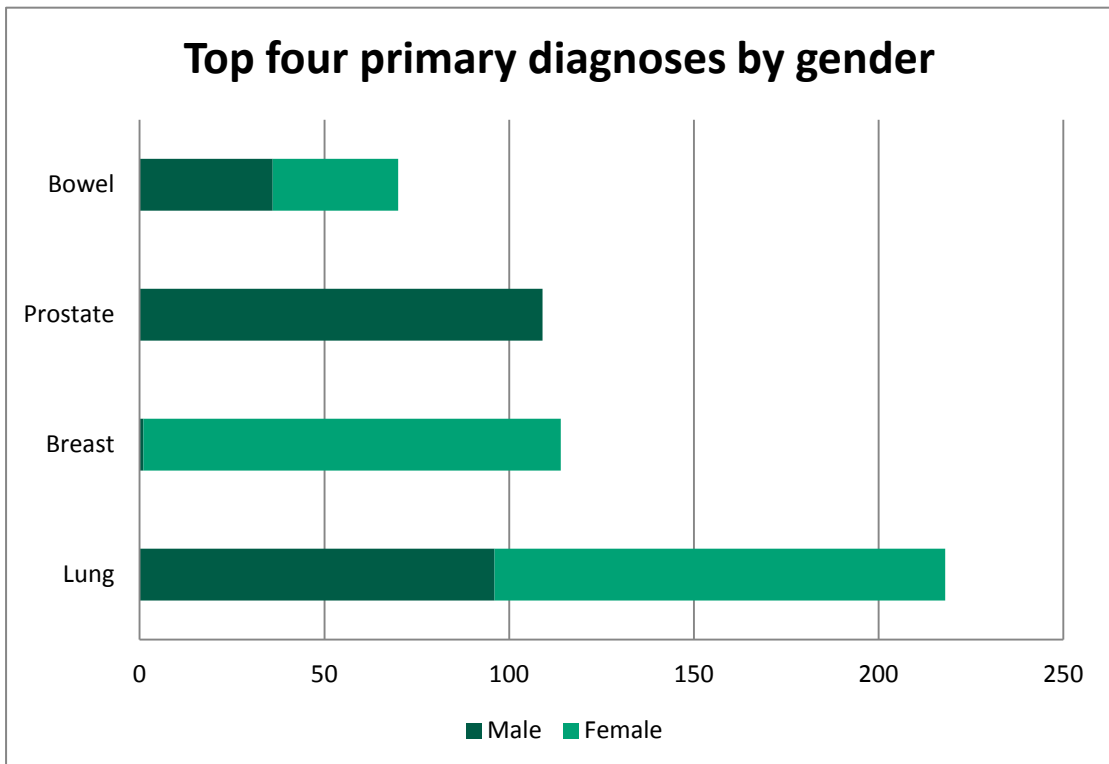


Figure 2.3. Top 4 primary diagnoses by gender

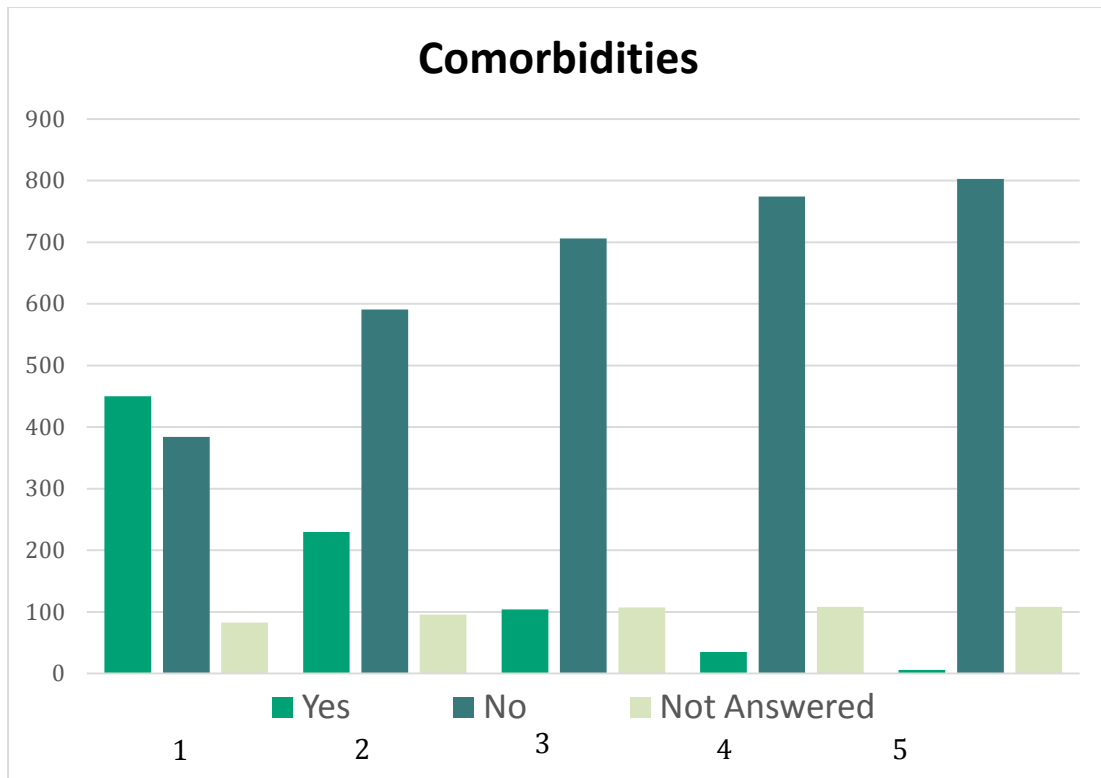


Figure 2.4. Number of comorbidities declared

<i>Ethnicities</i>	<i>Total Number</i>	<i>Male</i>	<i>Female</i>
White Scottish	1218	630	588
White Other British	21	8	13
Pakistani	15	3	12
White Irish	14	12	2
Not known	12	5	7
Not Answered	11	4	7
Black Africian	10	2	8
Any other ethnic background	9	5	4
Any other white background	7	3	4
Any Other Asain Background	6	5	1
indian	5	2	3
Any mixed background	4	3	1
Chinese	3	0	3
Black Carribbean	1	0	1

Table 2.1. Ethnicity of ICJ service users



Figure 2.5 shows the deprivation categories of the people who engage with ICJ. 61% were from the most deprived category with 16% from the second most deprived meaning the vast majority of people who have used ICJ live in the most deprived areas in Glasgow.

Quintiles

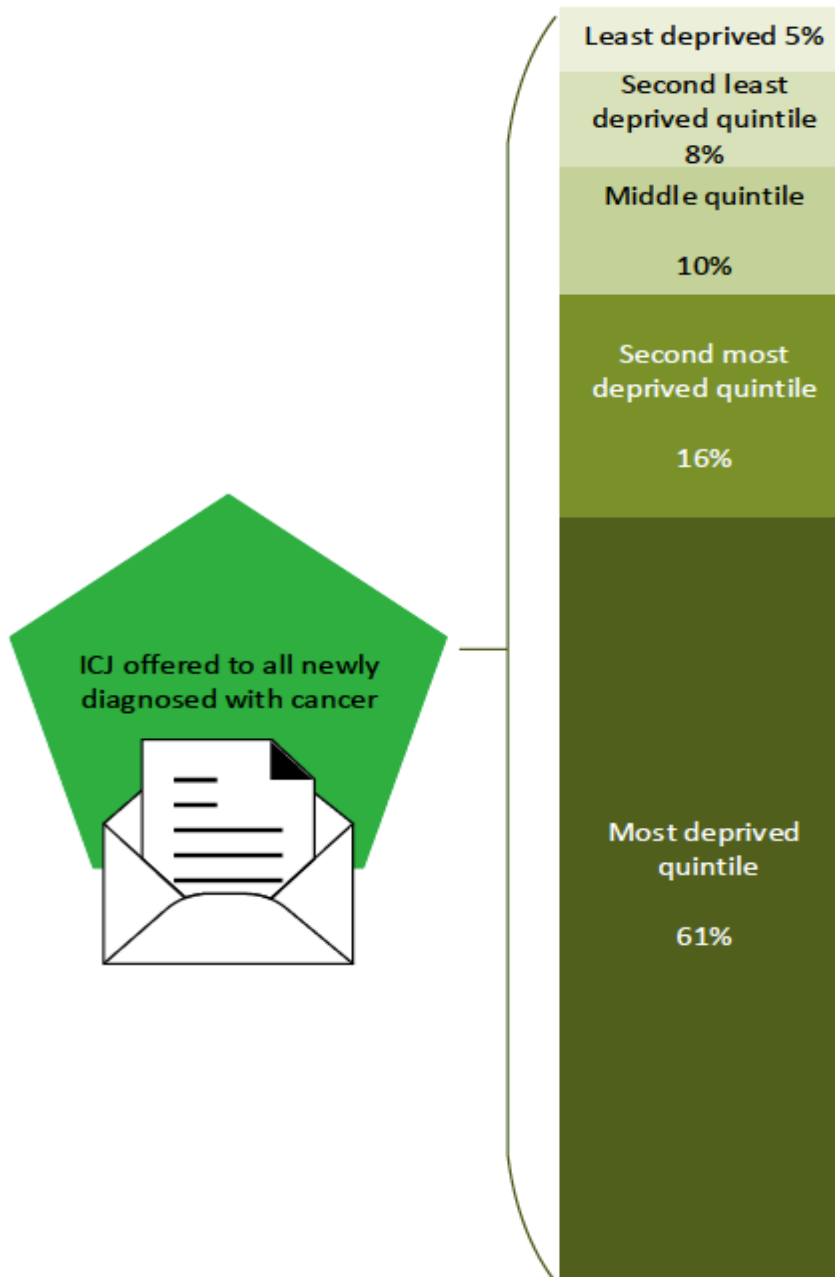


Figure 2.5 Deprivation categories of ICJ service users

### 2.3 Cancer stage

The largest proportion (36%) was undergoing treatment, 21% living with condition and 17% palliative. See figure 2.6.

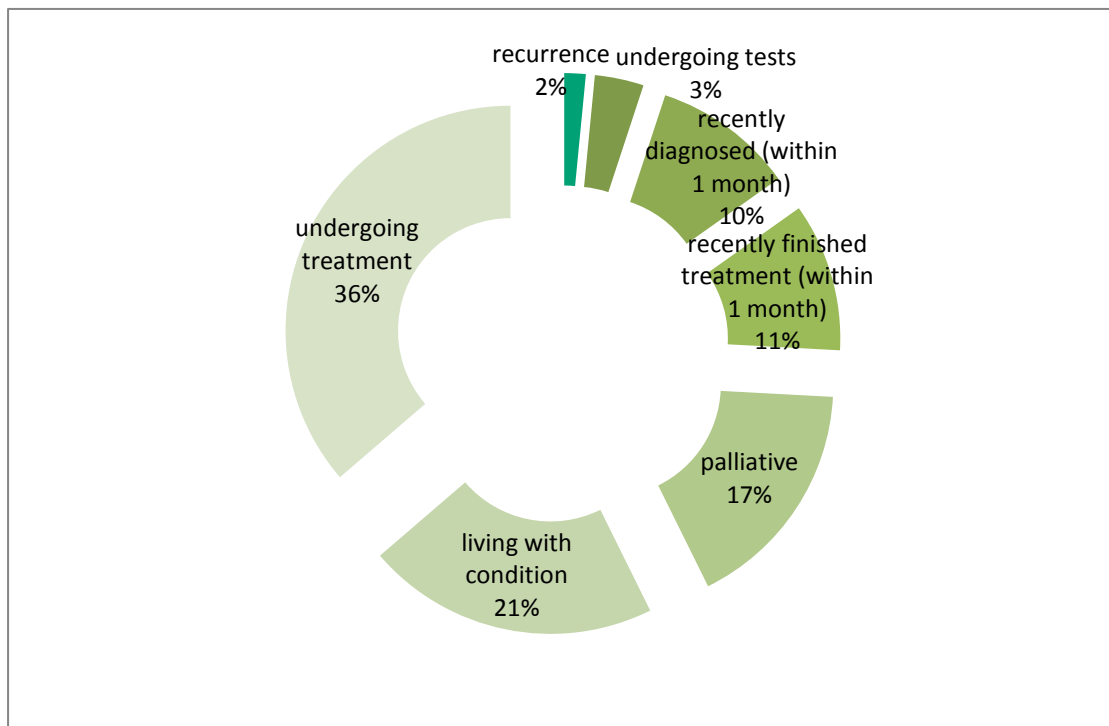


Figure 2.6. Treatment status

### 2.4 Needs identified

Over 6000 needs were identified in total. The top three concerns were money and housing, fatigue/tired/exhausted and getting around. Figure 2.7 shows the proportion of all people with either caring, financial or housing issues. Figure 2.8 shows the frequency of all needs identified, ranked by frequency.

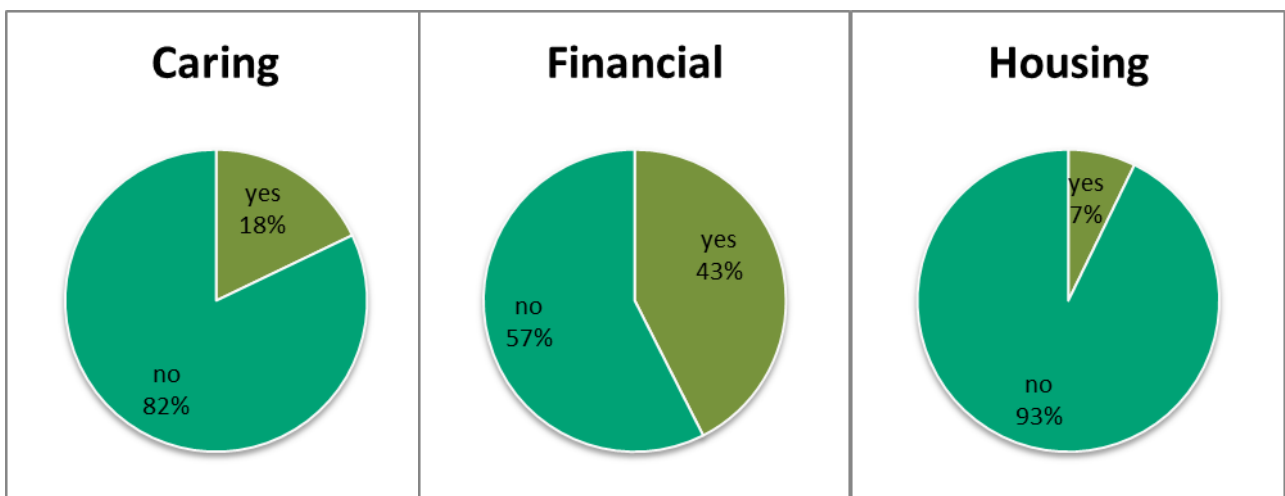
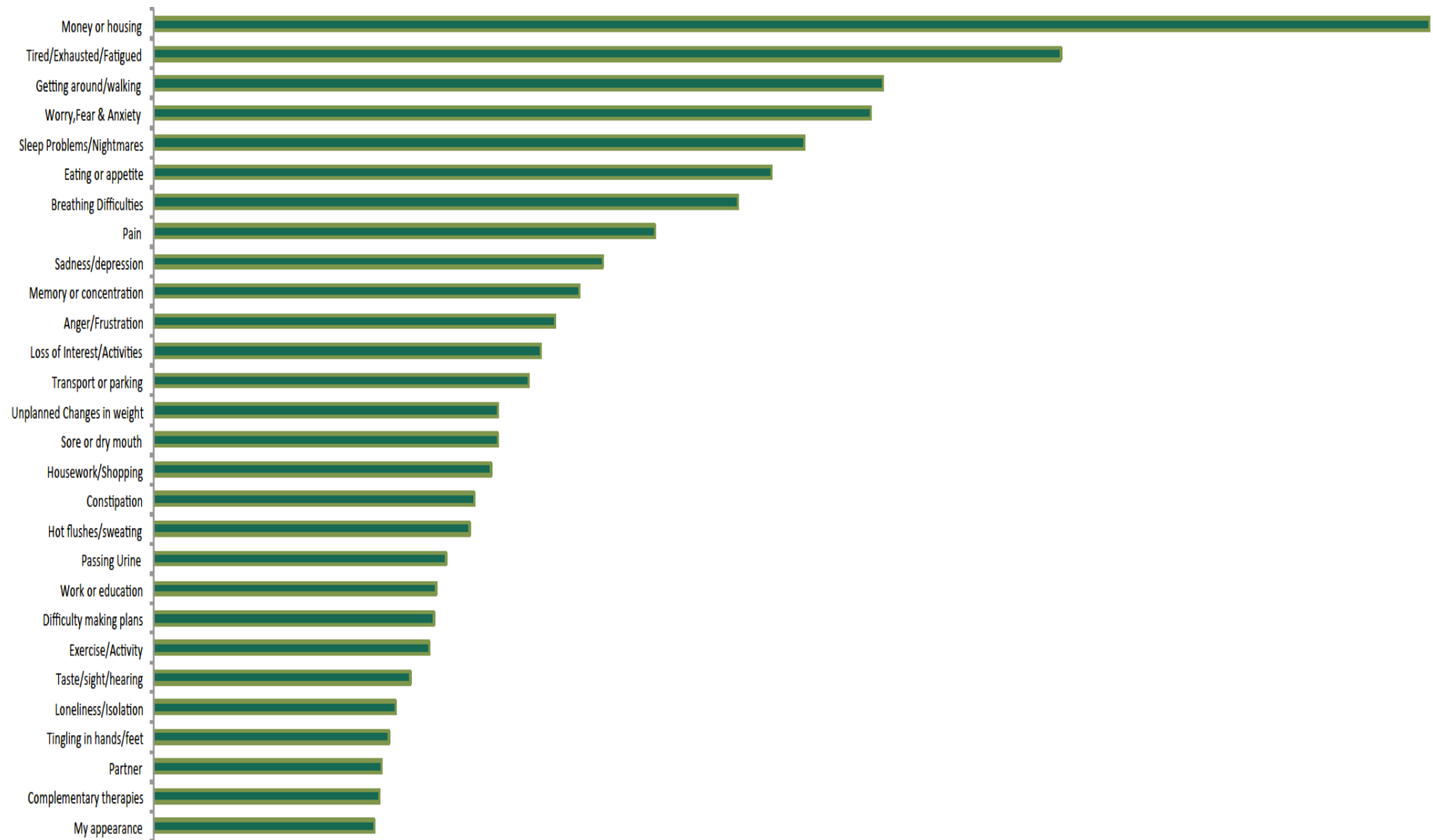


