EVALUATION OF IMPROVING THE CANCER JOURNEY

September 2020 - Final Report

MACMILLAN CANCER SUPPORT
RIGHT THERE WITH YOU

Edinburgh Napier UNIVERSITY

Glasgow CITY COUNCIL

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FOREWORD

JANICE PRESTON
HEAD OF MACMILLAN PARTNERSHIPS, SCOTLAND AND NORTHERN IRELAND

Macmillan knew the Glasgow Improving the Cancer Journey service was desperately needed. Decades of experience had shown us there were thousands of people struggling with the problems cancer caused, from debt to depression. While there were many support services available, there was no easy or systematic way for someone newly diagnosed to find out about it. Whether someone with cancer got help was often down to luck. Did they read the right leaflet? Did they pass the right poster in the waiting room? Did they talk to the right person during chemo who'd had similar problems and got help? Too many people were falling through the cracks in the system, struggling alone with problems when the support was there for them – they just didn't know how to find it.

When Macmillan Glasgow ICJ was launched, it made Glasgow the first part of the UK where people with cancer would be proactively offered support for all their individual needs, from paying their heating bill, to dealing with anxiety and depression. The service bridged the gap between health and social care, working with each individual to find out what they needed, then supporting them to get it; no matter whether the need was physical, emotional, financial or practical.

Almost six years on from the launch of the service, Macmillan Glasgow ICJ has, demonstrated through the wide ranging evaluation completed by Edinburgh Napier University, measurably improved the lives of people with cancer in the city. It has reduced their concerns, improved their quality of life, unlocked over £18m in benefits and grants and stopped 50 people with cancer from becoming homeless. It has freed up the time of nurses and doctors to focus on the clinical needs of their patients, with the vast majority of clinicians surveyed saying ICJ has made it easier for them to do their jobs.

Macmillan Glasgow ICJ has already become the model of cancer care for the rest of Scotland with similar services now running in Dundee, Fife, Renfrewshire and West Dunbartonshire with a developing service across Lothian. In 2019, the First Minister, in recognition of how integral ICJ was to the cancer care system, announced the Scottish Government and Macmillan were entering into an £18m partnership, part of which will be to set up ICJ services in every part of Scotland.

Covid has led to some delays in progressing this ambition, with the cancer system under considerable strain. However, as this report demonstrates, this only makes ICJ all the more essential. Personalised care that treats everyone as a person with their own fears, problems and priorities, isn't a nice to have. It is not an added extra. It is an essential part of the cancer care pathway that measurably improves the lives of people with cancer and frees up the time of clinical staff to focus on those with complex medical needs. It is one of the solutions to a system straining under the weight of the number of people with cancer; not a distraction from dealing with that challenge.

As we head towards the end of 2020, we look forward to working with the Scottish Government and the health and social care sector to further embed the ICJ personalised care model across Scotland. Despite the unique challenges of the year, we continue to be committed to making Scotland the first place in the UK where everyone with cancer is offered wraparound support, from benefits advice to psychological support, to meet their individual needs, crucially at the time that they most need it.

EXECUTIVE SUMMARY

Improving the Cancer Journey (ICJ) is the first supportive cancer service of its kind in the UK. It offers support to everyone eligible in the Glasgow city area by offering a Holistic Needs Assessment (HNA) to help identify and address all physical, psychological, social, financial and practical needs.

ICJ is led by Glasgow City Council and its main partner in both funding and support is the UK charity Macmillan Cancer Support. The service also has partners across health, social care and the third sector including NHS Greater Glasgow & Clyde, Glasgow Life, Cordia, Wheatley Housing Group and The Beatson Charity.

The service is unique because:

1. It is ***proactive*** – due to a novel data sharing agreement between Public Health Scotland and ICJ, everyone eligible in the Glasgow city area with a confirmed cancer diagnosis receives a letter of invitation for ICJ support.

2. It is ***multidisciplinary*** – ICJ has partners across a range of sectors and is governed by the Integrated Joint Board, reflecting the service's commitment to improving outcomes through integrated care.

3. It is ***non-clinical*** – the key intervention (Holistic Needs Assessment) is facilitated by a 'link officer'; a trained council employee, not a health service professional as is usually the case in cancer support services.

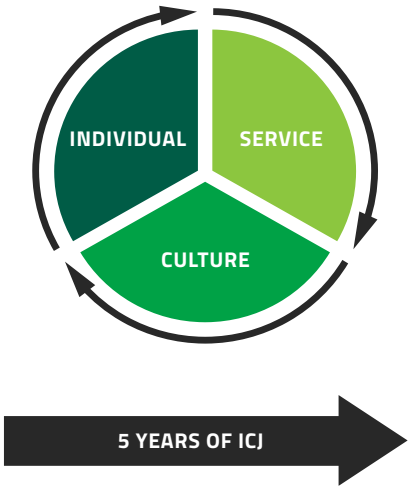
Since its inception in February 2014 to June 2020 the service has supported 7587 individuals and families.

Evaluation

In 2015, Edinburgh Napier University was commissioned to undertake a five-year independent evaluation of ICJ. The aim was to understand if ICJ improved outcomes for people affected by cancer. Key objectives were to understand how, why, when and where ICJ contributed to individual, service and system-wide cultural change.

This final report[1] begins by summarising the support needs of people who were helped by ICJ. We then analyse the field work conducted over the last year, including interviews with ICJ clients, health professionals and wider stakeholders, surveys involving ICJ clients, and health professionals, and analysis of link officer diary entries.

The report concludes by demonstrating how ICJ has transformed cancer care in Glasgow and how the model is now being replicated and rolled out nationally.



[1] Previous reports: https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html

Key Findings

The findings are presented under six headings – Improved Outcomes and Experiences, System Efficiency and Effectiveness, Support Based on Need, Skilled Workforce, Transformational Change, and Replication and Roll-out. These headings follow the aim and objectives, considering if, how, where and why ICJ has been a success at individual, service and cultural levels.

In summary, ICJ successfully reached those needing help in a timely manner. To do this, partners across health, social care and the third sector developed a shared understanding of what could be achieved by putting the person affected by cancer at the centre. ICJ is a working example of the type of service aspired to by policy makers worldwide – holistic, person-centred, needs-driven, and delivered through collaboration. Showing which elements of the service can be transferred is therefore key and concludes this summary.

The latest key findings are:

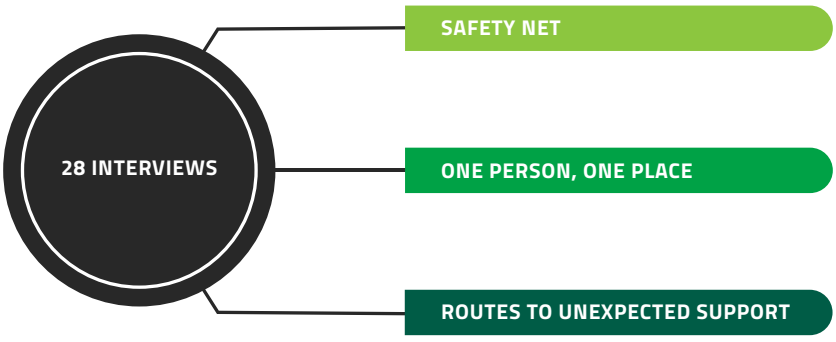
Improved Outcomes and Experiences

Across the 28 interviews conducted with ICJ clients (including patients and family members/ carers), we heard that people affected by cancer need social, emotional and practical support. Providing this support is central for wellbeing and quality of life.

Individuals benefited from having an outlet to discuss their concerns, particularly those related to financial burdens and emotional worries, as they did not feel it was appropriate, or did not alvways have the opportunity to discuss them in a clinical setting.

ICJ clients valued proactive, one-to-one support and the reassurance that, should they require any further support, they could access the service again. Link officers were praised for their ability to efficiently navigate different organisations to make helpful and sometimes unexpected referrals on their behalf.

We also measured self-reported health status (using EQ-5D) in a sample of ICJ clients between their first HNA and review. The results show that it is possible to make a meaningful improvement to an individual's health by reducing their concerns.



Perceived benefits of ICJ

System Efficiency and Effectiveness

Access to ICJ has widened since 2015. By 2019, ICJ supported people affected by cancer in Glasgow at a wide range of inpatient and outpatient hospital and hospice settings across the city. In practical terms this meant that health professionals worked physically alongside link officers for the first time.

What was unknown was how this development would affect the way in which clinicians worked and how the individual would experience it. Ten clinicians (nurses and doctors) were interviewed and another 55 completed a survey on what they thought of ICJ. After an initial short period of uncertainty, most of them understood the positive impact that ICJ had made on their practice and their patients and valued it highly. Highlights included:

92% **who agreed that referral to ICJ improves the patient experience.**

70% **who agreed that referral to ICJ saves them time.**

93% **who agreed that losing ICJ would have a negative impact on cancer care in Glasgow.**

'When we had to deal with the social issues, it was very time-consuming and took us away from clinical work. We didn't have the knowledge, so patients were getting a really raw, a really bad deal'

(Cancer Nurse Specialist, CNS).

'ICJ has allowed me to refer patients for advice and support during a very anxious and stressful time for them. ICJ has allowed patients to access help that they may not otherwise have had'

(CNS).

Process of change – the impact of co-locating ICJ link officers into clinical practice

Referrals to ICJ from the NHS have increased each year. In 2019, 66% of referrals came from the NHS, up from 37% in 2015.

Support Based on Need

The main areas of concern identified by ICJ clients remained constant: finances/housing, physical effects (mobility and fatigue) and emotional effects (worry/anxiety). These were common for individuals across different cancer types, stages, ages and socioeconomic backgrounds. Of note was that finance/housing was a priority concern, not just for individuals from the most deprived areas in Glasgow, but also the least. Almost every ICJ client interviewed did not know that they were entitled to financial support, or how to go about making a claim.

No matter a client's background, out-of-pocket expenses and more money spent on things like fuel and transport, when it was combined with a reduced income, imposed a financial burden on them and their families. Yet, through state benefits, grants, support with council tax and housing, assistance with fuel poverty, carer support and debt management, ICJ obtained £18.5 million for 4,138 clients. The average gain for each individual was £5,300. ICJ therefore played a part in reducing cancer poverty in the city.

'We thought, we don't know what we can get or if we can get anything. So having that [income], taking that stress away at a time that was stressful was so helpful.'

(ICJ Client).

As far as we know, ICJ is the only cancer service in the UK with a seconded housing professional, and demand is high. The housing officer had, as of June 2020, supported 730 families with housing issues. People were rehoused, moved to sheltered accommodation, had adaptations fitted to allow them to live for longer in their own home, and received support with rent arrears to prevent homelessness. Having dedicated expertise at hand was instrumental in improving outcomes. This is highly likely to be transferable to other needs.

'Without them [ICJ] there I don't know what I would've done. I honestly don't know. Gone to what, George Square to sleep?'

(ICJ Client).

Skilled Workforce

One of the unique attributes of ICJ is that the HNA is carried out by non-clinical link officers. Therefore, understanding their skills and approach was an essential part of the evaluation. Link officers kept diaries in 2016 and again in 2019.

The diary entries showed how varied, and at times unpredictable, their role can be. The diaries also revealed an emotionally intelligent and professional workforce. By flexibly adapting to a range of situations, they tailored support to needs and individual circumstances.

Induction training and ongoing learning from partner agencies plays an essential part in their delivery and approach. Supported by ICJ management, link officers take on ownership and responsibility for their cases guided by the ethos of 'conscious competence' – that if they don't know the answer to a particular issue, they will seek the information from another source, and always act within their sphere of competence.

Transformational Change

ICJ has succeeded in delivering a 'seamless service'[2], an aspiration of policy makers for 50 years at least. This required unprecedented collaboration across different organisations and processes. Achieving this required a change in attitudes and behaviours from all health and social care professionals with responsibility for treatment, support, information and help for people affected by cancer. However, it is fair to say that the contribution from clinical partners was particularly important.

Considering the impact ICJ had on clinical practice, the commitment and collaboration across hospitals, outpatient clinics and from individual clinicians was notable. Senior clinicians who were supportive of hosting ICJ at their clinics should be recognised as playing a major part in integrating the service into clinical practice.

Also, continuous measurement and interpretation of how individuals experience the service, something which was embedded in ICJ's development, is crucial to show its effectiveness and impact.

In 2016, the Scottish Government cited ICJ as an example of excellent practice and a model to follow in its 2016 Cancer Strategy[3]. Conditions for new programmes to flourish have been created by demonstrating that ICJ (and related programmes such as Transforming Care after Treatment) are a viable and beneficial way to care for and support people.

Building on this success, in 2019 it was announced that a new £18 million partnership will make Scotland the first country in the UK to offer cancer patients guaranteed emotional, practical and financial advice. The Scottish Government and Macmillan Cancer Support will invest £9 million each to ensure that everyone diagnosed with cancer has a dedicated support worker through the Transforming Cancer Care programme.

Replication and Roll-out

The ICJ model of care has now been launched in five areas across Scotland – Edinburgh and the Lothians is aiming to be the sixth in 2020. However, the coronavirus pandemic has had an impact on current and future plans. We summarise some of the challenges in Section 6 but also consider how the pandemic has created opportunities for new ways of working to support people affected by cancer.

[2] For example; https://www.nhsconfed.org/-/media/Confederation/Files/Wales-Confed/WNHSC-Briefing-Seamless-services-to-improve-outcomes-for-people.pdf
[3] https://www.gov.scot/publications/beating-cancer-ambition-action/pages/8/

As new areas launch their services it is vital that previous learning is incorporated into their development and delivery.

We suggested in 2016 that for new services to succeed, the key elements to focus on should be leadership, buy-in, process (HNA) and a skilled workforce. We argue that these factors are still essential to any future rollout, but there should also be one additional element.

During the evolution of ICJ there has been continuous evaluation of progress against a set of clearly defined aims and objectives. We would add 'evaluation' as the fifth and final essential element of success for any future venture. The final section of this report goes into detail on this essential element.