Figure 2.7 The proportion of people with caring, financial or housing needs



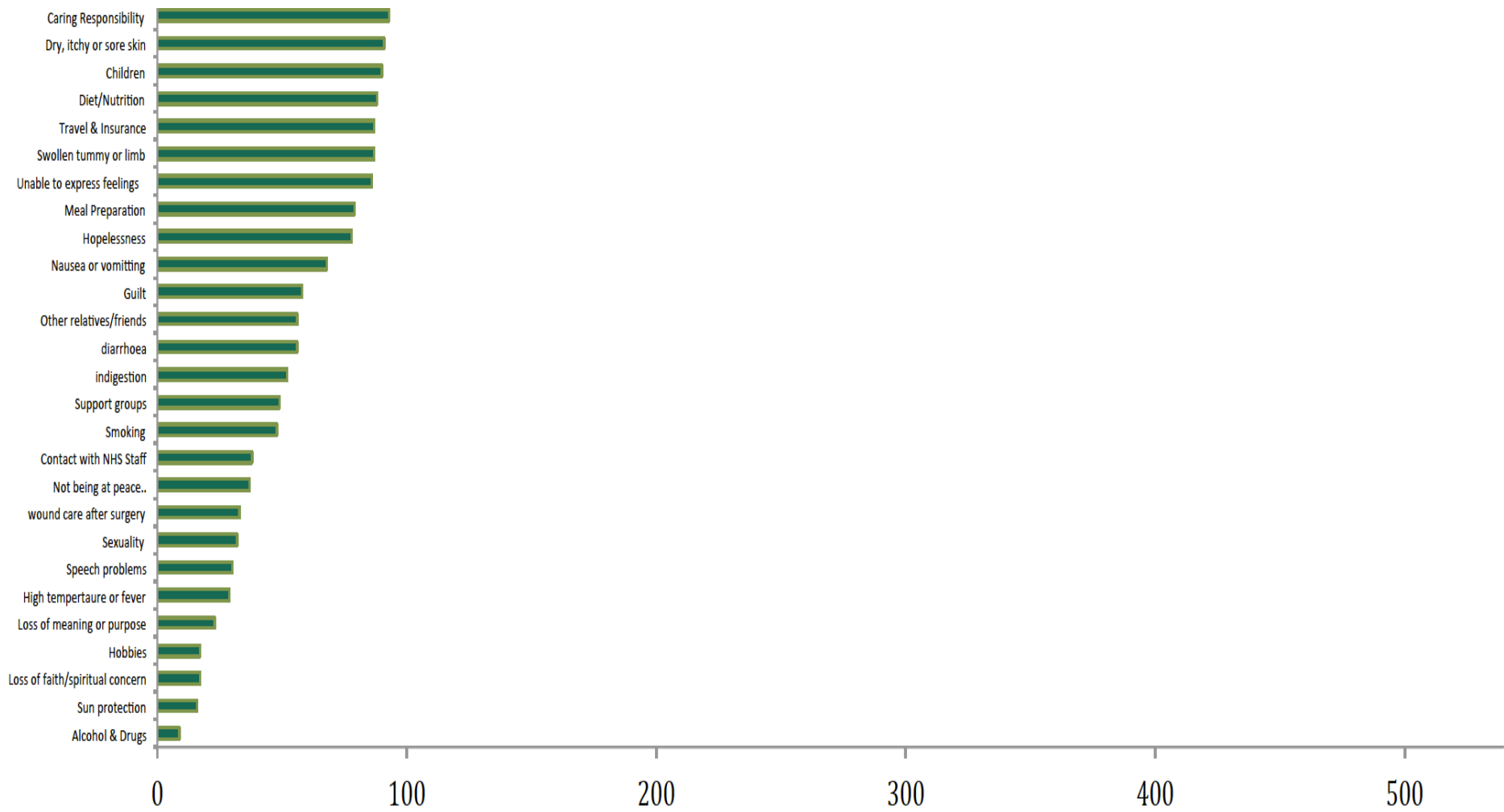
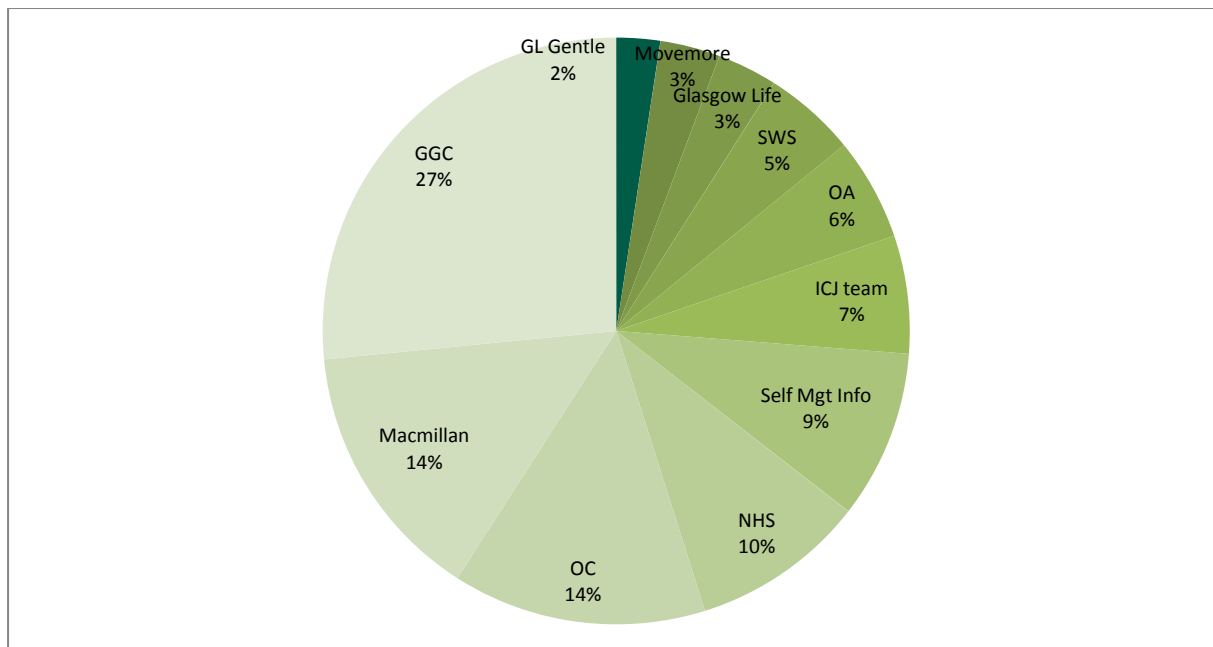


Figure 2.8 Frequency of individual probems

## 2.5 Actions

So far 4129 onward referrals have been made to over 220 agencies. All the agencies receiving more than 100 referrals are illustrated in figure 2.9. The full list of agencies is in appendix 11.



*Figure 2.9. Location of onward referrals*

## 2.6 Summary

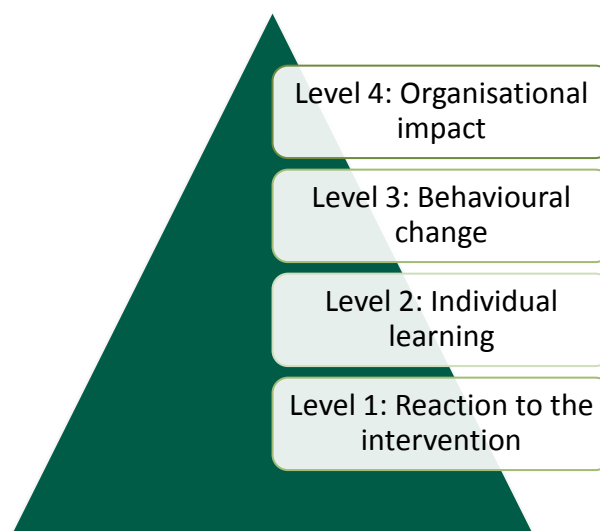
This section has described the background to ICJ and introduced the link officers. It has described the people who have taken up the service so far and summarised some key demographics such as age, gender, cancer type, number and type of problems presented and main onward referrals. Sections five to seven will go deeper into this data to examine connections and illustrate a typical patient journey. Before that, sections three and four outline the theoretical perspective of the evaluation and detail the evaluation questions.

## SECTION THREE: Theory

### 3.1 The theoretical framework for evaluation

During the planning stages of ICJ, Glasgow City Council and Macmillan Cancer Support jointly developed a logic model. As presented in table 3.1 the model depicts the aspirational relationships between ICJ activities and short, medium and long term outcomes. In order to evaluate these outcomes in a systematic manner a theoretical framework is needed. A theoretical framework makes sense of any information gathered during an evaluation by declaring what assumptions underpin the analysis before it starts. Without a theoretical framework it is difficult to understand the value of individual pieces of information. For example, what is the value of one person's account of their experience compared to another's? How do we take account of the different stakeholder outcomes to come to a fair conclusion? The answer is to ensure theoretical assumptions are 1) clear, 2) consistent with providing the best evidence and 3) coherent with the nature of the evaluation.

The first activity was therefore to examine the nature of the logic model as a whole. The outcomes in the logic model can be interpreted as existing on a continuum such that short term outcomes precede medium term outcomes and then long term outcomes. The short term outcomes relate to issues of learning and awareness, medium outcomes are about turning the learning into action and the long term goals relate to the wider psychosocial and economic consequences that the service aspires to achieve. This continuum view of outcomes of interventions is consistent with Kirkpatrick's hierarchy of learning and so this is the theoretical lens used in this evaluation. It is a clear, coherent and simple theory that sees individual and organisational behaviour change as a function of learning. Detail is in appendix three, and figure 3.1 illustrates the key elements.



*Figure 3.1 Theoretical lens: Kirkpatrick's Hierarchy*

<b>Short Term Outcomes</b>	<b>Medium Term Outcomes</b>	<b>Long Term Outcomes</b>
Relevant agencies agree and accept collective responsibility for delivering the actions within the plan	Gaps in support are addressed and unnecessary barriers and difficulties (and assoc. stress) minimised	Enhanced wellbeing for those living with, recovering or dying from cancer and their families/carers
Evidence/patient informed practice is identified and disseminated and used to develop integrated care/support pathways	Individuals, families and carers are better prepared and supported throughout their cancer journey	Increased resilience and sense of control amongst those with cancer and their families/communities
Agencies bring about change in practice reflecting the holistic needs approach reflecting common goal with organisational learning	All aspects of service delivery through the cancer journey are evidenced, informed and improved	Negative financial consequences of living with cancer are minimised, financial needs supported, income sustained
Those with cancer and their families are engaged in design and development of research, care pathways and services	Individuals, families and carers are informed and engaged in the decision making about their care and support (including palliative care)	Those who can/wish to be are supported back into work/full participation in their community
The current and future needs of those with cancer and their families are identified	Effective and integrated pathways ensure that transitions are carefully managed and opportunities to improve wellbeing maximised	Social and psychological needs of all those diagnosed with cancer (and their families) are addressed and feelings of isolation reduced
Service gaps are identified and services shaped to respond effectively	Employers/employment services develop policies and practices to support engagement of workers/families/carers living with and beyond cancer	GCC cancer support pathways and services are patient centred, integrated, high quality, visible, easily negotiated, responsive to emergent needs and continuously improving

Multi-agency approach taken to gather/share data on uptake across equalities and all cancer types	Individuals, their families/carers feel supported/empowered to engage in self management, rehabilitation and wider leisure, cultural and financial support services	ICJ impacted across all cancer types and reduced inequalities in relation to access to support services
Personalised, holistic, integrated evidence informed, support packages are jointly developed and put in place	Services are monitored and evaluated and learning used for service improvement, with robust equalities data	Reflective practice through holistic approach has enabled greater organisational learning, ability to enable greater empowerment for patients
Individuals, families/carers and communities and professionals are aware of the support available and how to access it	As a consequence of multiagency practice taken compares positively with other benchmarking groups/consequential learning advocated widely	
Professionals and volunteers have the necessary knowledge, skills to provide high quality support and services throughout the cancer journey	Areas of concerns identified are improved from HNA activity with increased patient empowerment	
Diagnosis is earlier and optimal treatment provided according to patients'/families' wishes		

*Table 3.1 ICJ Logic Model*

### **3.2 Creating evaluation objectives from the logic model**

In order to evaluate the expected outcomes of the programme in a systematic manner they need to be turned into research questions. For example, the first short term outcome is:

*Relevant agencies agree and accept collective responsibility for delivering the actions within the plan*



A research question designed to evaluate this could be:

*How is collective responsibility for delivering agreed actions evidenced between the relevant agencies?*

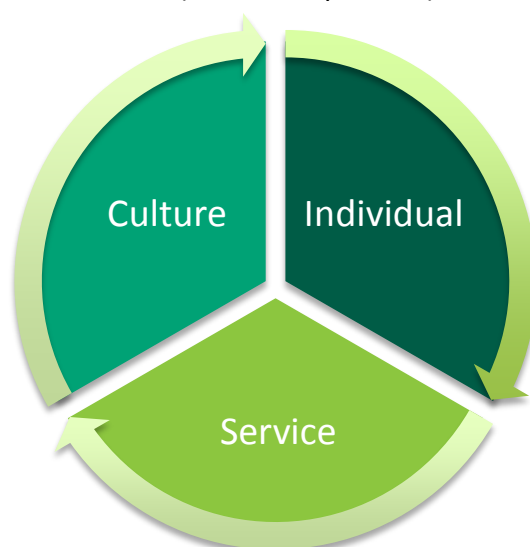
One way of undertaking this evaluation would therefore be to turn all these outcomes into questions and examine them individually. However this would be resource intensive and potentially not very insightful. A more efficient way is to 'theme' the outcomes and then investigate them as a whole along with the questions outlined in the evaluation tender (appendix 2). The result of this is that all logic model outcomes are still evaluated but more efficiently by grouping them together with other relevant outcomes.

So, at a high level the overarching question that best expressed the logic model as a whole was:

***How does the service improve outcomes for people living with and affected by cancer?***

In order to focus this question on relevant stakeholders it was broken down to concentrate on:

- The individual level (people affected by cancer),
- The service delivery level (including the link officers and wider stakeholders), and,
- The wider cultural level (social and political).



*Figure 3.2 Interrelated levels of ICJ impact*

A mapping exercise was then conducted to associate individual elements of the logic model with either an individual, service or cultural level 'theme'. Whilst it is acknowledged these elements are very closely connected this process allowed for the construction of a feasible and clearly targeted evaluation, keeping all elements of the logic model visible and evaluated whilst maintaining maximum efficiency for doing so. All the evaluation methods discussed in the next section originated in this exercise. The results of the mapping exercise begin each subsequent section in order

to show which logic model items are associated with it, be it individual, service or culture.

### **3.2.1 Summary**

This section has introduced the logic model against which the evaluation aims have been matched. It introduced Kirkpatrick's hierarchy as the theoretical model in order to explain why the evaluation is prioritising evidence of behaviour change over measures of satisfaction for example. It also introduced the segregation of individual, service and cultural level outcomes as a method for making the evaluation more coherent. In short this means that the evaluation investigates all short, medium and long term outcomes as specified in the logic model, whilst focusing on a particular set of stakeholders in turn, interpreting the evidence produced using Kirkpatrick's theory.

## SECTION FOUR: Measures

### *How does the service improve outcomes for people living with and affected by cancer?*

This section details the data collection methods by which this question is answered at the individual (patient and carer), service (link officer and dedicated ICJ team) and cultural (NHS, local authority and Scottish Government) levels. It introduces all the different methods individually for the purposes of understanding the detail of each. Subsequent sections use combinations of these methods to answer the question above pertaining to the focus of that section.

#### 4.1 Evaluation Method

This evaluation uses a mixed method design. This means there are two broad methods used to capture a range of outcomes relating to the programme. 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. Figure 4.1 summarises all methods and how they capture evidence on an individual, service and cultural level. This is followed by a short description of each method. For full details of the research protocol used in this study see Snowden and Young (2016).

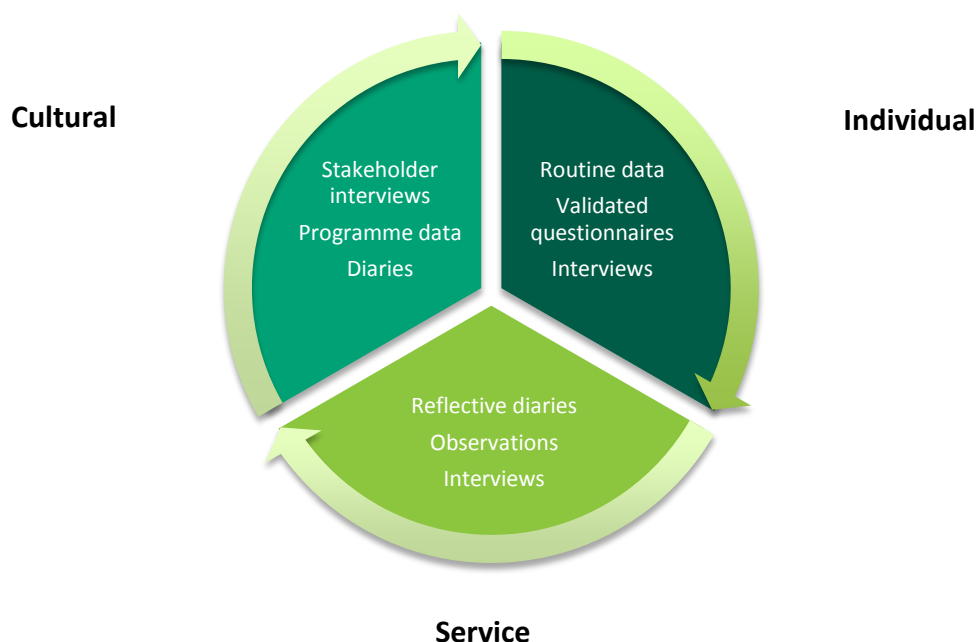


Figure 4.1 methods used in ICJ evaluation

## 4.2 Quantitative measures

### 4.2.1 Routinely collected programme data

The ICJ team collect routine data on all people who have received ICJ since inception. Much of these data informed section 2 this report. The aim is to use this data to provide a comprehensive baseline of service activity. There is demographic data on age, gender, marital status, ethnicity and socio-demographic band. Clinical data relating to cancer type and stage and data relating to the holistic needs assessment process (HNA) 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 can be analysed to better understand the range of people who use the service and identify those that may need more strategic targeting. There is also the opportunity to do comparative analyses with related datasets, for example HNA data from other organisations, so as to compare activities where the HNAs are delivered in different contexts.

### 4.2.2 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 [23]. 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 [24]. Consequently, if there are patterns of activation observed in clients who engage with ICJ this may be a useful source of information for the service.

### 4.2.3 Quality of life

Participants will 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 [25]. 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.

### 4.2.4 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 [26]. 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.

#### *4.2.5 Open-ended question*

At the end of the questionnaire a separate free-text box asks 'If you have anything else you would like to tell us about living with cancer please do so here'. The aim is to analyse the content for any themes relating to individuals cancer experiences.

In summary these measures were chosen as they reflect the aims of the service, they are validated, meaning we can be more confident they are accurately measuring the different concepts and importantly they have all been tested with a patient reference group who approved the wording and the length of the measures.

### **4.3 Qualitative measures**

#### *4.3.1 Interviews: patients and carers*

We will seek to recruit consenting participants who have experienced a wide range of outcomes as evidenced in their questionnaire responses. Interview schedules have been designed to align with the content of the questionnaire but provide enough flexibility to allow the participants to raise issues that are important to them (appendix 4). Specifically, they will provide richer insight into the relationship between the use of ICJ, wider service utility, satisfaction with support, quality of life and self-management/patient activation. Interviews will be conducted at 1 year, 2.5 years and 4 years. We plan to interview new clients with each iteration of the survey, targeted to provide context to the data from the most recent questionnaire. However, we also plan to maintain contact and re-interview consenting patients and carers interviewed previously in order to obtain longitudinal data on their experiences. The intention is to record peoples' experiences in depth as they move through their cancer experience (which may for example include a return to the ICJ service).

#### *4.3.2 Interviews: other stakeholders*

We will seek to recruit key partners and stakeholders from relevant health and social care 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.

#### *4.3.3 Observations*

A structured observation schedule (appendix 5) was derived from existing literature and the aims and theory of this study. Each link officer was observed during one visit with their client. Average length of visit was one hour. All visits took place in the client's home. The researcher, apart from introducing themselves, did not interact with the link officer and client during this time. Field notes were taken according to the schedule. Analysis of the field notes was conducted using framework analysis, which led to the emergence of the themes and subthemes.

#### *4.3.4 Reflective Diary*

To obtain deep and original insight into the experience of being a link officer each officer was issued with an electronic version of the diary. The diary contains prompt questions relating to: what went well today, what didn't go well, learning gains and needs. It was completed at the end of each working day for 10 days. The diary transcripts were analysed in order to identify common and/or unusual themes.

#### *4.3.5 Programme data*

There is considerable interest in ICJ nationally. It has already won national local council awards for achieving outcomes and been cited in the Scottish Government's Cancer Plan for example. Data such as this is also analysed here as it demonstrates cultural and political impact

### **4.4 Summary**

This section has introduced the data gathering methods employed in this evaluation. It has not been presented as a traditional 'methodology' chapter because this is published elsewhere<sup>8</sup> and this report is structured in such a way as to use these different methods in different sections for different purposes. The detail of how the methods were used, with whom and why will therefore be provided within the subsequent section.

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<sup>8</sup> Snowden, A. and Young, J. (2016) Evaluating 'Improving the cancer journeys': a study protocol *BMC Cancer* in press.