Key elements of success

Extending the Model

We have shown that holistic needs assessment and care planning supports people who require help due to illnesses such as cancer, but this approach can and should be extended to other health conditions. In Scotland, 42% of the population have at least one long-term health condition and 23% have two or more[4].

To that end, Glasgow City Council has put forward a business case to extend the ICJ model of care to people with other long-term conditions. As discussed above, research and evaluation should be embedded from the start to better understand what elements of the ICJ model can be transferred to other health conditions and which cannot, what works for whom, and under what conditions.

Conclusion

This is the final report from a five-year evaluation that aims to identify how ICJ has improved outcomes for people affected by cancer and the services designed to support them. By gathering evidence from people who have used ICJ, from those who deliver or work alongside ICJ, and from a wider cultural/policy perspective, we have identified that the service has had a demonstrable impact on the people of Glasgow and cancer services across Scotland and beyond.

It can be difficult to understand the impact of an individual project, idea or programme without the benefit of considerable hindsight. However, it is not unreasonable to consider that ICJ should be remembered as the first working example of a principle recognised 50 years ago – to give someone the best care you should listen to them in a careful and proactive way, create a plan together to deal with the most pressing problems, then help them to deal with these individual needs by working in partnership across the whole health and social care system.

Looking towards the future of personalised care – irrespective of health condition – health and social care professionals, patients and their families, should come together to identify what support is needed, make goals and take action, while monitoring every aspect of the process. This is no longer an aspiration. ICJ has provided the framework to follow.

[4] https://www.gov.scot/policies/illnesses-and-long-term-conditions/

REPORT STRUCTURE

section one

The findings in this report are presented under six headings, as introduced in the Executive Summary – Improved Outcomes and Experiences, System Efficiency and Effectiveness, Support Based on Need, Skilled Workforce, Transformational Change, and Replication and Roll-out. These headings summarise the aim and objectives, considering if, how, where and why ICJ has been successful at an individual, service and cultural level. To set the scene we introduce the context and background, essentially describing a timeline of ICJ development from inception to the present day, in **Section 1**.

section two

Section 2 introduces the methods used to undertake the analysis and reintroduces key interrelated components used throughout this five-year evaluation:
1. The impact of ICJ on ***individual*** service users, including families and carers.
2. The impact of the ***service*** – the people delivering the service, specifically the link officers, but also including all partners in delivery of care.
3. The impact of the service on the ***culture*** – the policy context and the ways of working between organisations.
These three distinctions frame the discussion of the latest results of the evaluation and also provide the headings for the subsequent three sections.

section three

Section 3 shows the impact of ICJ at the individual level. It details new information obtained since the previous report and integrates it with data already obtained to comment on improved outcomes and experiences. Specifically, we look at data from the HNA process and report on findings that show a link between reducing concerns and health improvements in a sample of ICJ clients.

section four

Section 4 explores service delivery. It includes subsections on 'system efficiency and effectiveness', 'support based on need' and 'skilled workforce' to show the effect of co-locating the link officer into clinical practice, tailoring support to need, and understanding the link officer's approaches and skills.

section five

Section 5 is the impact of ICJ at the cultural level. It includes subsections on 'transformational change', and 'replication and roll-out'. We reflect on what we believe are the key components of its success and highlight the way ICJ has influenced the delivery of cancer care across Scotland.

section six

Section 6 concludes the report by looking forward. We discuss how Edinburgh Napier University has been working with ICJ to help improve the efficiency of its data capturing systems, so that it can self-evaluate its service once our work has ended. This key aspect is essential and often overlooked when delivering new services.

section 1: IMPROVING THE CANCER JOURNEY

Launched in February 2014, Improving the Cancer Journey (ICJ) is a multi-agency approach to care which aims to improve the outcomes of people affected by cancer in Glasgow, Scotland, by giving structured individualised support to all eligible local people diagnosed with cancer. It is led by Glasgow City Council and the main partner in investment and support is Macmillan Cancer Support. Other partners currently include NHS Greater Glasgow & Clyde, Glasgow Health and Social Care Partnership (HSCP), Cordia Services, The Wheatley Group, Glasgow Life and The Beatson Charity.

Referral

Since, 2016[5], ICJ has been working in partnership with Public Health Scotland (previously Information Services Division). Due to an established referral protocol with NHS Scotland, Public Health Scotland sends a letter of invitation to all eligible[6] individuals in the local authority of Glasgow City and asks them to contact ICJ for an assessment of need, if they wish. This is one of the unique features of ICJ, that the service is proactive. It does not rely on word of mouth or for individuals to seek it out.

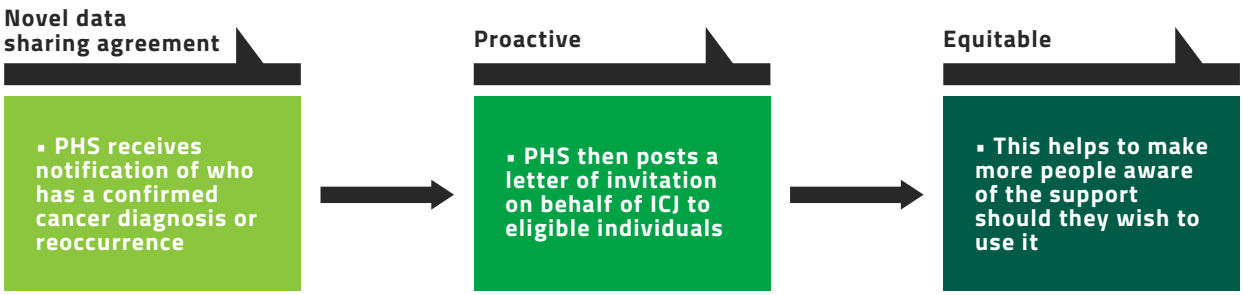


Figure 1: Public Health Scotland (PHS) and ICJ partnership

[5] Part of NHS Scotland (https://www.isdscotland.org/)

[6] Eligibility criteria - over 18, confirmed cancer diagnosis, resident of Glasgow City Council

Referrals to ICJ

Overall, with the exception of 2016 to 2017, referrals to ICJ have increased. From 2018 to 2019 there was a rise of 40%.

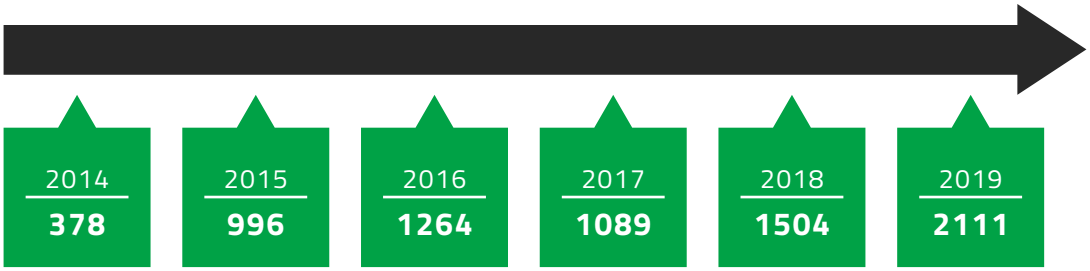


Figure 2: Number of referrals to ICJ

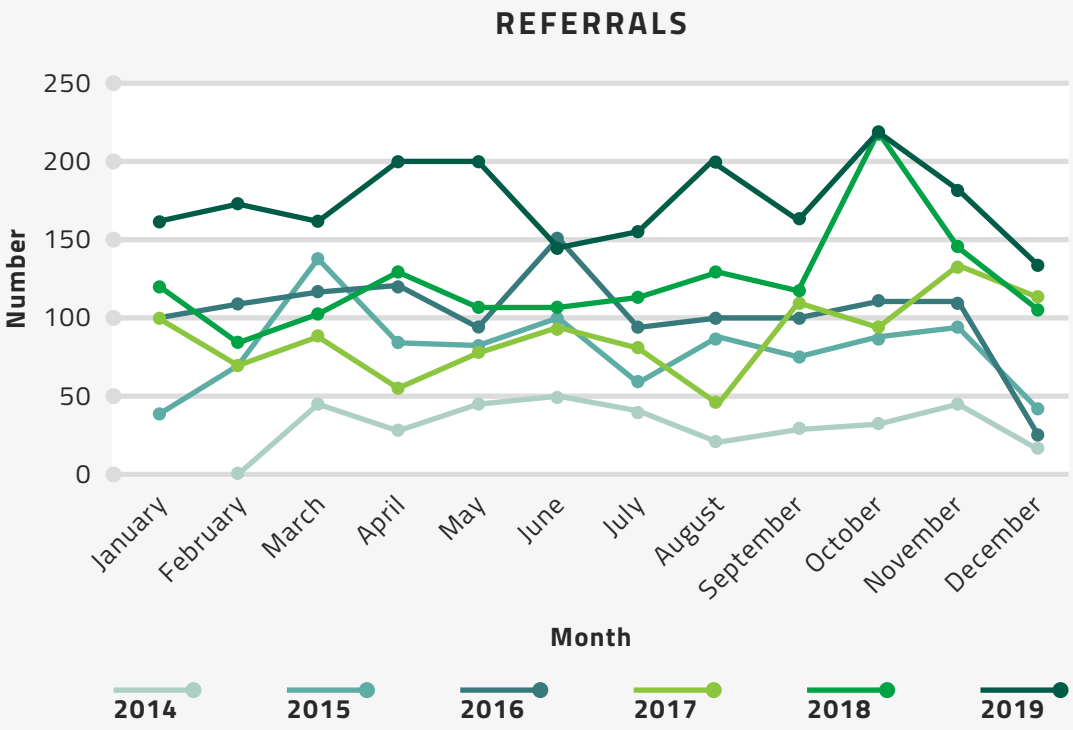


Figure 3: Referrals to ICJ by year/month

Figures 2 and 3 include all sources of referral, such as postal letter, self-referral, referral by health professionals and referral from other organisations.

Changing Patterns of Referral

In 2015, 37% of all referrals to ICJ came from health professionals[8]. By 2019 this had increased to 66%. This trend reflects a growing engagement and buy-in from clinical colleagues, which will be explored in greater detail in Section 4. The consequence of this is that fewer people now need to self-refer or make the first contact themselves. It also acts as a safety net and backup should the letter fail. For example, some people may feel overwhelmed, have unstable housing or may have forgotten to reply to the letter. It is encouraging that there are various routes to support (see Appendix 1 for full list of referral sources).

	2015	2019
Letter	16%	8%
Self/Family member	16%	11%
NHS Professional	37%	66%

Table 1: Different routes into ICJ

Uptake

From 2016[9] to July 2019, PHS sent out 5793 letters of invitation to individuals diagnosed with cancer in the Glasgow city area.

Deprivation in Scotland is classified under the Scottish Index of Multiple Deprivation (SIMD)[10] with SIMD 1 being the most deprived and SIMD 5 the least deprived. There are higher incidences of cancer in areas that are most deprived. Therefore, as expected, more letters are posted to people in SIMD 1 (48%) than SIMD 5 (10%). However, we would also hope and expect to see a greater uptake of referrals in the highly-deprived areas, because people with the greatest need are more likely to live there. Figure 4 shows that this is the case. Even accounting for the high proportion of people with cancer in high deprivation categories, uptake is still higher in those groups.

As represented by the light green bar in Figure 4, 65% of Glasgow residents live in areas classed as SIMD 1 and 2. A similar percentage (66%) of the letters sent by PHS (representing the prevalence of cancer) go to areas SIMD 1 and 2 (dark green bar). However, 76% of the people who receive support from ICJ live in SIMD 1 and 2. This increase is accounted for by a greater uptake in the most deprived group, SIMD 1. ICJ reaches and supports the people who need it the most.

[8] This includes; GP, CNS, district nurses, the 'opt in' lung team, hospice staff and other health professionals located across hospitals in Glasgow.
[9] ICJ and PHS began working in partnership in 2016 which is why the figures begin here and not 2014.
[10] https://www2.gov.scot/Topics/Statistics/SIMD