## SECTION FIVE: The individual

*How does the service improve outcomes for people living with and affected by cancer? At:*

### 5.1 The Individual Level

#### 5.1.1 Logic Model Outcomes

<b>Short Term Outcomes</b>	<b>Medium Term Outcomes</b>	<b>Long Term Outcomes</b>
The current and future needs of those with cancer and their families are identified	Gaps in support are addressed and unnecessary barriers and difficulties (and assoc. stress) minimised	Enhanced wellbeing for those living with, recovering or dying from cancer and their families/carers
Individuals, families/carers are aware of the support available and how to access it	Individuals, families and carers are better prepared and supported throughout their cancer journey	Increased resilience and sense of control amongst those with cancer and their families/communities
Diagnosis is earlier and optimal treatment provided according to patients'/families' wishes	Individuals, families and carers are informed and engaged in the decision making about their care and support	Negative financial consequences of living with cancer are minimised, financial needs supported, income sustained
	Individuals, their families/carers feel supported/empowered to engage in self management, rehabilitation and wider leisure, cultural and financial support services	Those who can/wish to be are supported back into work/full participation in their community
	Areas of concerns identified are improved from HNA activity with increased patient empowerment	Social and psychological needs of all those diagnosed with cancer (and their families) are addressed and feelings of isolation reduced

*Table 5.1. Logic model outcomes associated with individual level evaluation*

## 5.2 Data collection: methods and justification

1. **Analysis of routine service data** to develop understanding of who engages with the service and to highlight any patterns of behaviour to better understand the patient journey. This is discussed in section 5.3.
2. **Validated questionnaires** to measure key outcomes relating to quality of life, self-management and social support. This is discussed in section 5.4.
3. **Semi-structured interviews** to gain an in-depth understanding into experiences, motivations and attitudes of people who have received ICJ. See section 5.5.

## 5.3. Analysis of routinely collected service data

This section goes beyond the descriptions in section 2 to examine patterns and relationships that are useful to understand. Specifically it does the following:

1. Compares the deprivation categories of the people who took up ICJ with the population in Glasgow more widely.
2. Compares the relative number and type of problems identified by ICJ workers against the number and type of problems identified by clinicians in England using the same tool.
3. Examines the relationship between diagnostic categories and severity of concerns.
4. Examines relationships between age, gender, deprivation category, time spent in consultation and the number, severity and type of problems identified.
5. Introduces areas for further study.

These are discussed in turn.

1. Compare the deprivation categories of the people who took up ICJ with the population in Glasgow more widely.

One of the wider aims of the service was to help those who need it most. One measure of this is the deprivation index<sup>9</sup>. Those in the lower quintiles are more likely to be the ones in greater need. In section two we saw that the vast majority of the people taking up the offer of ICJ were in the lowest two quintiles and that one of the highest needs related to financial worries. This appears to indicate that the right people are getting help, but in order to be sure we need to understand the baseline

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<sup>9</sup> <http://www.isdscotland.org/Products-and-Services/GPD-Support/Deprivation/SIMD/index.asp?Co=Y>



of deprivation in the city. Figure 5.1 shows that the baseline levels of deprivation are in fact very high. However, there are still *more* people proportionately in the first two quintiles in the ICJ cohort than the wider population in general. This indicates that those most in need appear to be taking up the service. The conclusion is that ICJ is helping the right people.

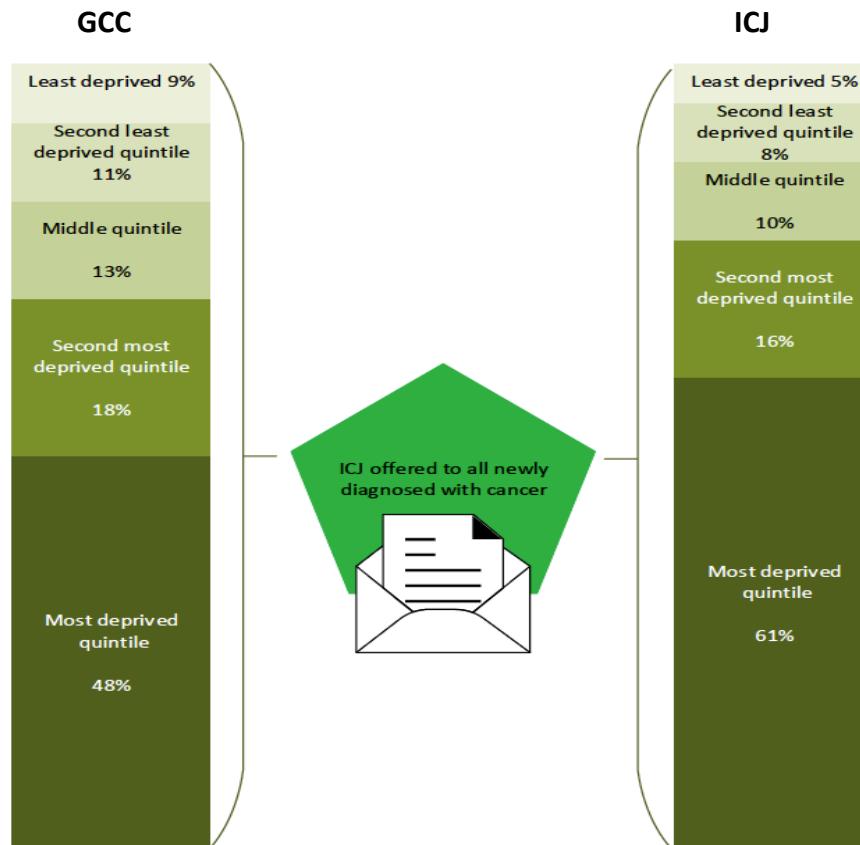


Figure 5.1. Deprivation quintiles of Glasgow City population (left) and people who took up offer of ICJ help (right)

2. Compare the relative number and type of problems identified by ICJ workers against the number and type of problems identified by clinicians in England.

Macmillan collects data on people who have received a holistic needs assessment. In 2015 their dataset of 5421 assessments conducted in NHS England was used to validate the electronic version of the tool [27]. This dataset also allowed for comparison between people who had completed a HNA with a health clinician with people who had completed a HNA with link officers in ICJ. The purpose of this comparison was to contextualise the work of ICJ by contrasting what they do with what is done elsewhere.

In relation to numbers of problems identified, the NHS sample reported an average of 6.39 concerns. ICJ average was similar at 6.13. Ranges in both cases were 0 to 48.

As each identified concern is rated out of ten, this gives a possible range of total scores between zero and 480. This is an important measure because in the NHS sample, this *total score was an even better predictor of time spent in consultation than number of problems*. The average score in the NHS sample was 30.5 with a range of 0-366. In the ICJ cohort the average score was 38.76, with a range 0-331. So, even though the ICJ cohort averaged slightly lower mean number of concerns, they averaged slightly higher total scores, which take into account severity of concerns identified. This suggests that ICJ may be dealing with a higher average level of distress overall.

In order to construct 'like for like' comparisons, the number of concerns in each dataset were converted to percentages. The numbers in figure 5.2 therefore represent the relative weighting of a particular concern in relation to the overall number of concerns in that cohort. Figure 5.2 illustrates a marked difference in the top concern according to group.

For the NHS sample, the biggest concern was being tired and exhausted, representing 6.99% all problems. For the ICJ cohort this was also a major concern, ranking second overall with 5.79%. However, the major concern for ICJ was money or housing, representing 8.15% all concerns identified. This is compared to 2.46% people in the NHS sample, a threefold difference. Interestingly, all the other concerns were relatively very similar. This shows that the main concern identified by ICJ is different from the main concern raised in the NHS sample.

It is not straightforward to interpret this but two suggestions are offered. The first is that there are simply more money and housing needs in the ICJ population. This is consistent with the deprivation category breakdown illustrated in figure 5.1. Those in lower deprivation categories would be expected to have more money worries. Unfortunately, there is no comparable deprivation data for the NHS dataset, but it seems the most likely explanation.

A second explanation relates to the identity of the person facilitating the holistic needs assessment. In short, it is reasonable to hypothesise that the person conducting the holistic needs assessment with the patient may influence the type of concerns raised by the individual. For example, if they introduce themselves as a doctor or nurse, patients may subsequently concentrate on problems they think the nurse or doctor could help with. Likewise, if the link officers introduce themselves as council employees, then this may have a similar effect, hence the focus on housing issues. It must be stated this is speculation and will be explored in more detail as the evaluation goes on.

It was not possible to compare like for like time in consultation because the NHS sample only included the time to complete the eHNA, whereas the ICJ link officers recorded the length of the whole visit. Nevertheless, as discussed above it was possible to examine the relationship between level of need and time taken. As in the NHS sample there was a small but strong correlation between number of concerns identified and time. Also, as with the NHS sample, this correlation was stronger

when using the total score measure, which supports the earlier finding that the total score is a better measure of severity [27] and that time is being given to those most in need.

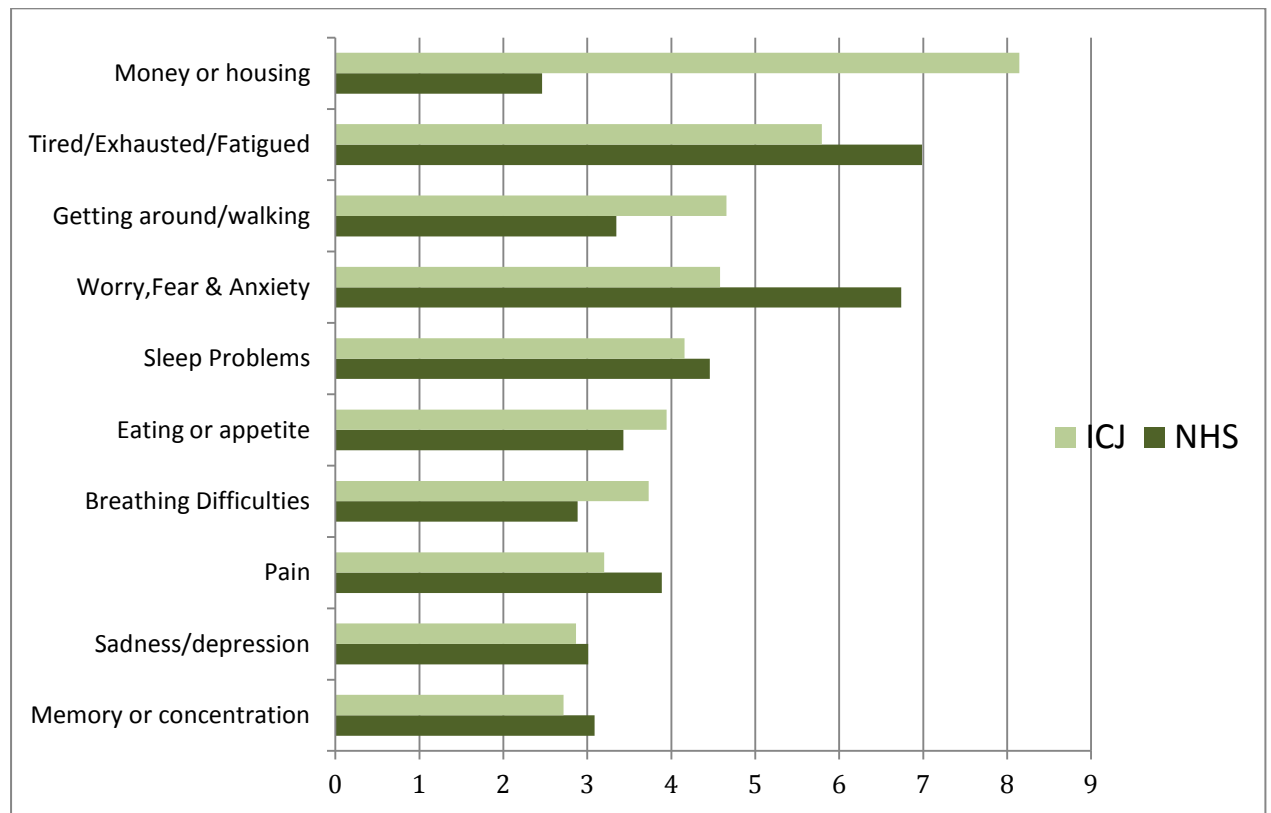


Figure 5.2 ICJ top concerns in ICJ and NHS sample

3. Examine relationship between diagnostic category and severity of concerns.

It is important to understand if particular cancers are related to high levels of distress so extra resources can be targeted accordingly. Figure 5.3 shows the mean number of problems and the mean age of the people according to their primary diagnosis. Each box represents a single primary diagnosis and also contains the mean age of the people in that category. Due to the number of different primary diagnoses some of the boxes are relatively small and therefore the diagnostic label could not be included in a print version of this paper. For full interactive version of this chart please see:

<https://public.tableau.com/profile/austyn.snowden#!/vizhome/agebyconcernanddiagnosis/Sheet4>

The chart shows that the most distressing cancers in this sample are cervical cancer, liver cell cancer, sarcoma and mouth. It is of note that the mean age of individuals diagnosed with these cancers is below the mean age for the whole sample (63 years), suggesting that age may be a factor in these severity scores. Also of note is the fact that cervical cancer is the sixth most common cancer in this cohort so the

finding that it is the most concerning cancer is unlikely to be an artefact of a small sample. The full table of diagnosis frequencies is in appendix 7.

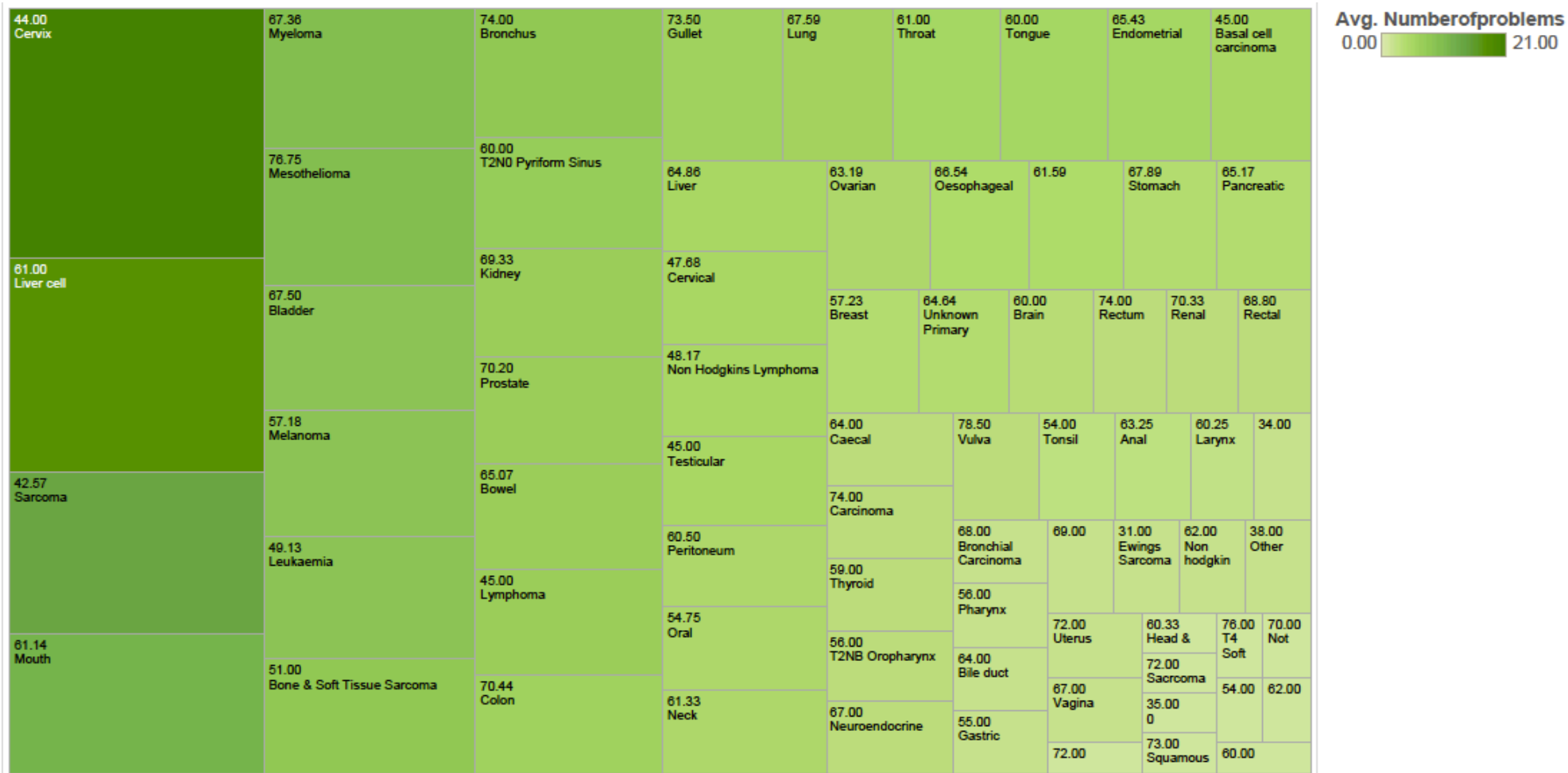
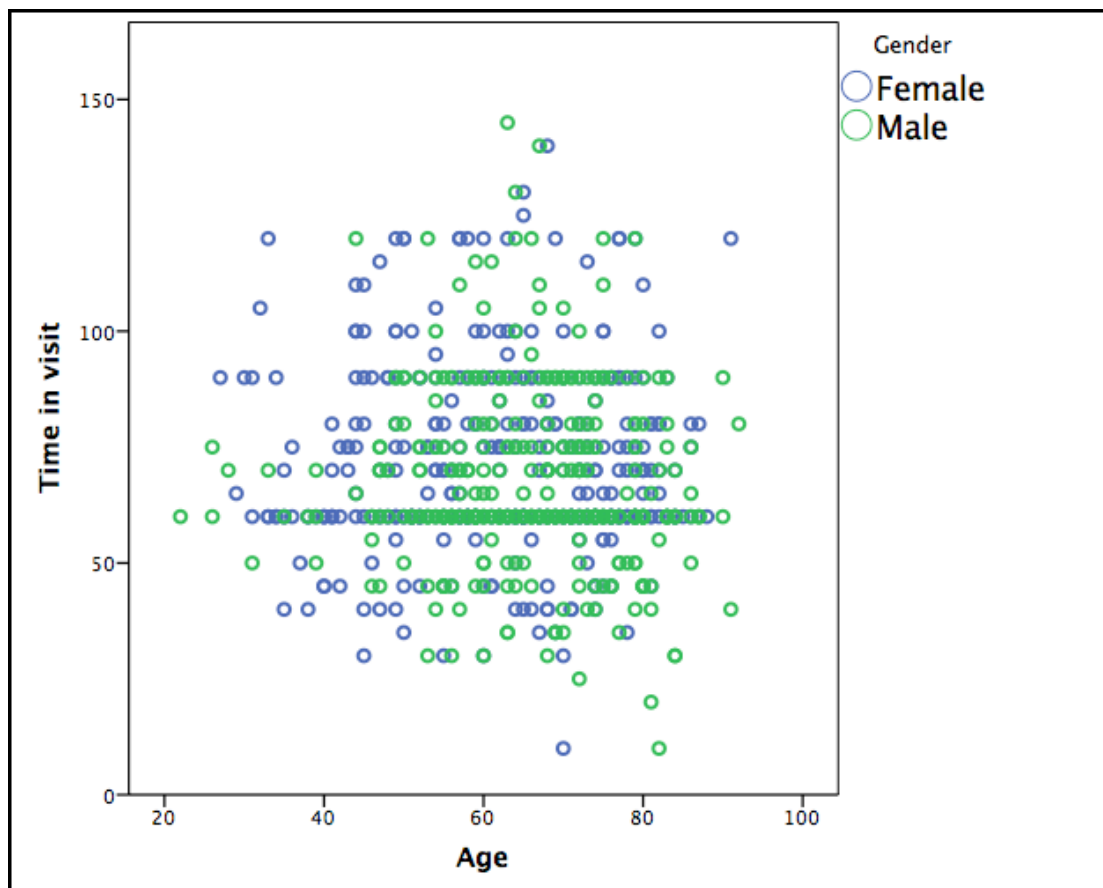


Figure 5.3 Concern severity by mean age and diagnosis  
The larger and darker the box the more serious concerns there are.

4. Examine relationship between age, gender, deprivation category, marital status and the time spent in consultation and the number, severity and type of problems identified.



*Figure 5.4. All ICJ service users by age, time in consultation and gender*

Again, in order to target support to those most in need we can look back on time spent with people so far in order to illuminate any potential relationships. Figure 5.4 illustrates each individual case by gender, time spent in consultation and age. It shows that the majority of people spent either 60 or 90 minutes with the link officer, hence the large groupings around those times. There was no other relationship between age, gender and time, showing that all people are treated equally in relation to age and gender.