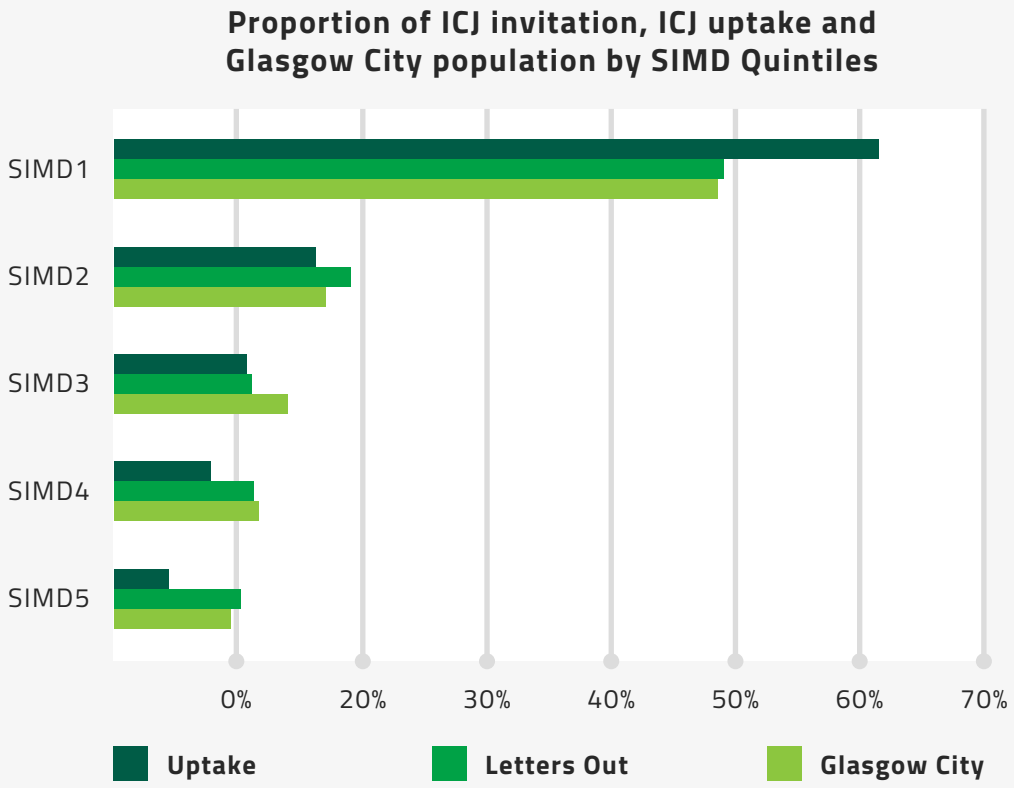


Figure 4: SIMD and uptake of ICJ

Service Delivery

Those who decide they would like support from ICJ are invited to complete a Holistic Needs Assessment (HNA) with a dedicated link officer. As of June 2020, ICJ employs eight link officers. This is another novel attribute of ICJ service delivery as HNAs are usually carried out by health professionals. When link officers first join the service, there is a three-month induction period where each officer becomes familiar with their role and completes a range of training (see Appendix 2 for induction checklist). Four officers have completed or are working towards being accredited with a Level 3 SVQ in healthcare support, to reflect their competencies in this area[11]. Ongoing learning and development was provided by Macmillan every six weeks through action learning sessions for the first year. This is currently supplemented with ad hoc refresher training provided by the service partners and supervision by ICJ management. We will return to the link officer role in more detail in Section 4.

Holistic Needs Assessment

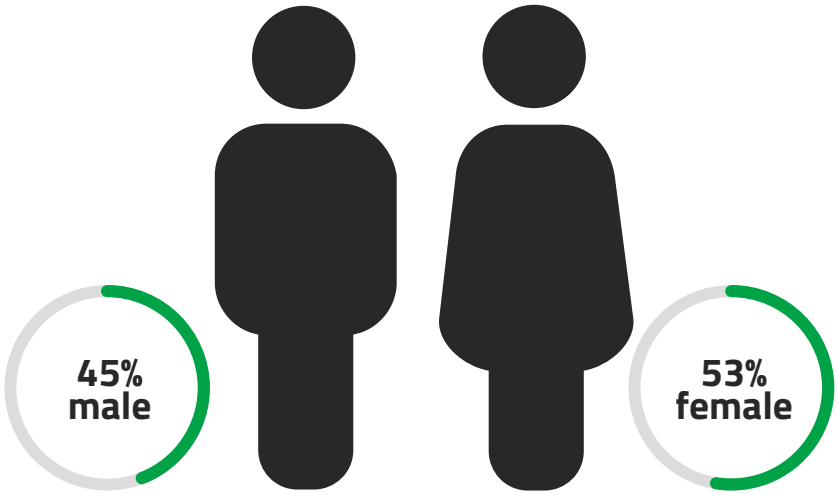
The Holistic Needs Assessment is a care plan that covers physical, emotional, family/relationships, spiritual, lifestyle/information and practical domains such as housing, employment and financial issues (see Appendix 3). The HNA is offered in a community setting, such as a local library, within the hospital (both inpatient and outpatient), in a hospice, or at the individual's home if they prefer, or it is necessary due to health or mobility issues. The assessment is recorded on a tablet and concerns are identified, which are then scored from 1 to 10 reflecting the severity of that concern for the individual. The link officer and the person completing the assessment work together to construct a care plan and ICJ takes action to help support the identified concerns. This may include providing information or referral to another service.

[11] This is academically equivalent to graduate diploma level, or second year of baccalaureate degree.

The link officer then reviews each case. The timing of this review depends on the client's circumstances. At this review (which may be in person or over the telephone), the HNA scores are taken again to identify how that person feels and if the original level of concern has changed. During this conversation the individual may raise more concerns, in which case a new HNA and care plan is triggered. This process continues until the individual and the link officer are satisfied that no further support is required. Finally, individuals are reassured that they should contact ICJ if they require any further support. We will return to the HNA process in more detail in Section 3.

Who uses ICJ?

From February 2014 to June 2020 7,587 people have used ICJ. Here is their profile[12]:



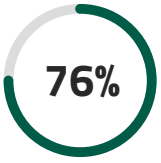
30% of ICJ users have lung cancer and 13% have breast cancer

44% retired
7% unemployed
14% not in education/ employment due long-term illness/ disability

Were receiving palliative care

Most have at least one co-morbidity

Majotiry aged from 50-64



Are in SIMD 1 and 2

Identify as White British

Live Alone

of ICJ users were receiving tratment at their first HNA

Figure 5: Profile of ICJ users

[12] Where the data was recorded. For example, certain demographic details such as sex and employment status are not always recorded.

Comorbidities

More than 45%[13] of ICJ clients reported at least one co-morbidity. Generally, people have comorbidities due to increased life expectancy and longer exposure to risk factors over time, particularly smoking, obesity, alcohol and physical inactivity, due to challenging personal, occupational and societal factors through the course of their lives, including persistent and widening inequalities.[14] The latter is particularly relevant to ICJ clients due to the high numbers who reside in SIMD 1 and 2.

As identified in Table 2, the most common conditions for people who use ICJ include mental health problems, COPD and difficulties with function and mobility. It is likely that these individuals will particularly benefit from ICJ's system-wide approach, which coordinates care and support across organisations and sectors.

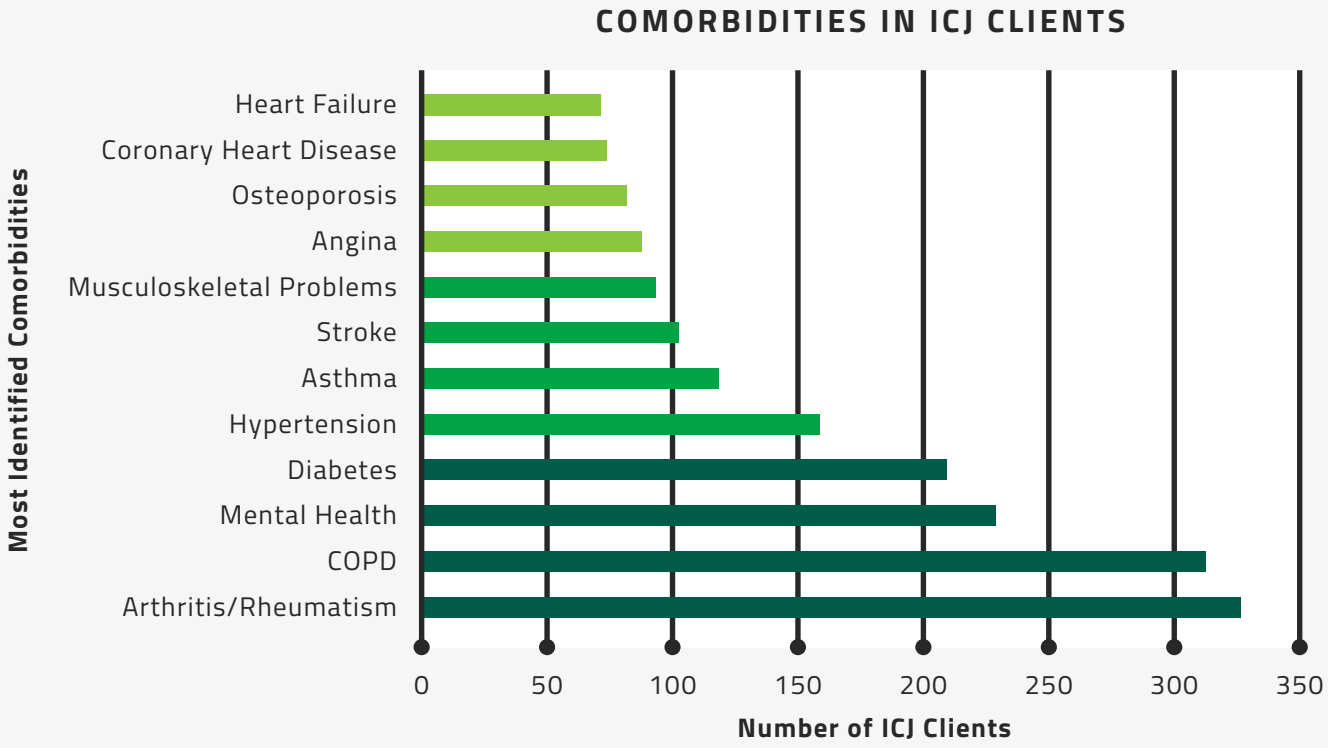


Figure 6: Comorbidities in ICJ Clients

[13] This corresponds to 1749 individuals from 2015- Jan 2020. Data from 2014 was not available.

[14] Department of Health: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/307143/Comorbidities_framework.pdf

WHAT DO PEOPLE NEED SUPPORT WITH?

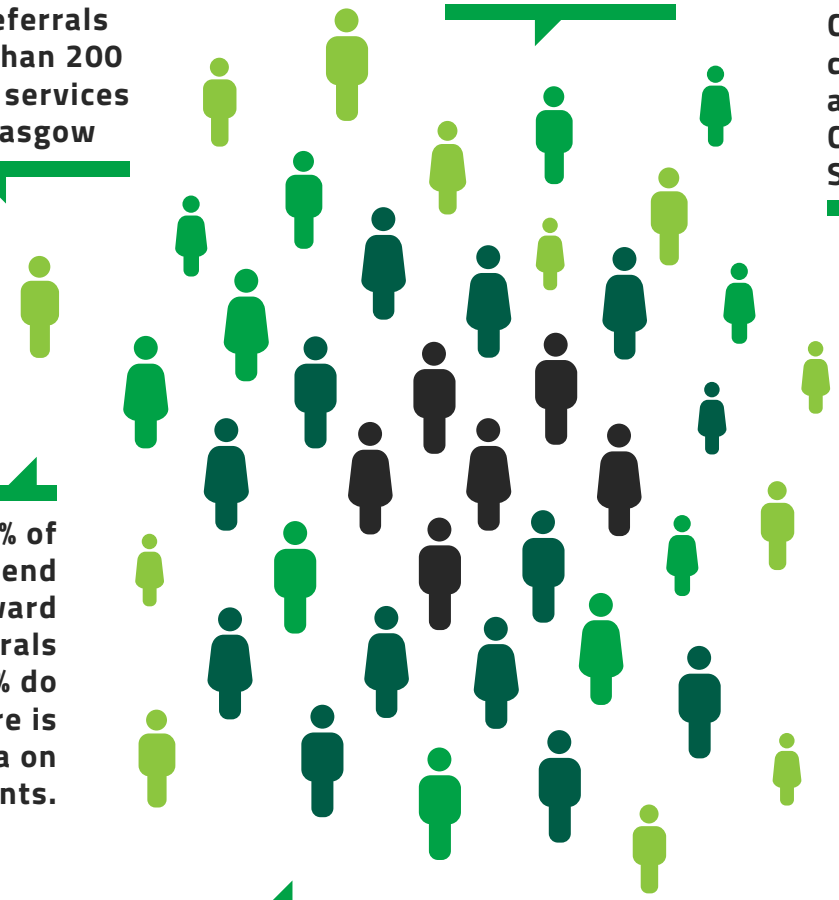
- On average, people identify six concerns during their HNA
- Those which people rate as most concerning (seven or over) are family, work/education and worry/fear/anxiety
- The most common concerns are money/housing, fatigue, mobility, breathing difficulties and worry/fear/anxiety
- On average, people receive support from ICJ for just under six months. This can include support for individuals and their families, and carrying out multiple HNAs

Where do people go for support?

ICJ has made 23,025 referrals to more than 200 different services across Glasgow

On average, four referrals are made per HNA

The most common agencies referred to are Macmillan, Glasgow City Council and other charities such as Maggie's and Cancer Support Scotland



Other common sources of support include self-manegement booklets, referral to Department Work and Pensions (DWP) and the Long Term Conditions service

Overall, 56% of clients attend their onward referrals and 17% do not. There is missing data on 25% of clients.

When people attend a service they were satisfied with the support, rating it on average 8 out of 10 (with 10 being the highest) for satisfaction

Some of the more unsual support put in place by the ICJ team includes arranging a wedding, finding care for pets, sourcing volunteer gardeners and arranging a nursery placement.

The majority of support that is taken up is community-based. 10% of referrals come back to a Cancer Nurse Specialist.

Figure 7: ICJ Referrals

Macmillan Cancer Support provides emotional, financial and physical support in person, online and over the telephone. There are also Macmillan information stands in every library in Glasgow.

Cancer Support Scotland and Maggie's Centre provide a range of emotional, social and practical support, including counselling, complementary therapies, exercise classes, nutritional advice and access to psychologists and benefits advisors.

Glasgow City Council's Long Term Conditions service provides support with debt, state benefit payments and housing issues.

section 1 SUMMARY

- **ICJ is reaching people with complex lives, as evidenced by the high proportion of people who are in SIMD 1 or 2, have money and housing concerns and have comorbidities.**

- **Through the HNA process, personalised care and support is put into place and actions are taken to ensure outcomes are delivered.**

- **By utilising the range of community assets within the city, ICJ improves outcomes for people affected by cancer. This report will detail how.**

TIMELINE OF ICJ DEVELOPMENT

2014

- ICJ is launched

2015

- ICJ link officers co-located in outpatient lung clinic
- ICJ wins Herald Partnership Award

2016

- ICJ wins Glasgow City Council Flourish Award and Macmillan Cancer Support Integration Excellence Award
- ICJ wins MJ award for Delivering Better Outcomes
- ICJ recognised as a model of best practice in the Scottish Government Cancer Plan

2017

- ICJ wins CoSLA award for Achieving Better Outcomes in Partnership
- Link officers support clients across the city including in hospitals, hospices and the workplace