In relation to marital status, people declared themselves to be married, single, partnered, widowed or divorced. One of the key aims of ICJ is to help people who may be lonely or isolated. It is probable that people living alone may be at greater need than those with a partner. In order to examine whether having a partner impacted on levels of concern these categories were transformed into a binary variable containing either people who were married or partnered, or people who were single for whatever reason. Statistical tests (independent t-tests) were then run to examine whether there were any differences in mean levels of concern or time spent in consultation. This analysis found no differences in mean time spent in

consultation, or in the number or severity of concerns raised. The only significant differences outside these main outcomes were in relation to mental health issues and housing issues. In both cases single people were significantly *less* likely to have housing issues or mental health issues.

55 people declared themselves to have housing issues. These people spent significantly longer in consultation (78 minutes as opposed to 69) and had more severe levels of concern overall (total scores of 35 as opposed to 29). People with housing issues came from a slightly lower mean deprivation category.

As in the NHS study, the best overall predictor of time spent in consultation was severity of concern, although the number of concerns was also indicative. These were highly statistically significant relationships, illustrated in Figure 5.5. As number of concerns increases so does time spent with that person.

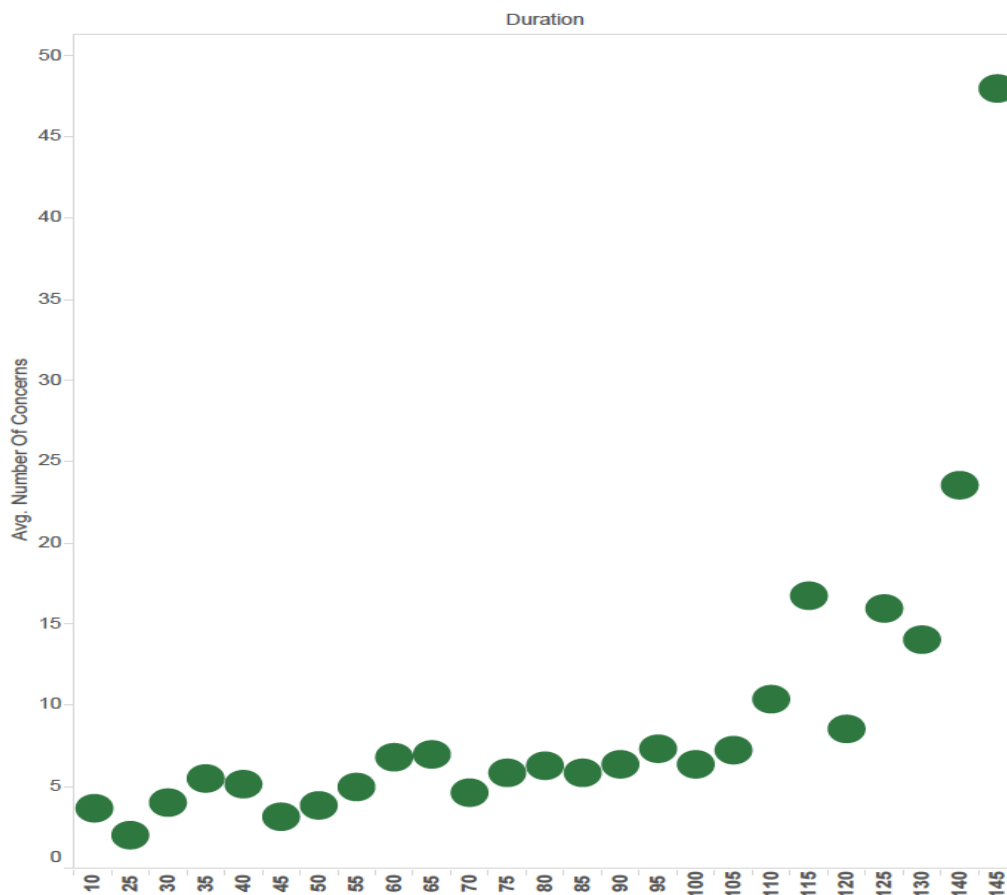


Figure 5.5 A significant relationship between concerns and time in consultation

## 5. Areas for further study

The data presented here facilitated examination of general trends and associations in regard to SIMD, gender, age, diagnosis, housing needs, mental health issues, level and severity of concern and onward referral pathways. There is much more data available and there are some notable elements. For example:

### *Contrasts between the sexes:*

- Money and housing is one of the main concerns for the whole cohort. However, females have a higher average level of concern for this issue than males. We can speculate this could be because females take on a greater intensity of domestic responsibilities than males meaning they score this a higher level of concern but this may not be the case. This requires further exploration.
- A greater number of males indicated that 'sadness/depression' was a concern for them than females. This is contrary to the literature, which suggests that depression is more common in women.
- A higher proportion of women indicated that pain was causing them concern. Tumour type and stage are likely to influence this, which also requires further exploration.
- Further, nearly an equal number of men have used the service. This contrasts much of the literature that suggests men are less likely to access support services. This is not the case here, suggesting ICJ has been successful in accessing this 'harder to reach' cohort.

Collectively, these observations when explored further will provide valuable information on more nuanced areas of concern for males and females. Subsequently, this will help the service to understand what is important for people affected by cancer.

Many other potentially important relationships were found. This work is not discussed here because it is limited in its validity. This work has however been very useful in facilitating future *hypothesis* driven exploration, and this will be developed in the next report with the next dataset.



#### 5.4 Validated Questionnaires (pilot)

In order to provide generalizable, transferable and robust evidence of impact, *valid* data must be obtained. In relation to questionnaires, this means they must have been through a rigorous process of psychometric testing in order to conclude that they are fit for purpose. The questionnaires chosen in this evaluation have all been through these processes. This means any conclusions that follow from interpreting the results are highly likely to be reliable. The questionnaires used in this evaluation are summarised in section two and included in full in appendix 8.

Recall the purpose of this section is to answer the following question from the perspective of the individuals who have used the service:

***How does the service improve outcomes for people living with and affected by cancer at the individual level?***

One way of answering this question is to understand how people who have taken up ICJ differ from those people offered ICJ but who did not take it up. This is also the standard method of populating a cost effectiveness analysis. Analysing responses to relevant validated questionnaires will provide pertinent data. However, even using validated questionnaires is not enough to ensure a particular research question will be answered. People may not answer the questions fully, or they may not answer them at all. Moreover, the method may not work. This is why we have used several methods in this evaluation and will continue to develop methodology iteratively. In order to test whether a particular research process is fit for purpose a pilot study is needed. Therefore, one was used here. A summary of this process is in figure 5.6.

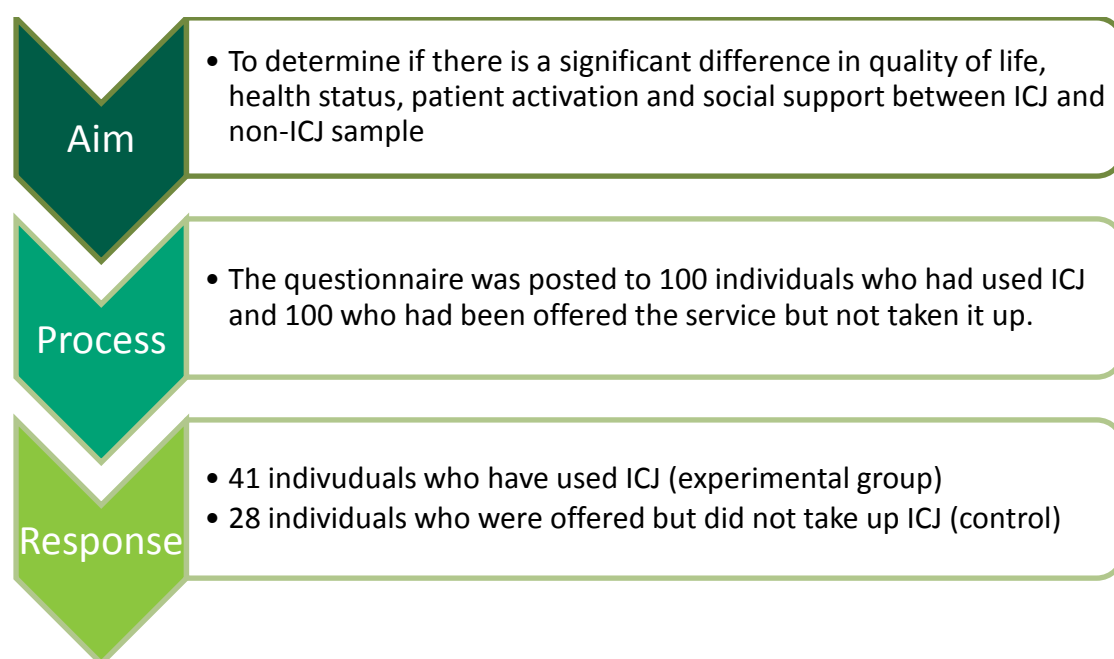


Figure 5.6 Pilot questionnaire process

### 5.4.1 Results of pilot

As of June 2016, from the 200 sent, 69 questionnaires were returned: 41 ICJ and 28 non-ICJ, a return rate of 41% and 28% respectively. The demographic profile of those who returned the questionnaire is in table 5.2.

	Gender	Mean Age (years)	Deprivation Decile
ICJ Sample	22 female 19 male	64	2.85
Non-ICJ Sample	10 female 18 male	69	4.8

*Table 5.2 Demographic profile of questionnaire respondents*

Those who have used ICJ are younger and there are proportionately more females. The non-ICJ sample had nearly twice as many males than females. The deprivation decile is a measurement taken from the Scottish Index of Multiple Deprivation (SIMD). Geographical areas can be ranked from 1 (most deprived) to 10 (least deprived). Comparing the deprivation deciles between the two samples indicates that the non-ICJ sample is better off in terms of deprivation category.

#### *Questionnaire Measures*

In order to compare responses from the two groups an average value for each measure (quality of life, health status, patient activation and social support) was calculated. Higher numbers indicate a more positive state. Due to the small sample it is unreasonable to generalise from the results but the means of each group were compared across the different measures within the questionnaire. Where available the results are compared to normative data in the literature to provide further insight into this sample. The key details are summarised below. The full questionnaire is in appendix 8.

#### **Quality of Life (FACT-G)**

Results indicate that whilst both groups scored lower than population norms, those who have *not* used ICJ record a statistically significantly better quality of life on this measure. See table 5.3.

Sample	Mean Score (Max 108)	Mean score for general population <sup>10</sup>	Mean score for a cancer population <sup>11</sup>
ICJ	61	89.3	83.9
Non- ICJ	72		

Table 5.3. FACT-G results and population norms

**Health Status (EQ-5D)**

Table 5.4 shows the proportion of individuals (in %) identifying with levels 1, 2 and 3 between the two samples. **The higher the level the greater the problem.**




























EQ5D dimension		ICJ sample	Non-ICJ sample
Mobility	Level 1	 45%	 61%
	Level 2	 55%	 39%
	Level 3	0	0
Self-care	Level 1	 63%	 82%
	Level 2	 32%	 18%
	Level 3	 5%	0
Usual activities	Level 1	 20%	 46%
	Level 2	 67%	 43%
	Level 3	 13%	 11%
Pain or discomfort	Level 1	 46%	 20%
	Level 2	 50%	 65%
	Level 3	 4%	 15%
Anxiety or depression	Level 1	 35%	 57%
	Level 2	 45%	 40%
	Level 3	 20%	 3%
<b>EQ5D mean score</b>		<b>0.47</b>	<b>0.76</b>

Table 5.4. EQ5D dimensions and scores

It can be seen that within the ICJ sample there is higher proportion of individuals who have indicated that they are experiencing more serious outcomes on every

<sup>10</sup> Holzner., B et al (2004) Normative data for functional assessment of cancer therapy General scale and its use for the interpretation of quality of life scores in cancer survivors, Acta Oncologica,43:2, 153-160

<sup>11</sup> Holzner., B et al (2004) Normative data for functional assessment of cancer therapy General scale and its use for the interpretation of quality of life scores in cancer survivors, Acta Oncologica,43:2, 153-160

dimension except pain. **The average EQ-5D score was higher in the non-ICJ group meaning that overall this group had better 'quality adjusted' life score.**

#### ***Patient Activation (PAM-13)***

PAM-13 results were practically equivalent for both groups. The mean score for ICJ was 59 and the mean score for non ICJ 60. This is a non-significant difference suggesting that both groups showed equivalent levels of activation.

#### ***Social Support (MOS-SSS)***

**The social support scale shows marked difference between the ICJ group (59) and the non-ICJ group (84)—this was a highly significant difference.** To put it in wider context the population norm for this scale in a non cancer population is 70.1, showing that a) the ICJ group has less social support than a non cancer normal population and b) this particular non-ICJ cohort is very well supported.

#### **5.4.2 Interpretation**

In summary, the non-ICJ group had higher mean scores on every measure: for cancer specific quality of life, health status, social support and patient activation. With the exception of the patient activation measure all these differences were statistically significant. This means that those people experiencing higher levels of need are more likely to be those seeking support. This shows that those people in most need are using ICJ.

The response rate to the questionnaire was fairly standard for the ICJ group (42%) but quite low for the non-ICJ group (28%), raising the risk that this may not be a representative sample. In order to get a better longitudinal understanding of the impact of ICJ we need to continue to follow up these people over time.

#### **5.4.3 Cost effectiveness**

EQ-5D is being collected at two time points for the ICJ group to gain evidence of any changes in their quality of life through the programme. There may also be a comparative group outwith Glasgow. This work strand of the evaluation will be reported on in the next report.

#### **5.4.4 Summary**

Again, with the caveat that this is a small sample and therefore not necessarily generalizable, it appears that those who would benefit the most from the service are currently using it. The people in the non ICJ group appear to be less in need of the support offered by ICJ because they are already well supported. This requires further investigation.

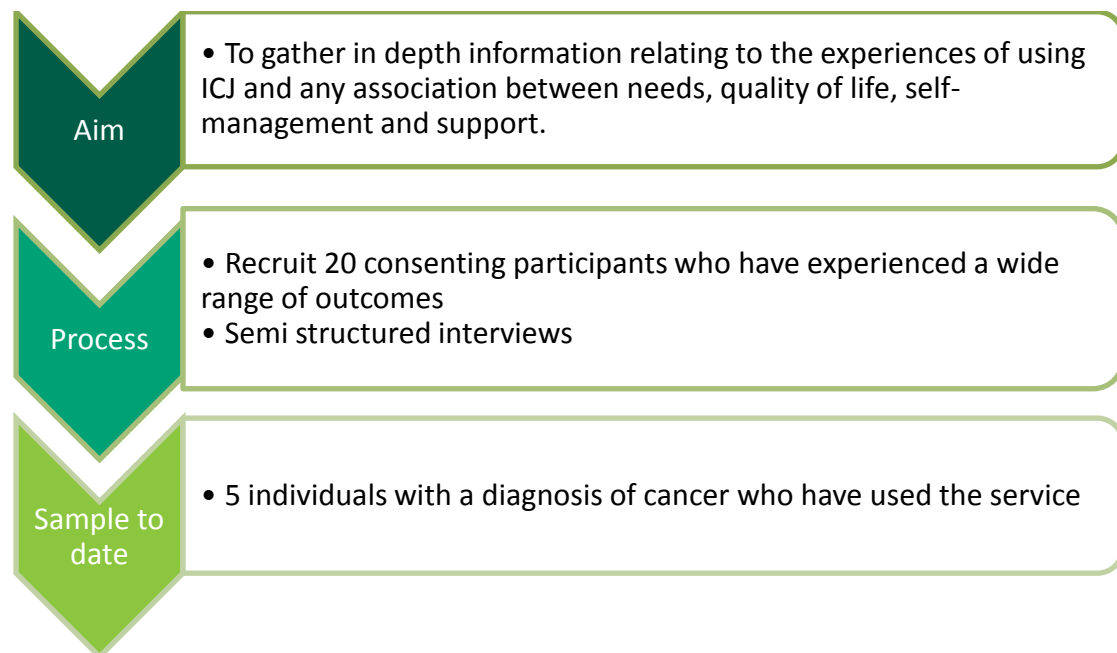
#### **Next steps**

One of the aims of this pilot was to test the survey process. This worked well and response rates were in the standard range for postal questionnaires. Next steps are to:

- Repeat this process exactly as above but with a larger sample (n=500) to see if the pilot produced unusual results.
- Repeat the survey in a larger sample and access a matched (for deprivation category, age, gender and cancer type) control group from a comparable Scottish city.
- Expand the cost effectiveness analysis by obtaining EQ-5D scores at various time points in the ICJ cohort.

## 5.5. Interviews

In order to gain an in-depth understanding of the individual experience of using ICJ, we conducted semi-structured interviews with a range of individuals who had used the service. In order to obtain as wide a range of views as possible we purposively sampled those who had agreed to be interviewed according to their individual questionnaire responses.



## Results

At the point of producing this report 5 interviews have been conducted. The remaining 15 will be presented in the next report. 1 participant was male and 4 female. Average age was 60 years old. They had been diagnosed with a range of cancer types and the majority described themselves as 'living with their condition'. All had used the service within the last 12 months. 3 interviews were conducted in the participant's home, 1 in a library and 1 in a cafe. Average interview length was 40 minutes. A semi-structured interview schedule was used (appendix 4). Interviews were recorded and transcribed verbatim. The interviews were analysed thematically and the interviewees were offered the opportunity to input on the analysis.

Theme	Example
Individual preferences	<i>"It's got to be tailored to the individual but then again it's up to the individual to say what they need and there's the balance"</i>
Transitions	<p><i>"I feel completely different. I think it's the fright you've had. Your outlook does change"</i></p> <p><i>"It's not over when they say it's over because you then start with a new way of life"</i></p> <p><i>"You are not the person who was diagnosed. Your body changes, your way of thinking changes your emotions change"</i></p>
Safety net	<p><i>"It's a safety net that's there; if it's taken away, don't ever get it taken away"</i></p> <p><i>"I didn't need anything but I knew where they were I had their numbers and emails"</i></p>

Table 5.5.1 Interview themes and examples

### Individual preferences

The participants acknowledged that support is effective when it is tailored to individual needs and preferences. For example, recognising what type of support people prefer is essential:

*Me I'm fine, you know but it's an individual thing. People like company and people like solitude. People have so much strength in their partners and some don't. I was asked to join a support group but said no. You can't force something on someone that they don't want and you can't keep things away from someone that they need.*

It is important that the link officers recognise these individual preferences when suggesting different types of support. For example, this participant preferred to use online rather than face-to-face support:

*I didn't want to communicate with other people. This probably made me be more by myself at home rather than being social. So I used Macmillan's forums online.*

Whereas, this participant wanted informal face to face support recognising this helped them to cope in between clinical appointments:

*I just like to have a chat and a cup of tea. Talking definitely helps, hearing how others are getting on. When you have questions and I have to wait 3 months before my next appointment you don't know if it's the kind of thing you can phone up the nurse with.*

While the HNA enables the service to identify individual concerns the link officer then decides how to support these concerns. Assigning an appropriate form of support is important. Such as, not everyone may benefit from attending a support group. The positive client feedback that the service has received so far indicates that the referrals are suited to client preferences.

The HNA guides the visit but it does not restrict the identification of concerns. Once more, there is evidence here of individual preferences being accounted for:

*Everyone was always asking if there's anything else apart from these issues on the form please tell us and they were always making notes there. They were always saying if you have any concerns or if you have anything to say please do share as it's important*

The benefit of this as highlighted in the next quote is providing a service that is truly responsive to the issues that are affecting their clients. This participant describes a situation where the link officer tried to support a concern that did not fall within the range of concerns on the HNA. While the outcome wasn't as hoped it had a beneficial impact on their perception of the service:

*My main problem in this time period was finding funding for my studies. This is the main obstacle. But it doesn't affect my chemotherapy. She tried her best and she called me back after 3 weeks and she was so sorry she couldn't do anything. Even if she couldn't do anything that was one of the best parts as she tried. I knew she tried that was quite impressive.*

Of note here is the fact the participant said 'but it doesn't affect my chemotherapy'. She seems pleasantly surprised and therefore impressed that ICJ could help with this type of concern. Collectively, these examples highlight the importance of listening to individual needs and the beneficial impact this can have in terms of confidence and empowerment.



## **Transitions**

Participants discussed a shift in relation to physical and emotional changes following their cancer diagnoses. This appeared to generate a new way of thinking and being. The description that things are 'not over' suggests that individuals may benefit from further or a different form of support. Specifically, the time following treatment was described as a new stage in the cancer journey:

*During the chemo you see the doctors every 3 weeks but then after you have stopped the chemo it's all ended you are all by yourself. So the recovery process is as important as the chemotherapy time period. You should admit at this point that many things have changed for you so you have a different life and you should realise that and go on with a different perspective.*

Despite finishing treatment the detrimental impact of cancer on well-being can continue. These participants describe some of the long-term emotional issues:

*What is really hard is see the cancer adverts they are extremely hard to watch, I have to leave the room when they come on. It's the realisation, I was there. I feel guilty and these people have survived it the same as me they're just telling their story. It's the emotional part I don't like.*

*I'm just waiting now they say you can get on with things but I don't feel I can. Every pain makes you think. Do I have back ache or is it something else*

For these individuals the transition into recovery signalled a new way of being that was emotionally difficult. There is wider evidence that the phase following treatment can be a challenging time for people affected by cancer. Consequently, providing access back into the service, should someone need it, is important. This was described by one of the participants:

*We will close your documents but I'm still here. Even if I close it, it doesn't mean anything I'm always here if you just want to talk or have a coffee come by.*

Recognising that individuals support needs may fluctuate through their cancer journey has been acknowledged by the service. As described in the final theme 'safety net' the participants describe knowing where to go for support if their circumstances change.

## **Safety net**

All participants described knowing where they could access support should they need it in the future. This was described by one participant as a 'safety net' providing

reassurance that should their situation change ICJ is still available. Using this language implies the service helps to protect the individual from distress. ICJ and its partners seem to be a comfort and an integral part of maintaining well-being.

*I really count on Macmillan I know anytime, even after 2 years if I need to share something I know they will listen.*

*I've got lots of phone numbers written down but I usually go to the library when I need something. I would be lost without them.*

*I honestly don't know what I would have done if this service didn't exist.*

The aspiration is that this provides individuals with a sense of control because as described they will not find themselves 'lost' as they can access what they need, no matter how much time has passed. Whilst the three themes were described individually they are all interlinked. The overarching narrative to develop from these accounts is the importance of personalised, appropriate and well-timed support. There is a vast amount of literature that links support (both perceived and received) with various positive outcomes. As the evaluation progresses and further interviews are carried out we can explore this in further detail. For example, the point at which the support is received may influence factors such as feelings of control and self-esteem in both positive and negative ways.

## 5.6 Conclusion

<b>Logic model item</b>	<b>Evidence? Y/N</b>	<b>Where? (section/page)</b>	<b>Kirkpatrick level: 1= reaction 2= individual learning 3=behavioural change 4= organisational learning</b>
The current and future needs of those with cancer and their families are identified	<b>Yes</b>	<b>Throughout this section</b>	<b>4</b>
Individuals, families/carers are aware of the support available and how to access it	<b>Yes</b>	<b>Throughout this section</b>	<b>4</b>
Diagnosis is earlier and optimal treatment provided according to patients'/families' wishes	<b>No</b>	<b>Not in control of ICJ</b>	<b>NA</b>
Gaps in support are addressed and unnecessary barriers and difficulties (and assoc. stress)	<b>Yes</b>	<b>Interviews</b>	<b>4</b>

minimised			
Individuals, families and carers are better prepared and supported throughout their cancer journey	<b>Yes</b>	<b>Routine data and Interviews</b>	<b>4</b>
Individuals, families and carers are informed and engaged in the decision making about their care and support	<b>Yes</b>	<b>Routine data and Interviews</b>	<b>4</b>
Individuals, their families/carers feel supported/ empowered to engage in self management, rehabilitation and wider leisure, cultural and financial support services	<b>Yes</b>	<b>Routine data and Interviews</b>	<b>3</b>
Areas of concerns identified are improved from HNA activity with increased patient empowerment	<b>Yes</b>	<b>Routine data and interviews</b>	<b>3</b>
Enhanced wellbeing for those living with, recovering or dying from cancer and their families/carers	<b>Yes</b>	<b>Interviews</b>	<b>3</b>
Increased resilience and sense of control amongst those with cancer and their families/communities	<b>Yes</b>	<b>Interviews</b>	<b>2/3</b>
Negative financial consequences of living with cancer are minimised, financial needs supported	<b>Yes</b>	<b>Routine data</b>	<b>4</b>
Those who can/wish to be are supported back into work/full participation in their community	<b>No</b>	<b>To examined n next report</b>	<b>NA</b>
Social and psychological needs of all those diagnosed with cancer (and their families) are addressed and feelings of isolation reduced	<b>Yes</b>	<b>Routine data and interviews</b>	<b>2</b>

*Table 5.6 Evaluation of the logic model outcomes*

**How does the service improve outcomes for people living with and affected by cancer at the individual level?**

Table 5.6 shows the vast majority of the logic model items associated with this section have evidence for their achievement. The ones that do not are largely outwith the control of ICJ, such as diagnosis. Perhaps the most striking element of this snapshot view is the fact that most of the outcomes are being met at level 4 (organisational change), which is Kirkpatrick’s highest level of learning. This goes some way towards explaining the success of the programme so far. The interventions ICJ facilitate cross health and social care boundaries, and so individual success stories necessarily impact on those organisations and the relationships

between them. So, even though this section has focused entirely on the *individual* experience of ICJ it is interesting to note that the successes at this level are directly attributable to inter organisational cooperation. This will be returned to in subsequent sections.

## SECTION SIX: The service

*How does the service improve outcomes for people living with and affected by cancer? At:*

### 6.1 The Service Level

<b>Short Term Outcomes</b>	<b>Medium Term Outcomes</b>	<b>Long Term Outcomes</b>
Service gaps are identified and services shaped to respond effectively	All aspects of service delivery through the cancer journey are evidenced, informed and improved	GCC cancer support pathways and services are patient centred, integrated, high quality, visible, easily negotiated, responsive to emergent needs and continuously improving
Personalised, holistic, integrated evidence informed, support packages are jointly developed and put in place	Services are monitored and evaluated and learning used for service improvement, with robust equalities data	
Professionals and volunteers have the necessary knowledge, skills to provide high quality support and services throughout the cancer journey	Those with cancer and their families are engaged in design and development of research, care pathways and services	

*Table 6.1. Logic model outcomes associated with service level objectives*

### 6.2 Data collection: methods and justification

This section of the report evaluates how the service operates. Three methods were used:

1. **Analysis of service evaluation forms.**
2. **Observations** of the link officers to gain an in-depth understanding of the link officer role
3. **Reflective diaries** to capture the subjective experiences of delivering the service from the perspective of the link officer.

As in the previous section these will be discussed in turn.

### 6.3 Analysis of service evaluation forms

The ICJ service systematically gathers data to provide itself with continuous feedback. This is a real strength of the programme. They ask for written feedback on the patient and carer experience of the service. This section examines this data to look for evidence in relation to the logic model outcomes in particular.

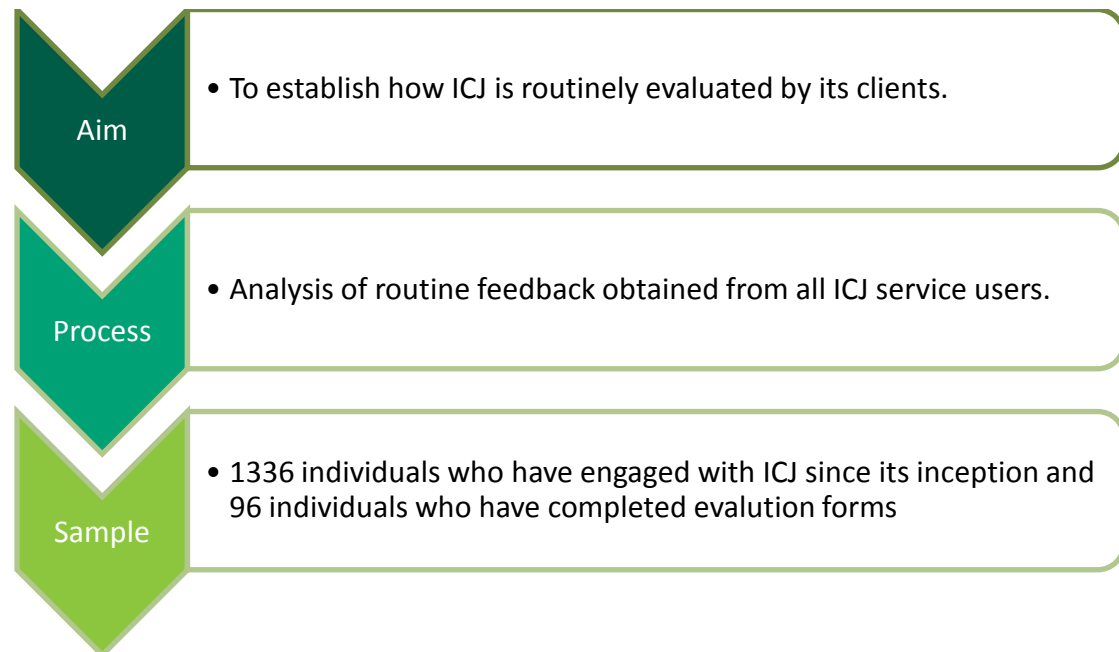


Figure 6.2. Service evaluation process

#### 6.3.1 Results

In summary, the feedback from these client evaluations was very positive:

- **93%** agreed that the assistance from their link officer ensured they felt **supported** through their cancer journey
- **81%** agreed the service had improved their **quality of life**
- **90%** agreed their concerns had been **reduced**
- **93%** agreed that support from their link officer had reduced their feelings of **isolation**
- **86%** agreed that their link officer had encouraged them to raise **physical issues** with their medical professionals

A final free text box on the evaluation form asks:

*Is there anything else you would like to tell us about ICJ service/link officer?*

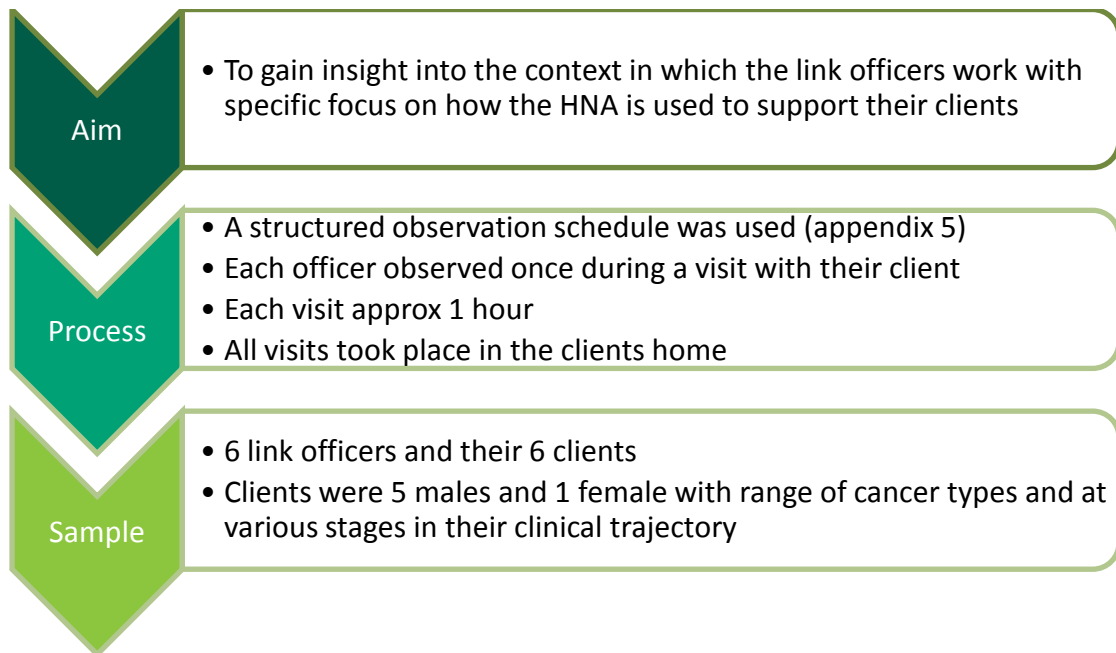
Figure 6.3.1 is word cloud of the most commonly occurring words in response to this question. The larger the text the more frequently it was used to answer this question. It can be seen that the service/link officer was frequently described as being 'helpful' 'excellent' and 'supportive'.



Figure 6.3.1 commonly occurring words to describe the link officer

#### 6.4. Observations

In order to gain a deeper insight into how the process of ICJ succeeds the link officers were observed at work. The idea is to illuminate consistent elements of the process in order to support others to follow. The focus of the analysis was on actions people took where possible.



*Figure 6.4 Observation process*

### 6.4.1 Results

Field notes were taken during each observation. All field notes were then read several times to obtain a complete impression and codes were generated based on significant areas of inquiry (appendix 6). As the analysis was refined coding became more focused around key themes. The themes were: ‘setting the scene’, ‘holistic support’ and ‘person centred interactions’. They reflect the stages of the visit and the interpersonal and environmental issues associated with the visit. They can be summarised as a process (figure process). The results are presented as descriptions from the field notes supplemented by verbatim examples from the clients.



*Figure 6.3.1 Process of delivering ICJ*

#### Theme 1: Setting the scene

There was little variation across the observations in terms of how the link officers began their visit. All observed visits took place in the home setting and after taking a seat all officers clearly described the function of ICJ and what they were going to cover during the visit. As part of this introduction to the service every officer also



clarified that they were not medically trained. This was framed positively in terms of the support they can offer. For example:

*I'm not medically trained but I do have experience to refer to other agencies for you.*

This part of the visit was officer led as they worked to establish rapport and put the client at ease. This was conveyed through open body language, a calming tone of voice and sitting (where possible) in close contact to the client. In situations where there was a lot of family present establishing who was in the room was done at this point.

Practically, at this point in the visit the officer had to open their laptop. Using technology during the visit has been a recent change to the way the link officers' conduct their visits. It was acknowledged in the team that this may bring an unwanted level of formality to the visits. However, the benefits that technology brings to the service in terms of information gathering and sharing and the beneficial impact this has for their clients in terms of providing multiagency support has alleviated these concerns.

First impressions are important. Across all visits the officers displayed a friendly and warm introduction to the service providing a clear explanation as to the purpose of the visit within the first few minutes. This put the client at ease, set expectations and signalled that this service is tailored to individual needs. There was consistency in the team's approach to each visit, demonstrating a skilled team of officers who had all been through the same training. **This has been recognised by the service and all officers are now working towards being accredited with a SVQ level 3 in healthcare support. One of the aims of this is to maintain motivation and commitment of link officers.**

## **Theme 2: Holistic support**

The HNA allows the officer to focus on their client's needs. As a tool it facilitated conversation around areas of concern and it provided opportunities for the link officer to offer their client various forms of support based on their physical, practical, emotional, spiritual, social and/or lifestyle needs. This process promotes multi-agency partnerships across health and social care as the officers put referrals in place based on their client's needs.

Before the client completed the HNA the officers checked this was possible and that there were no sight or literacy issues. This allowed complete focus on the client and signalled that they were moving away from routine information gathering to the crux of the visit. There were no time pressures and the clients were encouraged to relax and think about how the officer could help.

*Don't be put off by the form it's just tick boxes. Why don't you get comfortable and have a read.*

*I'm looking for up to 4 ticks and I'll work on those for you.*

The HNA is client centred, and the client was often accompanied by their family. Usually the client and their family worked together to provide a full picture of their needs demonstrating the value of treating the individual diagnosed with cancer and their family as a unit. However, there were situations where the link officer needed to balance conflicting views from family members about their client's needs. This appeared to be quite challenging to remain respectful yet acknowledge that the aim of a visit is to put support in place for the client according to their individual needs and wishes. In the visits where this clash was observed the officers reiterated that it was a client led assessment but used this moment as an opportunity to ask if they (the family member) would benefit from support. This aligns directly with the aim of the service to support not just the individual diagnosed with cancer but their carers and family members too. Further, it reiterates the skill levels demonstrated by the link officers.

In one visit the family members completed the carers assessment referral form while the client completed the HNA. This allowed the client and family to both feel involved in the visit yet give them time individually to think about their own needs. This has been highlighted as an exemplary way of increasing the identification of carers<sup>12</sup>. Currently, **the service has a 36% completion rate for carers assessment which is over seven times higher than the average rate of 5%**. However, as carers assessments are completed by social work services the service recognises that there remains a gap in support for carers. Therefore, they propose to develop a HNA specifically for carers.

The HNA process provides an opportunity to explore client concerns in depth allowing the link officers to provide the most appropriate forms of support and guidance. In order to understand the level of concern and monitor it over time clients score their concern from 1-10, with 1 being very little concern and 10 being high concern. For some clients this was difficult. For some (notably elderly) clients they seemed to struggle with the concept of ascribing a numerical value to a concern. Therefore, by the time they had to repeat this a few times for each concern it seemed to get quite tiring. Also, one client stated that he was not a complainer so was reluctant to mark anything high meaning he gave the same value to each concern. This raises the risk that severity of concern may not be mutually understood. This issue will be explored with the service to understand how they engage with clients who find the scoring difficult.

In summary, the process of offering holistic support using the HNA was skilfully handled by the link officers and elicited useful information about type and level of concern leading to the next part of the process: person centred interventions.

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<sup>12</sup> Macmillan Cancer Support (2015) Do you care? Making identification and support for carers a priority.

### **Theme 3: Person centred interventions**

The link officers naturally have their own interpersonal style when conducting the visits. Furthermore, they need to adapt to their surroundings and their clients' needs, meaning every visit observed was different. Nevertheless, all succeeded to provide high quality support. Some visits felt informal and conversational with information being gathered naturally as the conversation developed. In contrast some were more formal. Each was appropriate to the situation. Knowing very little about their client before they began a visit each link officer adapted quickly with factors such as the clients age, gender, their home environment, others present and clinical issues all having an impact. This requires specific skills that are developed during the link officers' communication skills training.

Active listening and offering personalised support is central to what this service aims to do for people affected by cancer. Subtle elements of personalised care were observed throughout each visit. Examples include, establishing what name the client would like to be called, checking throughout that they understand and were happy to proceed and remembering details gained earlier in the conversation so the client did not have to repeat themselves.

The product of this process is a care plan consisting of relevant person centred actions.

#### **6.4.2 Summary of observations**

The link officers are highly skilled professionals delivering an individualised service to those most in need. Although every person was treated uniquely there were parallels that could be drawn. Every visit began with expert introduction and the link officer clearly articulating their role (setting the scene). The assessment was then undertaken in a systematic manner but contextualised to every different scenario (holistic needs assessment). The outcome was a range of signposting and referrals coherent with the needs of the individual (person centred intervention).

## 6.5 Reflective Diary

There is evidence that personal diaries provide more authentic and less ‘filtered’ information than other types of qualitative evidence<sup>13</sup>. Diaries therefore provide a unique opportunity to capture the subjective experience of delivering ICJ. As ICJ is dependent on the continued capacity of link officers we considered this to be a very important element of the evaluation.

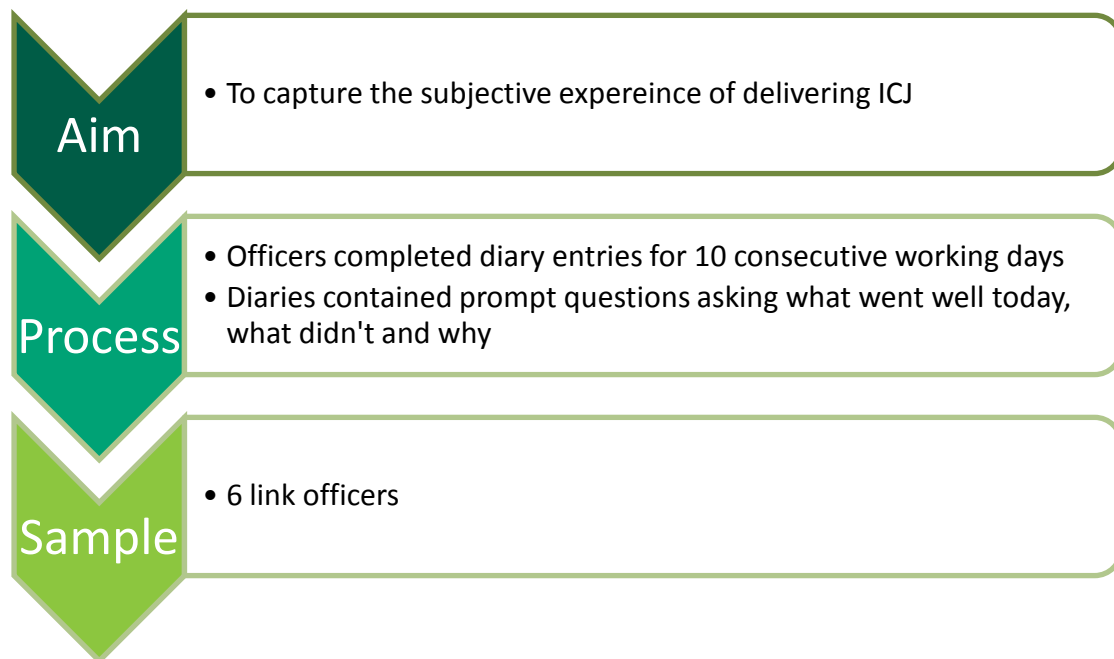


Figure 6.5. Reflective diary process

### 6.5.1 Results

A total of 70 days diary entries were obtained. The diaries contained prompt questions asking ‘what went well today’ and ‘what didn’t go well’. In order to analyse the diary entries they were formatted into transcripts and thoroughly read to identify codes and themes. The four themes are; ‘Engagement’, ‘Balancing their time’, ‘Integration in action’ and ‘Knowledge exchange’. Each theme is presented along with examples from the diary entries.