2018

- ICJ works in partnership with the Acute and Prescribing Pharmacists in the city to support lung cancer patients with medicine reviews
- ICJ wins The Integrated Foundation of Integrated Care (IFIC) Awards for a Collaborative Model of Integrated Care in a Community Setting

2019

- Glasgow Royal Infirmary hub established. ICJ working with Macmillan Bereavement, NHS Support & Information & NHS Homeless Liaison to deliver support services to a vulnerable and complex clientele
- Working in partnership with the HSCP training delivered to ICJ on Anticipatory Care Plans (ACPs). ICJ will introduce ACP with the person affected by cancer at HNA meeting
- ICJ in collaboration with Scottish Partnership for Transport agreed a bespoke process for clients at end of life.
- ICJ Housing officer now situated within the Beatson to identify housing issues on admission, not discharge
- Scottish Government and Macmillan Cancer pledge £18 million to support 'Transforming Cancer Care'

2020

- Phase 1 volunteer drivers recruited to enable more people to get to their HNA appointments, reducing isolation and increasing ICJ capacity. Phase 2 will help people get to their referrals
- ICJ model now live in Dundee, Fife, Dunbartonshire & Renfrewshire with Edinburgh and the Lothians due to go live late 2020

section 2: HOW WE EVALUATED ICJ

The main aim of this evaluation is to answer the question, how does ICJ improve outcomes for people affected by cancer?'

This question is broken down to concentrate on three distinct but interrelated levels:

- ***The individual level*** – people affected by cancer.
- ***The service level*** – including the link officers and relevant stakeholders.
- ***The wider cultural level*** – including policy and organisational strategy.

One of the significant factors of a five-year evaluation is that the context – and therefore the aims and objectives – evolve over time. However, we also had to ensure that we met our original aims as agreed in 2015. Therefore, a mapping exercise was carried out to ensure the aims of the original evaluation tender, the Macmillan Logic Model, ICJ service aims and our previous evaluation reports[15] were explicitly included. The diagram below summarises the key elements that form the structure of the report:

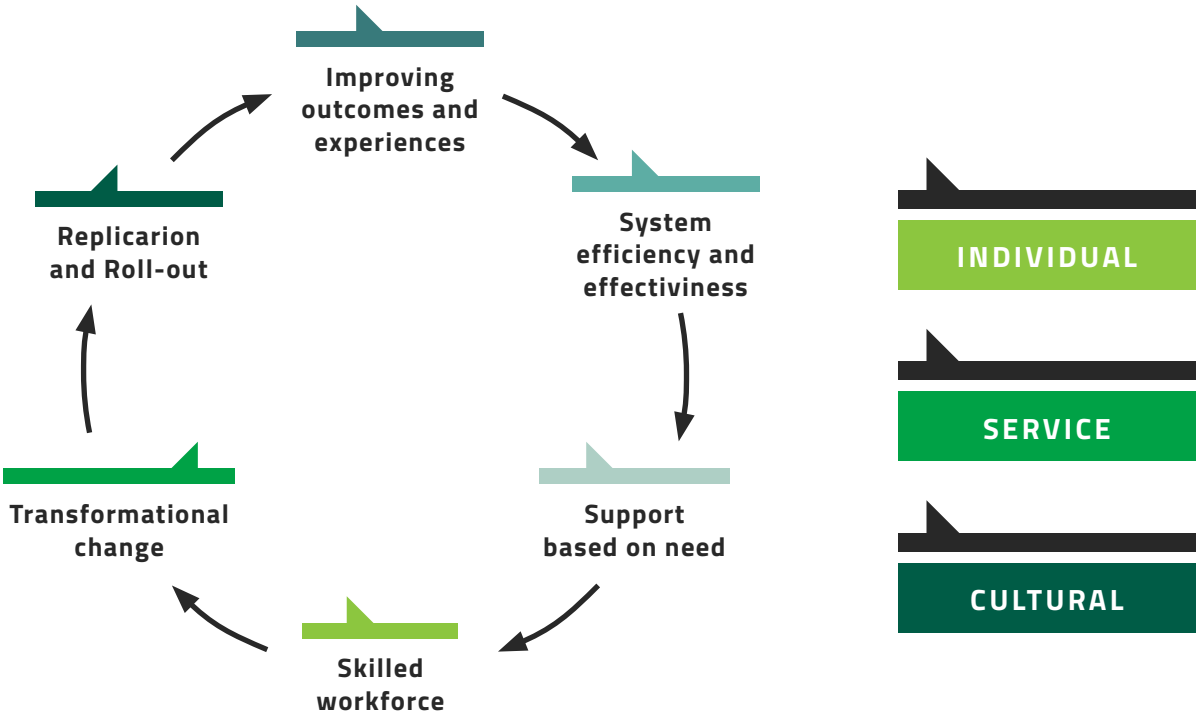


Figure 8: Report structure

[15] 2018 and 2016 reports on The Macmillan Cancer website: https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html#283506

Guiding Framework

These themes were chosen as they encapsulate how and why ICJ has had a considerable impact across these three levels – such that ICJ is now part of national policy and the ICJ model is being implemented across Scotland[16] through the Transforming Cancer Care programme. While Sections 3 and 4 detail new evidence to support these claims, the final two sections draw everything together to look forward and reflect on how this learning may be used in other settings.

Method

This evaluation uses a longitudinal mixed method design. This means there are two broad methods used to capture these outcomes relating to the programme over time. Quantitative methods seek to understand behaviour through descriptive interpretation and statistics. Qualitative methods such as interviews facilitate an in-depth understanding into experiences and behaviours. For a detailed description of all methods used throughout this evaluation, please refer to our published protocol[17] and see Appendix 4. Table 2 shows a summary of all methods used during this reporting cycle (2018-2020).

GUIDING FRAMEWORK		MEASURE	RATIONALE
INDIVIDUAL	Improving outcomes and experiences	ICJ Routine data	Description of ICJ/HNA process and outcomes
		EQ-5D (Health Status)	To evidence any changes in quality of life following intervention from ICJ
		Semi-structured interviews with ICJ users	To understand more about the process of identifying concerns and receiving support
SERVICE	System efficiency and effectiveness	Semi-structured interviews with cancer professionals	To analyse the impact of ICJ on clinical practice
		Clinician questionnaire	To investigate the impact of ICJ on clinical practice in a larger and more diverse sample
	Support based on need	ICJ routine data	Analysis of financial and housing data
	Skilled workforce	Link officer diaries	To understand the role in more detail including successes, challenges and training needs
CULTURE	Transformational change/Replication and roll-out	Document analysis	To detail the impact of ICJ on policy and alignment to other organisational strategies
		Semi-structured interviews with stakeholders from the partner organisations	To explore key successes from the stakeholder perspective

Table 2: Evaluation methods used in this reporting cycle

[16] https://news.gov.scot/news/gbp-18-million-funding-for-cancer-support-workers-1