Theme	Sub-theme
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<sup>13</sup> See for example Travers, C. (2011). Unveiling a reflective diary methodology for exploring the lived experiences of stress and coping. *Journal of Vocational Behavior*, 79(1), 204–216.

Engagement	Complex cases Rewarding feedback Unusual cases Spending extra time with clients Hard to reach clients Financial assistance
Balancing their time	Autonomy Challenge balancing admin and client time
Integration in action	Promoting ICJ to others Making referrals Working with partners
Knowledge exchange	Benefit of action learning Presenting to other services Peer support

*Table 6.5.1 Themes and sub-themes from diary entries*

### **Engagement**

Unanimously, when asked to write about what went well in their day, the link officers wrote about positive interactions with their clients. This was described as being a particularly good experience when the link officer managed to interact with people who seemed harder to reach. For example:

*Good client visit today as had initially felt client was not going to engage very well with service but took up a lot of services he felt may assist him*

*Getting to talk with client who has been difficult to reach and her agreeing to referral to psychologist*

*Was able to use my experience and communication skills to get a client who was initially very difficult to get focused and complete the review by telephone*

These interactions with their clients highlight effective interpersonal skills and the benefit of proactively bringing the service to the individual rather than waiting for them to seek it out. As discussed in earlier sections the population using ICJ are predominantly from SIMD groups 1 and 2. There is evidence these groups are in the main harder to reach but these quotes on engagement show how ICJ has succeeded where others may have struggled.

The diaries also revealed that receiving encouraging feedback from their clients, putting resources into place and reducing feelings of isolation were also given as examples of 'what went well today'. For example:

*The carer advised that the information I had given was extremely beneficial, as they had not received any help or support up to that point.*

*HNA went well and managed to organise a new mattress for a lady who said she wouldn't be able to afford a new one until her rent arrears were paid off which would take her another 6 months.*

*Chatting to and supporting a man whose wife had recently died. He said it was nice to have the company.*

The link officers value these experiences, describing them as successful parts of their day. Furthermore, these instances of emotional, practical and financial support all directly align with the aspirations of this service to address gaps in support and minimise feelings of stress.

### **Balancing their time**

This theme describes some of the difficulties the link officers encounter as they balance their time between client visits and paperwork. The desire to have greater autonomy, especially in relation to the allocation of visits was described by most workers when they were asked to comment on 'what didn't go well today'. For example:

*Timing of visits. We should advise clients that the link officer will arrive at a rough time due to the fact I am out all day visiting.*

The majority of the team described a level of anxiety relating to managing the paperwork, referrals and the administrative element of client support:

*Travelling was terrible, visits too spaced out, felt under pressure on return to office as I had so many people to email and return calls to.*

*I have been covering additional client visits this week losing my only office day so was unable to do reviews and have all paperwork cleared.*

*The volume of waiting paperwork, call-backs, phone calls and outstanding reviews.*

Balancing their time between face-to-face support and administrative support appears to cause concern. Notably, it seems from these accounts this is due to the volume of paperwork that accompanies each assessment. While all workers recognised this is an essential part of their role, these comments demonstrate the risk this conflict poses.

When asked what may have helped to balance their time more effectively most link officers wrote about the desire to work more flexibly suggesting it would be beneficial in terms of managing their workload.

*Being able to work remotely would give me more time to do paperwork for a client rather than having to return to the office at the end of the day.*

*As my first visit was cancelled being able to use this time writing records rather than travelling to the office would have been beneficial.*

Collectively, there seems to be quite an emotional response to this part of the job profile. Delivering holistic needs assessments within a community setting is novel. The strengths lie in a service that is accessible. However, the key operational resource is the link officer and this section illuminates some of the pressures they face. These could become risks to the project. All officers receive supervision from line management and a clinical psychologist and as the service keeps expanding management within ICJ have indicated that they intend to review how the administrative team can assist the link officers with the volume of paperwork and different systems of arranging visits. The next cycle of data collection will review any progress around this issue.

### **Integration in action**

New and positive parts of the link officers' day were described in their interactions with wider stakeholder:

*The practice engagement was really good and the staff were keen to work with us to increase referrals and support their patients.*

*Good day; felt a sense of achievement as the presentation [to library volunteers] was great*

*The continued engagement with the service is fantastic*

These engagement sessions appear to reinforce positive perceptions around the credibility of the service. This increases confidence knowing that the service is having a wider impact and other services are keen to engage. Further, working successfully in partnership with other colleagues provided reassurance that their clients are well supported.

***(What was new today?)** Working together with a district nurse to obtain equipment for a terminal client.*

Team working across the numerous agencies and organisations is a central part of this role. Seeing the readiness of other services to engage was a clear indication of the credibility and impact of ICJ for members of the link officer team.

## Knowledge exchange

All link officers described gaining professional personal satisfaction through learning. This was mainly done through their action learning sessions:

*I feel our action learning days are a great way to discuss with other members of the team what they would have offered differently to the client*

*Action learning is beneficial and insightful*

*Action learning is hugely important and invaluable to me*

*The session with the CPN was very informative*

These action learning sessions focus on a particular area of need that help the workers better support their clients. This is because the HNA process facilitates conversation around a range of subjects, meaning the link officers may be exposed to a range of situations where they are asked for information that is not immediately known to them.

***(What was new today?)** Clients and some of the questions they asked I didn't know the answer to so I explained this and advised I would check this out and telephone them.*

***(What was new today?)** First patient I supported with a brain tumour*

Action learning is also a 'protected time' where the officers can come together and learn from each other. Peer support is an important dynamic within the team as described by one officer who had been organising a wedding for a terminal client

*It was a good day. I couldn't have done it without the support of my colleagues.*

It is clear from these descriptions that action learning sessions should continue with the content suggested by the link officers to address their learning needs.

### 6.5.2 Summary of diary entries

The diary entries allowed for unique insight into the role of the link officer, showing just how important they are to the successful delivery of ICJ. The formal support structures they have in place such as action learning are highly valued, as are the informal support they offer each other. They all describe personal and professional satisfaction from this challenging role and feel valued by their professional colleagues. They struggle as many do with balancing administrative tasks with



patient visits, but this risk is known to ICJ management and solution focused discussions are ongoing.

## 6.6 Conclusion

This section has examined the service level elements of ICJ. Through analysis of patient feedback, observations of link officers in action and analysis of diary entries it has offered deeper insights into the mechanisms by which ICJ service delivers positive outcomes for people living with and affected by cancer. The evidence is in table 6.6.

<b><i>Logic model item</i></b>	<b><i>Evidence? Y/N</i></b>	<b><i>Where? (section/page)</i></b>	<b><i>Kirkpatrick level 1= reaction 2= individual learning 3=behavioural change 4= organisational learning</i></b>
Service gaps are identified and services shaped to respond effectively	<b><i>Y</i></b>	<b><i>Throughout</i></b>	<b><i>4</i></b>
Personalised, holistic, integrated evidence informed, support packages are jointly developed and put in place	<b><i>Y</i></b>	<b><i>Observations, interviews and diaries</i></b>	<b><i>4</i></b>
Professionals and volunteers have the necessary knowledge and skills to provide high quality support and services throughout the cancer journey	<b><i>Y</i></b>	<b><i>Observations, interviews and diaries</i></b>	<b><i>4</i></b>
Those with cancer and their families are engaged in design and development of research, care pathways and services	<b><i>Y</i></b>	<b><i>Workshops</i></b>	<b><i>3</i></b>
All aspects of service delivery through the cancer journey are evidenced, informed and improved	<b><i>Y</i></b>	<b><i>Throughout</i></b>	<b><i>3</i></b>
Services are monitored and evaluated and learning used for	<b><i>Y</i></b>	<b><i>Throughout</i></b>	<b><i>4</i></b>

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service improvement, with  
robust equalities data

GCC cancer support pathways and services are patient centred, integrated, high quality, visible, easily negotiated, responsive to emergent needs and continuously improving	<b>Y</b>	<b><i>Throughout</i></b>	<b>4</b>
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*Table 6.6. Evaluation of the logic model outcomes*

**How does the service improve outcomes for people living with and affected by cancer (from the perspective of the service)?**

As can be seen from the logic model the service improves outcomes for people by responding effectively to identified needs, including those not previously managed in this way. Holistic needs assessment has led to joint working between different agencies to better support people. The link officers are highly skilled and have the ability to provide the necessary support or signpost/refer where necessary. They gather routine data on all people using the service and this facilitates high quality service evaluation and improvement through the use of robust data.

## SECTION SEVEN: The culture

***How does the service improve outcomes for people living with and affected by cancer? At:***

### 7.1 The Cultural Level

One of the key aspirations of ICJ was to improve proactive person centred care by joining up services across organisations where appropriate. This section focuses on evidence to investigate the degree to which this has happened and to highlight important achievements so that success can be sustained within ICJ and mirrored elsewhere. The relevant logic model goals are in table 7.1.

#### 7.1.1 Logic Model Outcomes

<b>Short Term Outcomes</b>	<b>Medium Term Outcomes</b>	<b>Long Term Outcomes</b>
Relevant agencies agree and accept collective responsibility for delivering the actions within the plan	Employers/employment services develop policies and practices to support engagement of workers/families/carers living with and beyond cancer	Reflective practice through holistic approach has enabled greater organisational learning, ability to enable greater empowerment for patients
Agencies bring about change in practice reflecting the holistic needs approach reflecting common goal with organisational learning Multi-agency approach taken to gather/ share data on uptake across equalities and all cancer types Evidence/patient informed practice is identified and disseminated and used to develop integrated care/support pathways	Effective and integrated pathways ensure that transitions are carefully managed and opportunities to improve wellbeing maximised	

*Table 7.1. Logic model outcomes associated with the cultural aspirations of ICJ*

## 7.2 Data collection: methods and justification

Three methods were used in this section:

1. **Analysis of routinely collected service data** to highlight the range of partnerships being utilised across Glasgow.
2. **Semi-structured interviews** to gain an in-depth understanding into the experience of using different organisations across health and social care
3. **Documentary analysis** to evidence the wider cultural impact of ICJ

## 7.3 Analysis of routinely collected service data

Previous sections have described the demographic and clinical factors of those who have used ICJ. This section focuses on the patient 'journey' to illuminate the range of agencies that these individuals are being referred to in relation to the concerns identified. This overview allows us to see the range of partnerships being utilised across health and social care within the city. Specifically, this routine data identifies:

1. The range of services that clients are being referred to and actions taken to support any identified concerns
2. The relationship between concerns identified and movement across health and social care

These are discussed in turn.

1. The range of services that clients are being referred to and actions taken to support any identified concerns

As discussed in section two referrals have been made to over 220 different agencies. The most frequent referrals were made to the Glasgow City Council and Macmillan Long Term Conditions (LTC) team, followed by self-management information, usually in the form of information leaflets, referral to the ICJ team for further support and referral to the client's GP. Figure 2.9 showed these referrals by organisation as proportions of the whole. Figure 7.1 presents a more detailed breakdown of the most frequent referrals by specific category (ie sub organisation level) in descending order.

Nearly a quarter of all the individuals (23%) who have used ICJ were referred to the Glasgow City Council (GGC) and Macmillan Long Term Conditions (LTC) service making it the most common action to occur from the HNA process. This service offers free and confidential advice in relation to money and housing issues. As

highlighted in section two the top area of concern for this client group was money and housing making this an appropriate and helpful source of support.

Tiredness/fatigue and mobility issues were the other top areas of concern for this client group. Based on the frequency of referrals these appear to be supported through a range of suitable actions consisting of self-management information, GP support and Occupational Therapy. This indicates that there is a needs led and appropriate association between client concerns and support.

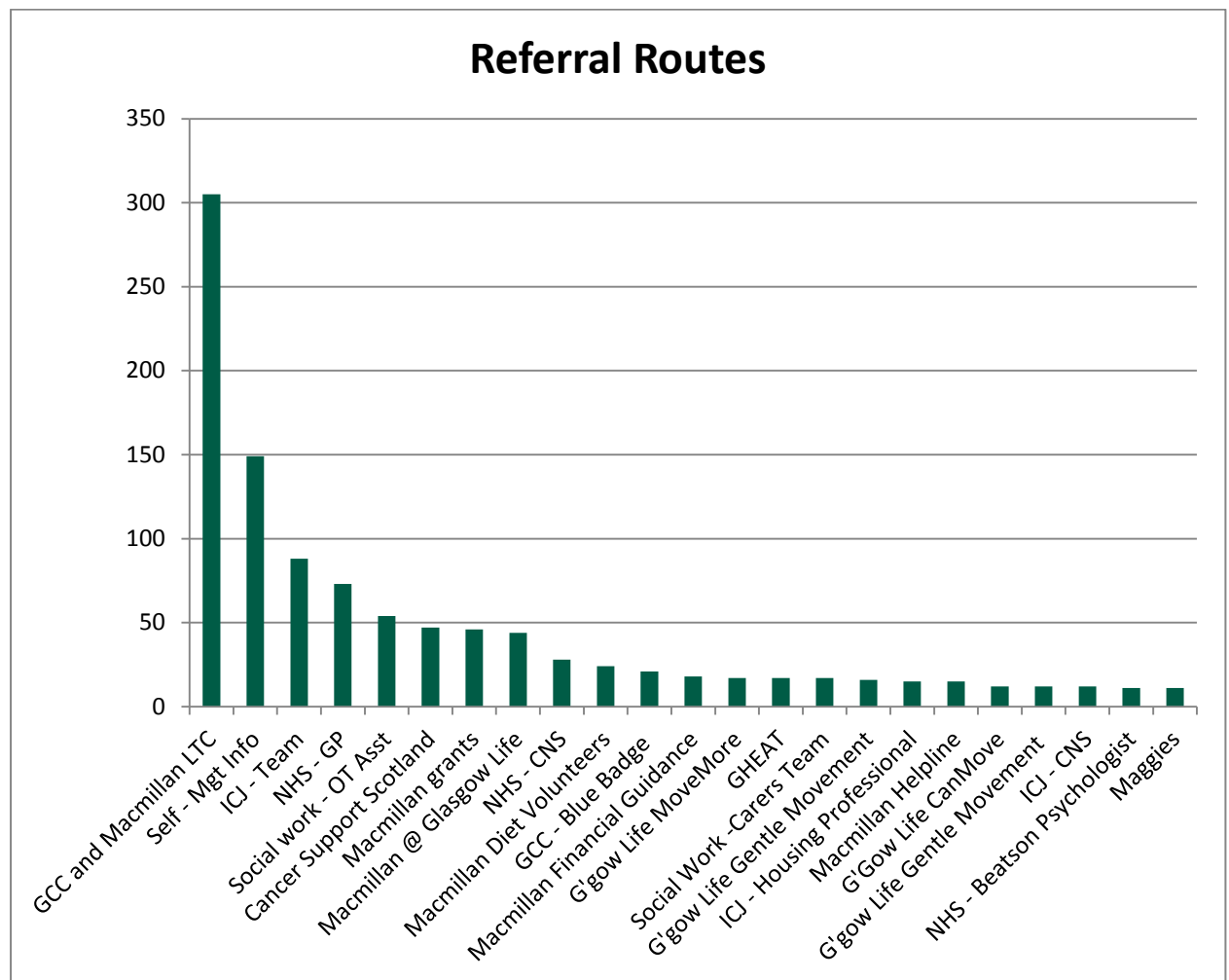


Figure 7.1 Number of clients and the agencies where they were referred

2. The relationship between concerns identified and movement across health and social care

As presented in section two (figure 2.9 and also below) individuals are supported with referral to a range of agencies. The number of agencies highlights the range of actions the service uses to reduce concerns and improve outcomes. Further, it highlights the growing partnerships between ICJ, health and social care services and the 3<sup>rd</sup> sector. Figure 7.2 summarises these referral routes highlighting the way in which the service is generating movement across services and sectors. It is this

movement along with the outcomes identified that have hailed ICJ as a model example of health and social care integration.

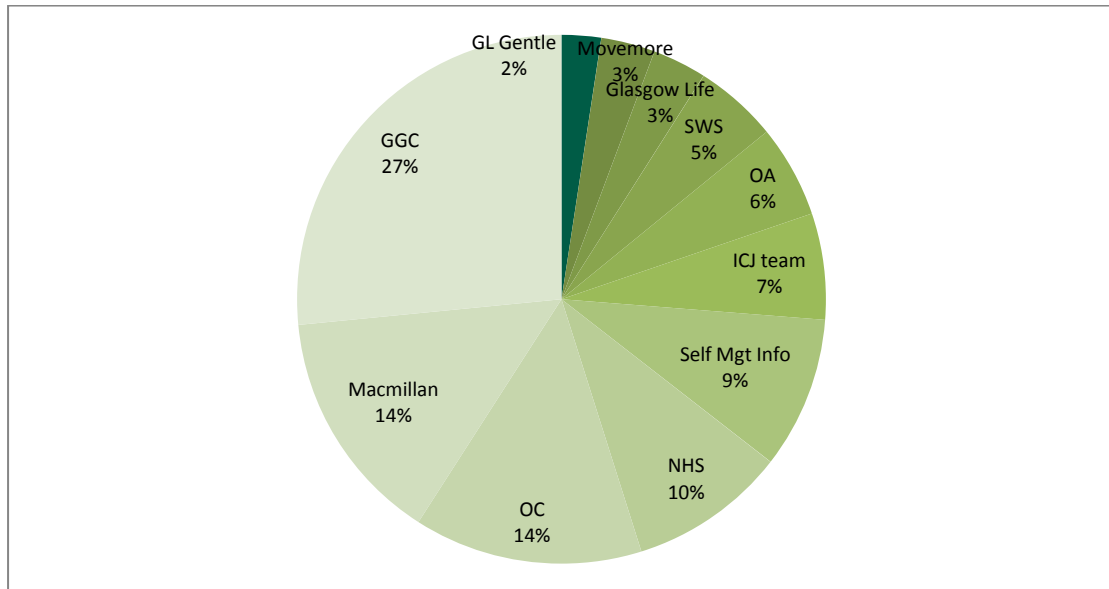


Figure 2.9. Location of onward referrals

Macmillan and Glasgow City Council (GCC) receive the most referrals. Collectively, these two organisations support a range of concerns relating to social, practical, clinical and emotional needs. Specific council organisations and support include Cordia (home help service), GCC blue badge applications and GCC Attendance Allowance applications. Macmillan services include diet volunteers, information volunteers, financial guidance, vocational rehabilitation and the Macmillan helpline. **This indicates that a large number of concerns can be appropriately addressed within the community.** What is more, these referrals are supported by volunteer services. Macmillan has funded information and support services in many libraries across the city. These services are run by volunteers who offer signposting to local services and provide emotional support. This voluntary service existed before the launch of ICJ and should be viewed as a key component to the programme’s success.

There was concern when this service was launched that there would be an unmanageable number of referrals to the NHS. As in other studies of proactive cancer care [29] this has proved not to be the case. Further from a policy perspective this finding aligns with the Scottish Government’s 2016 Cancer Strategy “Beating Cancer: Ambition and Action:

*“... health, social care and third sector services to deliver sustainable and innovative approaches to cancer care which meet the changing requirements of people with cancer to support them to live healthy lives at home”*

There is evidence here of ICJ responding to these strategic aspirations. **It represents an explicit shift from ‘treating the disease’ to person centred health and well-being activities such as supported self-management.**

### **A map of the patient journey**

Figure 7.2 shows the journey from assessment to referral for all people who have received ICJ so far. It is split into layers, such that the flow goes from the left to the right. The left layer represents all the people who have been through ICJ. It splits people into their SIMD category, such that the top category refers to SIMD 1, the most deprived, then goes down to the least deprived (SIMD 5) on the bottom left.

The next (centre) layer is main concern. The tubes going in to this level represent the number of people from a specific SIMD level prioritising a particular main concern. For example, most people, regardless of SIMD level, prioritise physical concerns.

The final layer on the right is referrals. Recall that figure 2.9 showed the referrals ranked by *individual unit*. In this model all the referrals are grouped together under the umbrella of their main organisation, so for example, referrals to NHS for a GP or to the NHS for a clinical nurse specialist are grouped under the umbrella organisation ‘NHS’. It shows that of those people who had mainly physical problems, most were referred to Glasgow City Council (GCC), then to ICJ. In relation to emotional concerns most were referred to GCC and so on.

One of the problems with this representation is that it does not pick out individual journeys. This would be impossible to represent on paper. However it gives a good idea of the overall flow through the system. It shows that people express a wide range of concerns regardless of SIMD and that nobody at all prioritised spiritual concerns. Finally, there is a wide spread of referrals, and this spread is pretty evenly distributed across the service providers regardless of type of problem. For example, it might have been expected that NHS would get most referrals for physical problems but more referrals for physical problems were made to both GCC and ICJ. All agencies received some referrals.

Of particular note is the number of self-management outcomes. Self-management was the third most frequent referral outcome overall. This is particularly encouraging as one of the key aims of the ICJ programme is to support self-management. It is clear from this ‘bird’s eye view’ that this is happening.

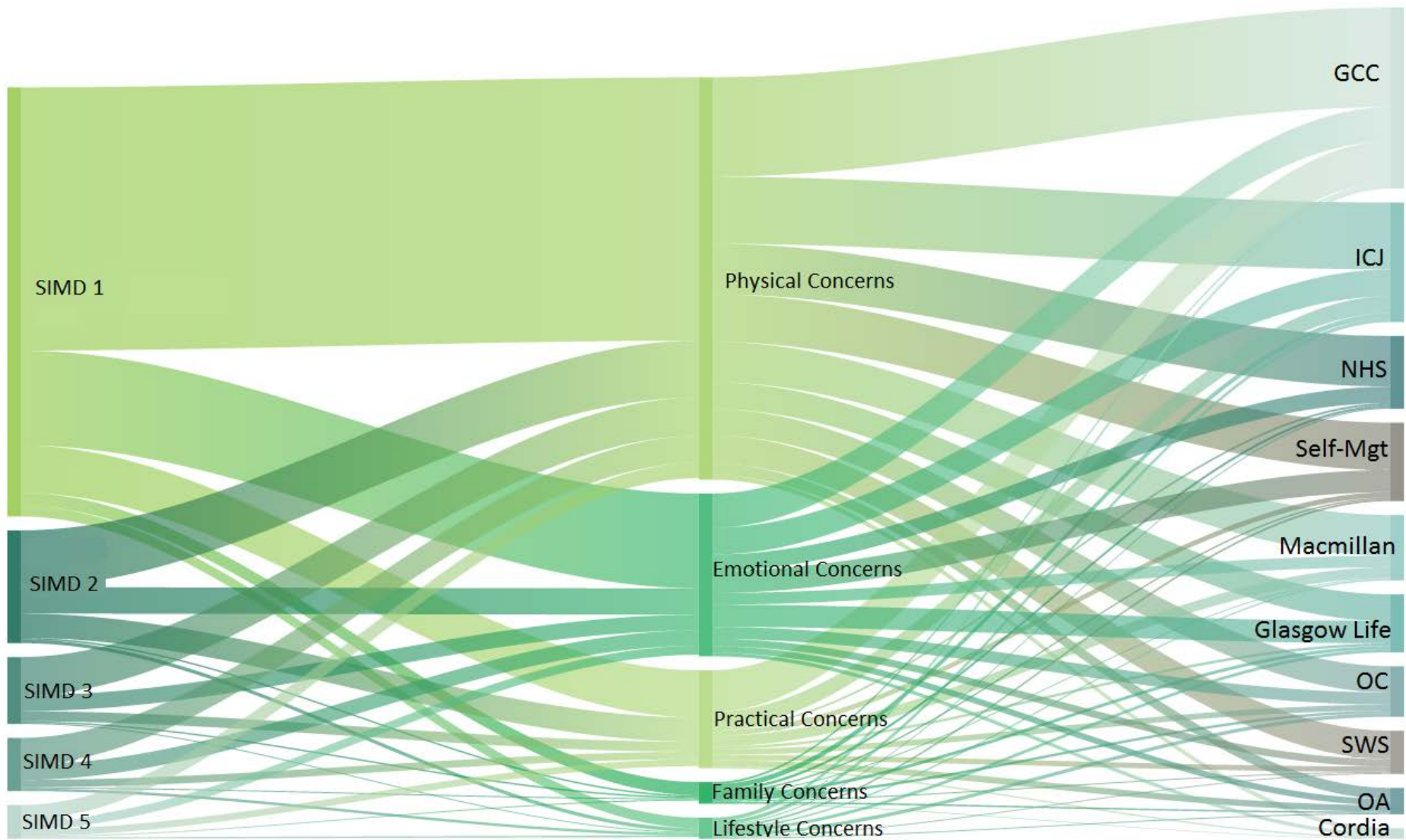


Figure 7.2 The journey through ICJ



## 7.4 Client interviews

Analysis of referral routes provides insight into the ambitions of ICJ in relation to delivering integration across health and social care, acute and community. However, while we can make comments on the suitability of these partnerships at a strategic and political level, the impact on those affected by cancer must be explored.

As part of the interviews that explored general issues relating to the thoughts and actions of those who have used ICJ, there were several examples relating to the range of services that were offered and used. For example:

*Before my hair fell out they give me support for a wig. They [ICJ] paid me some money. They suggested for daily care if I needed it. From my point of view everything was fine.*

*The leaflets you get, you know, you read them and think that's not for me just now but you don't throw them away*

*There's someone just now trying to get me money backdated as they've said I'm owed money. So I've got their names in my phone. You get so many offers. You can go to Reiki classes or have a massage. I've never had a massage but it can't be a bad thing!*

*They [ICJ] came and talked to me about my benefits and I got a small grant which helped with things in the house. I'm on the waiting list for counselling so while I'm waiting for that I will probably go down to the library.*

It is evident here that the clients are happy with the range of referrals being made. They discuss how support can come in many forms such as information leaflets, counselling and the Glasgow Life library service. Of note is that the majority chose to mention financial support suggesting this was well important to them. One participant went on to describe a situation where ICJ had shared information with the clinical team. This has a positive impact on this individual.

*He asked me do you want me to contact them I said I don't mind but when I go I will tell them also but then the nurse comes to me and says you have some problems right we got your information and I said yeah I do, it was impressive. It made me believe I was being taken care of that they were taking good care of me.*

Consequently, there is evidence here of the service providing easy access to support across agencies and sectors. In particular, appropriate data sharing was received well.

## 7.5 Documentary analysis

ICJ's winning bid for the MJ awards is included in Appendix 10. It illustrates the

cultural impact the programme is making, including its partnerships with a wide range of stakeholders and its proactive use of existing community assets to better support people. For example they have formed projects with Boots, GPs, the Beatson charity, Energy Action, Scottish Transport and welfare benefits agencies. Please see appendix 10.for details.

## 7.6 Conclusion

These data all illustrate the wider cultural impact of ICJ and its active integration into the community on numerous levels. It has made partnerships with many organisations to provide many relevant services more efficiently than would otherwise be the case. It has achieved this through actively networking with relevant partners and creating innovative solutions where necessary to better support people. Within policy this activity is recognized at national level as an example of excellent practice.

In order to make sense of these achievements table 7.6 revisits the logic model items identified at the beginning of this section. The section concludes by returning to the overall question posed in this section: *How does the service improve outcomes for people living with and affected by cancer at the cultural level?*

<b>Logic model item</b>	<b>Evidence? Y/N</b>	<b>Where?(section/page)</b>	<b>Kirkpatrick level 1= reaction 2= individual learning 3=behavioural change 4= organisational learning</b>
Relevant agencies agree and accept collective responsibility for delivering the actions within the plan	<b>Y</b>	<b>Throughout</b>	<b>4</b>
Agencies bring about change in practice reflecting the holistic needs approach reflecting common goal with organisational learning	<b>Y</b>	<b>Throughout</b>	<b>4</b>
Multi-agency approach taken to gather/ share data on uptake across equalities and all cancer types	<b>Y</b>	<b>Documentary analysis</b>	<b>4</b>

Evidence/patient informed practice is identified and disseminated and used to develop integrated care/support pathways	<b>Y</b>	<b>Documentary analysis</b>	<b>4</b>
Effective and integrated pathways ensure that transitions are carefully managed and opportunities to improve wellbeing maximised	<b>Y</b>	<b>Figure 7.2</b>	<b>4</b>
Employers/employment services develop policies and practices to support engagement of workers/families/carers living with and beyond cancer	<b>N</b>	<b>Evidence not seen</b>	
Reflective practice through holistic approach has enabled greater organisational learning, ability to enable greater empowerment for patients	<b>Y</b>	<b>Action learning?</b>	<b>2</b>

*Table 7.6. Evidence for logic model items at the cultural level*

**How does the service improve outcomes for people living with and affected by cancer (from the perspective of the wider cultural elements)?**

Table 7.2 shows the answer to this question is: extensively. The changes ICJ has achieved at an organisational level have been considerable. As a consequence it has made a positive impact on people living with cancer. The relationship between the individual, service and cultural level outcomes are discussed next.

## SECTION EIGHT: Bringing it all together

This final section revisits the key findings from the preceding sections in order to:

1. Examine how well the findings provide evidence for the stated aims of the service.
2. Identify key drivers of success in order to replicate these where possible.
3. Discuss the logic model elements not evidenced so far.
4. Make recommendations to support future evaluations.

### 8.1 Key findings

The most significant finding is undoubtedly the degree to which the aims of the service are already being met. The individual level data showed that the service is engaging with the people who need the service. It is helping them in a person centred proactive manner by systematically eliciting concerns and then referring on to relevant services. These people are happy with their experience of the service. The service level analysis showed that these positive outcomes are a function of the professionalism and skills of the link officers.

These elements are in turn possible because of the cultural findings: the clear evidence of inter agency collaboration from board level down to operational levels. On top of this, the ICJ leadership has been dynamic in disseminating the success of ICJ such that it has won awards and become part of national policy. ICJ has therefore moved beyond being an excellent example of translating policy into practice. **It is driving policy, such that government funds have been set aside to support projects in the mould of ICJ.**

The body of this report has provided evidence against the logic model goals. In order to put this in wider context, recall the aspirations underpinning Scotland's cancer Strategy (figure 1.1). Some of the objectives are beyond the scope of ICJ, such as affecting diagnosis or survival rates. Nevertheless, they have demonstrated very strong evidence for reducing health inequalities by attracting those who appear most in need of the service.

The process of HNA is designed to involve people with cancer and their families to provide the most coherent information and support decision-making. There is evidence throughout this evaluation that peoples' quality of life has been improved as a consequence of the service. The range of referrals shows that people are being referred successfully to the service they need, thus demonstrating equitable access to services and treatment. Further, the proportion of people referred for self-management shows that people are being encouraged to support themselves wherever possible, with all the associate benefits that brings.

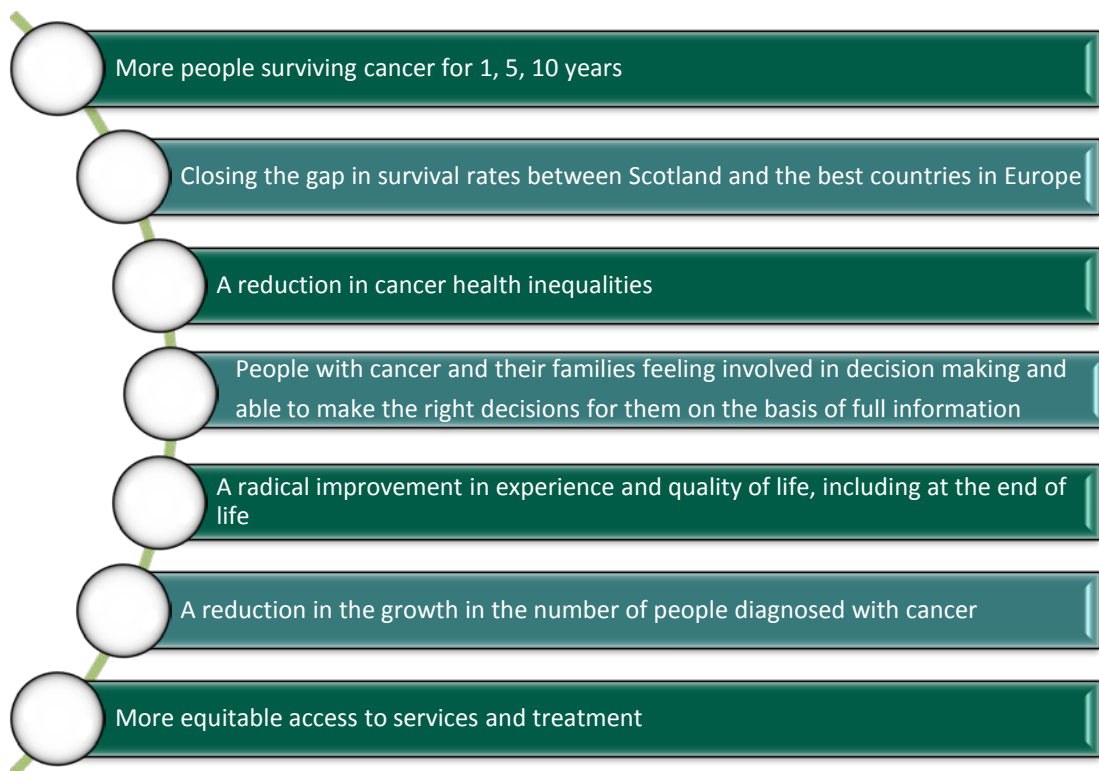


Figure 1.1 What would success look like? Objectives of the 2016 Cancer Strategy

Given that ICJ is successful at every level of this evaluation it is beneficial to analyse the components of success in order to replicate this success where possible.

## 8.2 Key drivers

This evaluation has separated its analyses in order to look at the individual, service and cultural levels impacting on outcomes. This technique was used in order to focus on smaller parts of the evaluation for methodological reasons. It found that for nearly every outcome the evidence is strong. We suggest the reason the evidence is strong is because of the level of integration *between* these individual, service and cultural levels. They all impact upon each other. **The question therefore becomes: how did this happen?** Interagency proactive person-centred care has been aspirational policy for decades, yet it rarely materialises to the level and extent seen here. This report suggests four key reasons:

### 1. Strong leadership

The driving force behind ICJ is its manager. Her drive and passion for the programme are outstanding. Her previous experience in successfully addressing inequalities at a strategic level has been invaluable and entirely transferable to this programme. She is respected both within and outwith the programme for her integrity. Her clarity of vision makes it easy for her colleagues to understand exactly what is expected of them. Her ability to disseminate ICJ success and therefore not just implement policy but **influence it** has been instrumental. This dissemination project was facilitated in

part by her recognition that evaluation metrics needed to be embedded in the delivery of the service, so that key achievements could be articulated easily.

## *2. Strong buy in*

ICJ has 'buy in' from the leadership of all partner agencies. The ICJ board is constructed from several organisations across health, social care and the third sector. All the partner agencies are strongly invested in the success of ICJ. This has resulted in the breaking down of traditional organisational barriers that have historically hampered numerous previous attempts to bridge cultures of care.

## *3. Highly skilled workforce*

Even with the best leadership and inter organisational partnership, operationalization can stall at the delivery level, but not so in ICJ. The delivery of ICJ by highly skilled practitioners has ensured that the third piece of the jigsaw is in place. The link officers have translated the principles of ICJ into practice by systematically and professionally supporting those in most need. The ICJ workforce also includes the administrative support, who as well as the link officers, all display high levels of professionalism, competence and commitment.

## *4. A workable process*

In order to translate all this vision, skill and energy into practice, the operational process needs to be clear, manageable, and efficient, whilst simultaneously being capable of dealing with diverse individual needs. Macmillan's holistic needs assessment is at the heart of this and has proved to be up to the challenge.

These elements are pictured together in figure 8.1, shown as interlocking elements of the whole.

### **8.3 Logic model elements not evidenced so far.**

The level of evidence obtained for the vast majority of the logic model items is extraordinary considering the relatively short period of operation and evaluation. This section briefly examines those items against which there is little evidence in order to ensure that these elements are not lost. Each item is discussed in turn.

*Diagnosis is earlier and optimal treatment provided according to patients'/families' wishes*

Diagnosis is not in ICJ's remit and so this is not an achievable goal. However, the providing treatment element is, so perhaps this item could be reworded to focus on the element within ICJ control

*Employers/employment services develop policies and practices to support engagement of workers/families/carers living with and beyond cancer*

We know from discussion with team members that this is happening but it was not within the scope of this report to review these policies.

*As a consequence of multiagency practice taken compares positively with other benchmarking groups/consequential learning advocated widely*

This appears to incorporate a number of aspirations and is not clear. We would recommend this be broken down into its constituent parts so that the individual elements can be evaluated in the next report.

*Those who can/wish to be are supported back into work/full participation in their community*

Again this is happening according to anecdotal evidence but the datasets available make it difficult to point to where this evidence is. So far the interviews conducted have been with older adults who have not been at work, but this will change as the evaluation continues. Also, future interviews will specifically ask about what may constitute 'full participation in the community' as this is different for everyone.

## **Conclusion**

ICJ is meeting its goals. It is helping those most in need when they need it most. It has transformed cancer care in Glasgow and become a beacon of excellent inter organisational practice for others to follow. The key conclusion from this evaluation is that the components of its success are reasonably straightforward to identify. Strong leadership, strong buy in from partners and a highly skilled workforce practising within a clear process. So, whilst ICJ has set the bar extremely high the components of success are there for others to follow (figure 8.1).



*Figure 8.1. Key elements of success*



## 8.4 Recommendations

### *ICJ leaders should:*

- Maintain current steer in terms of clarity, vision and strategy.
- Continue to take opportunities to engage external partners to further grow ICJ.
- Use their current platform of being UK leaders to translate the key elements of success to similar projects.

### *ICJ link officers should:*

- Continue to participate in bespoke training and action learning as part of structured supervision.
- Be aware that those with cervical cancer were the most concerned of the cohort. These people and others identified in figure 5.3 may require more time because severity of concerns was associated with time taken in consultation.
- Consider a mechanism to systematically contact and follow up people at the end of their treatment.

### *ICJ partners should:*

- Identify methods of further improving joint working where possible, building on the outcomes already achieved.
- Construct a mechanism of reporting back to ICJ so outcomes of signposting and referrals can be assessed and client journeys fully traced.

### *Evaluators should:*

- Advise relevant stakeholders on the type of data they should be collecting in order to further enhance the evidence base.
- Work with ICJ to identify best practice on managing large volumes of data.

### *Macmillan should:*

- Celebrate the success of ICJ by disseminating the key findings of this evaluation.
- Support the evaluators in obtaining relevant data and resources to generate economic evaluation for the next report.
- Reduce risk when attempting to replicate ICJ elsewhere by using the key findings of this report to identify the requisite building blocks to success. Use figure 8.1 to introduce these.

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## APPENDICES

### Appendix 1: 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

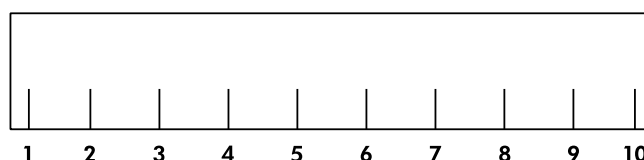
- Loss of faith or other spiritual concern
- Loss of meaning or purpose of life
- Not being at peace with or feeling regret about the past

#### 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.



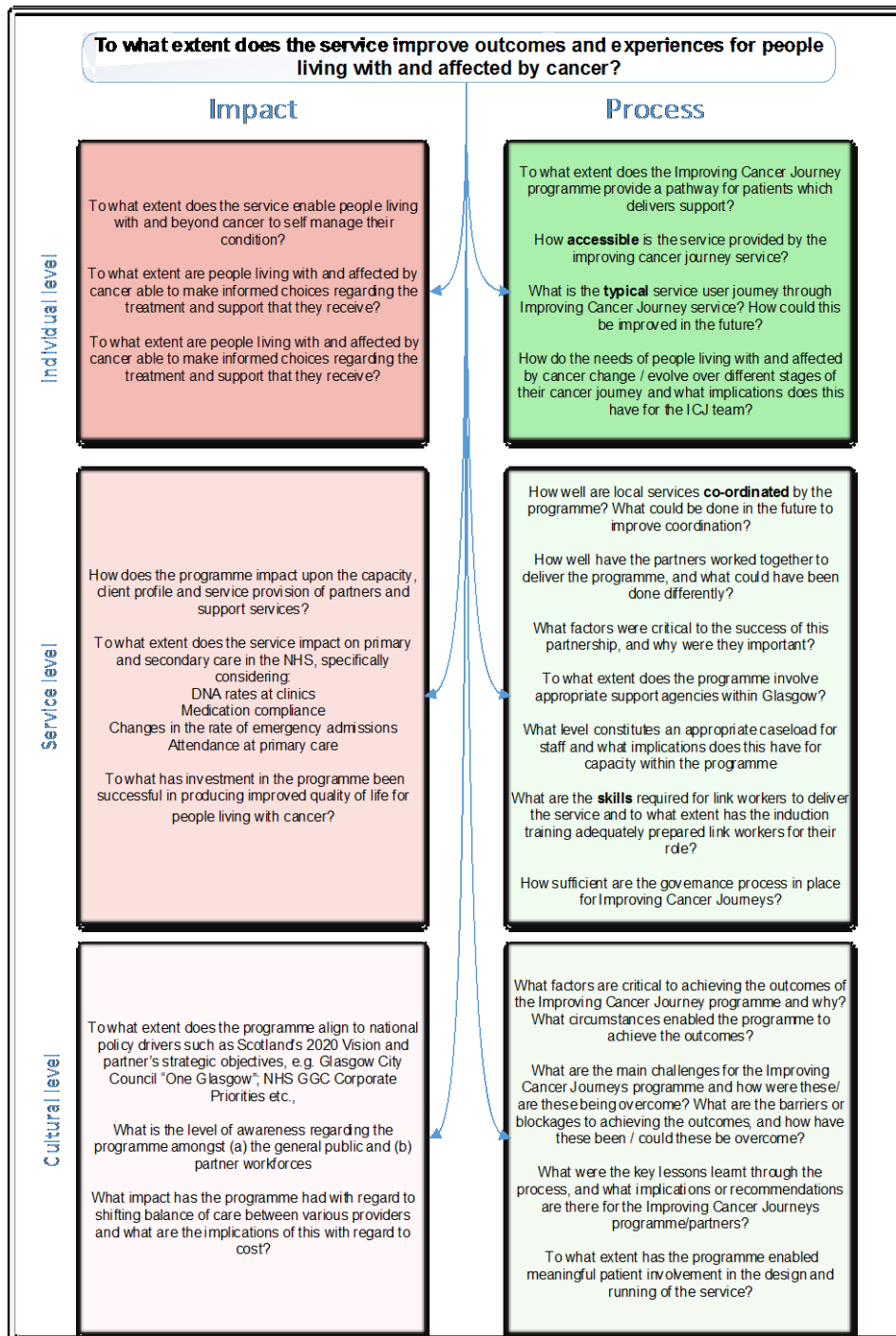
**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

**(DH)** Department  
of Health

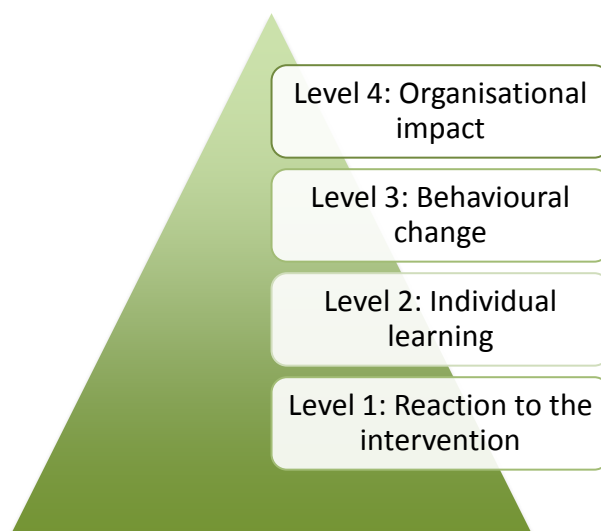
**NHS**  
NHS Improvement

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## Appendix 2: Evaluation Questions



### Appendix 3: Kirkpatrick's Hierarchy



*Kirkpatrick's Hierarchy*

level	evaluation type (what is measured)	evaluation description and characteristics	examples of evaluation tools and methods	relevance and practicability
1	Reaction	<b>Reaction evaluation</b> is how the delegates felt about the training or learning experience.	'Happy sheets', feedback forms. Verbal reaction, post-training surveys or questionnaires.	Quick and very easy to obtain. Not expensive to gather or to analyse.
2	Learning	<b>Learning evaluation</b> is the measurement of the increase in knowledge - before and after.	Typically assessments or tests before and after the training. Interview or observation can also be used.	Relatively simple to set up; clear-cut for quantifiable skills. Less easy for complex learning.
3	Behaviour	<b>Behaviour evaluation</b> is the extent of applied learning back on the job - implementation.	Observation and interview over time are required to assess change, relevance of change, and sustainability of change.	Measurement of behaviour change typically requires cooperation and skill of line-managers.
4	Results	<b>Results evaluation</b> is the effect on the business or environment by the trainee.	Measures are already in place via normal management systems and reporting - the challenge is to relate to the trainee.	Individually not difficult; unlike whole organisation. Process must attribute clear accountabilities.

For a critique see Yardley, S., and Dornan, T. (2012). Kirkpatrick's levels and education "evidence." *Medical Education*, 46(1), 97–106. doi:10.1111/j.1365-2923.2011.04076.x

#### Appendix 4: Interview Schedule

- Can you tell me about how you got involved with the ICJ service?
  - Motivations to engage
  - Barriers (any nerves/hesitations)
  - What worked well/didn't
  
- Can you tell me about what is what like to have an assessment with a link officer?
  - Where complete it
  - How did that feel
  - Comfort
  - Raising sensitive issues
  - Did you talk about anything that you didn't expect to
  
- What happened after the assessment?
  - Referrals
  - Knowledge of services
  - How feel after identified concerns
  - Notice a difference in emotions/stress/activity
  
- How confident do you feel about accessing support in your local community?
  - Mobility
  - Do feel 'part' of community (what ICJ hadn't signposted you?)
  - Movement between health and social care
  
- How useful is it having someone to help you with these issues?
  - What would you have done without the service
  - Would you have had the confidence to do this anyway
  - Does it help you take control of your situation
  
- Was there anything that you wanted to talk about that you didn't get the chance?
  - Are needs adequately met?
  
- Do you see yourself using this service throughout your illness?
  - Expectations around the service/other service
  - Anything else you would like to tell us?

## Appendix 5: Observation Schedule

---

<b>Category</b>	<b>What was noted</b>
Environment	Client characteristics- gender, age, ethnicity and physical appearance.  Number of people present and characteristics of these people  Noise
Behaviour and interactions - beginning of visit HNA process	Time and length of visit What people do, who does what, who speaks to whom and for how long, who initiates interaction, tone of voice, content of discussion, non-verbal behaviour and clients manner Any way the link officer responds to any individual needs of the patient, reactions, completing the HNA, advice and referrals
Behaviour and interactions- close of visit	As above but with particular focus on what is said and done to end the visit.

---



## Appendix 6: Codes and themes from observation field notes

Theme	Code	Extract from field notes
Setting the scene	Welcome –coats and tea	Client is relaxed, he establishes that’s his friend not his wife who is in the house, jokey and pleasant atmosphere.
	Introductions	X gives an overview of ICJ tells him they are going to do a HNA (explains what that is) but ‘get boring bit out way first’. Good way of phrasing it- puts client at ease.
	Who and why	
	Expectations	While computer is loading- ‘can you tell me what has been happening?’ This seems a useful technique to begin with as it means there isn’t a silence while the computer loads and also it allows the client, in his own words to describe his situation.
	Purpose	
	Not medical	
	Link officer led	

Theme	Code	Extract from field notes
HNA process	Client focused	X advised client to prioritise top 4. Client really struggled with the ratings. Daughter wanted him to increase the score up from 5 and adds that he’s not a complainer so it will never be high. For every concern he struggles to give it a score but manages to decide that passing urine probably biggest worry. X explained that if they get rating for each then they will prioritise for him.
	Carers voice	
	Emotion	
	Client/carer balance	
	Scoring	
	Confusion	

<i>Theme</i>	<i>Code</i>	<i>Extract from field notes</i>
Person centred interactions	Adapting	X remembered all names throughout such as doctor and CNS and from previous sections in the assessment eg when filling out clients comorbidities remembered he had diabetes from earlier discussion. Also when asked client to complete the HNA I noted X leant down to his eye level, asked if he wanted a light on and went though it with him.
	Weaving information out	
	Making client comfortable	
	Personalised	
	Listening	

## Appendix 7: All primary diagnoses by frequency

218	Lung
113	Breast
111	Prostate
70	Bowel
39	Oesophageal
24	Bladder
19	Cervical
18	Brain
18	Colon
17	Ovarian
17	Throat
14	Myeloma
12	Kidney
12	Pancreatic
12	Tongue
11	Melanoma
11	Unknown Primary
9	Stomach
8	Larynx
8	Leukaemia
8	Testicular
7	Endometrial
7	Liver
7	Mouth
7	Sarcoma
6	Non Hodgkins Lymphoma
5	Lymphoma
5	Rectal
5	Thyroid
4	Anal
4	Mesothelioma
4	Oral
4	Rectum
4	Tonsil
3	Corpus Uteri
3	Head and Neck
3	Neck
3	Oral cavity
3	Renal
2	Bone and Soft Tissue Sarcoma
2	Carcinoma
2	Gastric
2	Gullet

2	Hodgkins Lymphoma
2	Liver cell
2	Non hodgkin lymphoma
2	Peritoneum
2	Vulva
2	Womb
1	Acute myeloid leukemia
1	Basal cell carcinoma
1	Bile duct
1	Bone Marrow
1	Breast cancer
1	Bronchial Carcinoma
1	Bronchus
1	Caecal
1	Cervix
1	Cholangiocarcinoma
1	Chronic lymphocytic leukaemia
1	Colorectal
1	Duodenal
1	Essential thrombocythaemia
1	Ewings Sarcoma
1	Gall bladder
1	Gastrointestinal
1	Gastrointestinal Stromal Tumour
1	Groin
1	Gynecological
1	Multiple Myeloma
1	Multiple Myeloma
1	Nasal
1	Neo-endocrine tumour (bowel)
1	Neuroendocrine
1	Not Answered
1	Oropharynx
1	Other
1	Other Cancer
1	Ovarian cancer
1	Pancreas
1	Penile
1	Pharynx
1	Rhabdomyosarcoma
1	Sarcoma
1	Squamous cell carcinoma
1	Squamous Cell Carcinoma
1	T2N0 Pyiform Sinus
1	T2NB Oropharynx
1	T4 Soft Palate Squamous Cell Carcinoma

1	Thrombocythemia
1	Uterus
1	Vagina
1	Vaginal
1	Vocal cord carcinoma

## Appendix 8: ICJ pilot 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.

Version 1.0 3/9/15

**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 past 7 days.

<b>PHYSICAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
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
<b>SOCIAL/FAMILY WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
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
<b>EMOTIONAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
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

Version 1.0 3/9/15

<b>Section 1</b>	<b>Quality of Life</b>				
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. <b>Please circle or mark one number per line to indicate your response as it applies to the past 7 days.</b>					
<b>FUNCTIONAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
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

#### Health Status

This section is about your health outcomes

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

<b>Mobility</b>	<b>Tick one box only</b>
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"/>

<b>Self-Care</b>	<b>Tick one box only</b>
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"/>

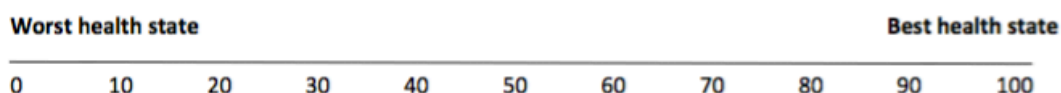
<b>Usual Activities</b> e.g. work, study, housework, family or leisure activities)	<b>Tick one box only</b>
I have no problems with performing my usual activities	<input type="checkbox"/>
I have some problems with performing my usual activities	<input type="checkbox"/>
I am unable to perform my usual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

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<b>Pain/Discomfort</b>	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"/>

<b>Anxiety/Depression</b>	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 cross on whichever point on the scale indicates how good or bad your health state is today**



## Section 2 Social Support

Here are some questions about the support that is available to you.

**About how many close friends and relatives do you have? (people you feel at ease with and can talk to)**

**How often is each of the following kinds of support available to YOU if you need it?**

Please tick <b>ONE</b> 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	Not Applicable
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"/>	<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"/>	<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"/>	<input type="checkbox"/>

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**Section 2****Social Support**

Here are some questions about the support that is available to you.

**How often is each of the following kinds of support available to YOU if you need it?**

Please tick <b>ONE</b> 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	Not Applicable
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"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>
Someone who hugs you	<input type="checkbox"/>	<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"/>	<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"/>	<input type="checkbox"/>
Someone whose advice you really want	<input type="checkbox"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>
Someone to do something enjoyable with	<input type="checkbox"/>	<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"/>	<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"/>	<input type="checkbox"/>

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**Section 3** 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 <b>ONE</b> box on each line.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Not Applicable
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"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that 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"/>	<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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Please tick <b>ONE</b> box on each line.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Not Applicable
I am confident that 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"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Section 4</b>	<b>About You</b> This information will help us to identify if different groups of people have different experiences.
<b>Question 1</b>	Do you look after, or give any <b>regular help or support to family members, friends, neighbours or others</b> because of long-term physical / mental ill-health / disability or problems related to old age? <i>(Exclude any caring that is done as part of any paid employment or formal volunteering)</i>
	<input type="checkbox"/> <b>No</b> - please go to <b>Question 2</b> <input type="checkbox"/> Yes up to 4 hours a week <input type="checkbox"/> Yes, 5-19 hours a week <input type="checkbox"/> Yes, 20-34 hours per week <input type="checkbox"/> Yes, 35-49 hours per week <input type="checkbox"/> Yes, 50 plus hours per week
<b>Question 2</b>	<b>Is someone (other than a professional who is paid to) caring for you? This may be emotional and/or physical support and care.</b>
	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>Question 3</b>	<b>Which of the following best describes how you think about yourself?</b>
	<input type="checkbox"/> Heterosexual (straight) <input type="checkbox"/> Gay or lesbian <input type="checkbox"/> Bisexual <input type="checkbox"/> Other <span style="float: right;"><input type="checkbox"/> Prefer not to say</span>

**Section 4** **About You**  
This information will help us to identify if different groups of people have different experiences.

**Question 4** **Do you currently access any support/assistance from any organisations/charities? (other than Improving the Cancer Journey Service)**

- No – please go to Question 5
- Yes – please describe here:

**Question 5** As part of our evaluation a researcher would like to talk to people by themselves to learn more about their experiences. If you would like to take part please provide your **name** and **contact details** (email, telephone number or address). We can then get in touch with you to organise this. Please don't feel any obligation to do this. Your input so far has been very valuable.

If you have anything else you would like to tell us about living with cancer, please do so here:

**Thank you for completing this survey.**  
**Please post in the stamped addressed envelope provided.**



**Appendix 9. Workplace induction for link officers**

**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		

Visit the Vocational Rehabilitation Team		
Visit the Financial Guidance Team		
ESA training		
Introduction to Universal Credit training		
PIP training		
Scottish Welfare Fund training		
Older People Benefits training		
Housing Benefit training		
Carers and Benefits training		

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 10: MJ Award - Winning ICJ bid

For full report please see

<http://awards.themj.co.uk/library/media/pdfs/Glasgow%20City%20Council.pdf>

# Improving the Cancer Journey



## MJ Awards 2016 'Delivering Better Outcomes'

**WE ARE  
MACMILLAN,  
CANCER SUPPORT**



**NHS**  
Greater Glasgow  
and Clyde



**cordia**  
HEALTH CARE





## Appendix 11: List of organisations ICJ referred to

Cordia - HR  
Cordia - Community Alarms  
Cordia - Help at Home  
Cordia - Home Care Support  
Cordia - Personal Care  
GCC - Attendance Allowance Application  
GCC - Blue Badge Application  
GCC - Care and Repair  
GCC - Ctax & Housing Benefit  
GCC - ESA Application  
GCC - FS  
GCC - LES  
GCC - LTC Mac  
GCC - Scottish Welfare Fund  
GCC - Social Care Direct  
GCC- CBS Parking  
GHA/Other RSL - Linthouse HA  
GL - CanMove  
GL - CanMove leaflet  
GL - CanMove referral  
GL - Digital Learning Team  
GL - ESOL classes  
GL - Gentle Movement  
GL - Gentle Movement Information  
GL - Gentle Movement Leaflet  
GL - Gentle Movement referral  
GL - Library Resources  
GL - Macmillan @ Glasgow Life  
GL - MoveMore  
GL - Paths for All  
ICJ - CNS  
ICJ - Housing Professional  
ICJ - Team  
Mac - Financial Guidance Team  
Mac - Macmillan at Boots  
Mac - Macmillan clothes bank  
Mac - Macmillan Diet Volunteers  
Mac - Macmillan Financial Guidance  
Mac - Macmillan grants  
Mac - Macmillan Helping Matters Service  
Mac - Macmillan Helpline  
Mac - Macmillan Vocational Rehabilitation  
Mac - Macmillan Website

Mac - Vocational Rehab Team  
NHS - Beatson Information & Support Officer  
NHS - Beatson Psychologist  
NHS - Beatson Treatment Helpline  
NHS - CNS  
NHS - Community Palliative Care Team  
NHS - Complaints Procedure  
NHS - Consultant Dentist Gartnavel  
NHS - District Nurse  
NHS - Falls prevention  
NHS - GP  
NHS - Heart Failure Nurse  
NHS - Macmillan Palliative Care Nurse  
NHS - Occupational Therapy  
NHS - Palliative Care Nurse  
NHS - Prosthetics  
NHS - Psychologist  
NHS - Rapid Response  
NHS - Smoke Free  
NHS - Smoking Cessation  
NHS - Sphere Bladder & Bowel  
NHS -Beatson Treatment Helpline  
NHS -GP  
NHS Palliative care nurse  
OA - Arklet HA  
OA - Bowel Support Group  
OA - Bus Pass  
OA - Dial-a Bus  
OA - GAMH  
OA - GHEAT  
OA - Glasgow Mosque  
OA - James Gibb Residential Factors  
OA - Jobs & Business Glasgow  
OA - Lifelink  
OA - London Road Nursery  
OA - Mobility Solutions  
OA - My Bus  
OA - National Entitlement Card  
OA - North West Community Rehab Team  
OA - Other Local Authority  
OA - Red Cross  
OA - RSL  
OA - Specsavers  
OA - Speech Therapist for Servox  
OA - West of Scotland HA  
OA - Westmarc

OA - WW & J McClure Solicitors  
OA -Careline Support  
OA -Clydeside Action on Asbestos  
OA -Good Morning Service  
OC - Breast Cancer Care  
OC - Cancer Support Scotland  
OC - Friends of the Beatson  
OC - Maggies  
OC - Marie Curie  
OC - Marie Curie Hospice  
OC - MASSCOT  
OC - PCUK  
OC - Prince & Princess of Wales Hospice  
OC - Red Cross  
OC - Roy Castle Foundation  
OC - Salvation Army  
OC - St Margarets Hospice  
OC - Transport Ambulance Service  
OC - Westmarc Wheelchair  
OC - Winston Wish  
OC- Cancer Support Scotalnd  
PCUK -  
RSL - Aspire HA  
RSL - Bield HA  
RSL - GHA  
Self - Mgt Info  
Self - PHQ  
Self Mgt Info - Fatigue Booklet  
SWS - Carers Team  
SWS - Children & Families  
SWS - Home Support  
SWS - Homelessness  
SWS - Older People  
SWS - OT  
SWS - OT Assessment  
WG - GHA  
WG - Glasgow Housing Association