[17] Protocol for a mixed-methods longitudinal enquiry into the impact of a community based supportive service for people affected by cancer: https://bmccancer.biomedcentral.com/articles/10.1186/s12885-016-2757-4

section 3: THE INDIVIDUAL LEVEL

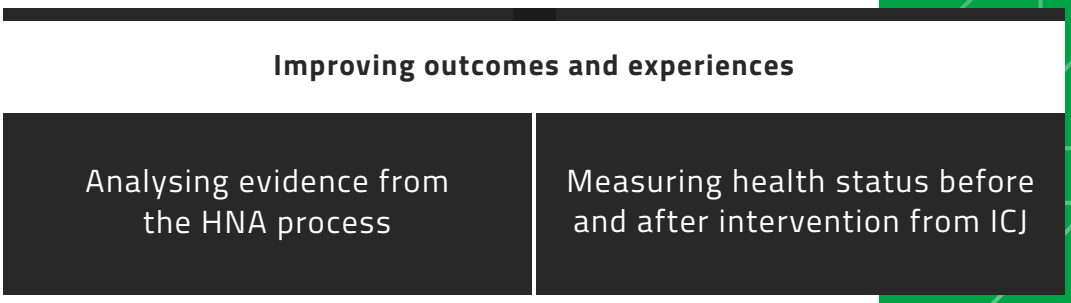


Figure 9: Section 3 evidence overview

ANALYSING EVIDENCE FROM THE HNA PROCESS

Holistic Needs Assessment is a discussion in which the ICJ link officer can tailor information, care and support based on need. Traditionally HNAs are carried out in a health setting by a health professional, which makes ICJ's approach novel. By analysing data relating to the HNA process we can report on:

- The type of concerns raised by ICJ clients.
- If different groups of people report different concerns.
- The severity of people's concerns and any changes over time.
- How actions by HNA assessors, such as referral and signposting, can lead to improved outcomes.

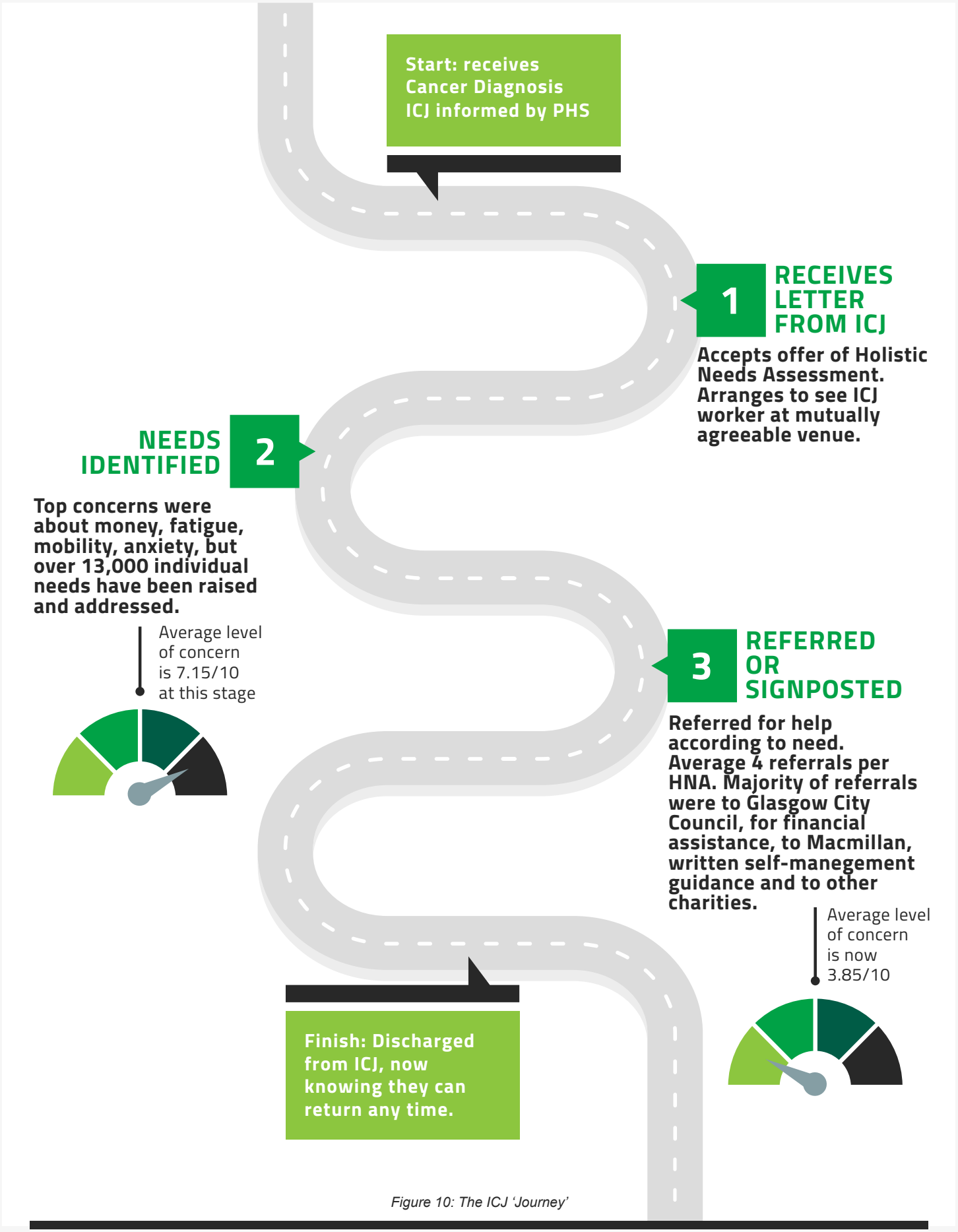


Figure 10: The ICJ 'Journey'

ICJ HNA Process

WHO	WHERE	CLINICAL CIRCUMSTANCES	CONCERNS	WHAT HAPPENS
Since 2014 to June 2020 6130[18] HNAs have been carried out.	Overall: Clinical setting 55% Home 22% Telephone 15% Other (7%) (Library, workplace or not recorded)	30% clients are receiving treatment 20% receiving palliative care 14% living with condition 11% recently diagnosed 5% completed treatment 4% undergoing tests	Most reported concerns: 1.Money/housing 2.Worry/fear/anxiety 3.Tired/exhausted/fatigued 4.Getting around 5.Breathing difficulties Average severity of concern across all areas is 7.1 (out of 10)	87% of clients are referred/signposted to another service for support or provided with written information. Overall, 56% of clients attend their onward referrals and 18% do not attend. There is missing data on 25% of clients. Average severity of concern by review is 3.8 (out of 10)

Table 3.1: HNA process and outcomes

Who, Where, When: Understanding the Process

In 2014, when ICJ was first launched, 85% of the first appointments were done in the home. However, in order to make the service more sustainable, to accommodate growing numbers and to enable the link officers to work more closely with their clinical colleagues, more people have opted to meet the link officer in a hospital environment. In 2019, 55% of people met with ICJ at a hospital or hospice setting. Link officers upload the HNA and care plan onto the clinical portal to share with the clinical team. Subsequently, in 2019 only 23% of visits were conducted in the home. If this shift had not occurred, ICJ would not have been able to meet the demand for its service or build connections with clinical colleagues.

Of note is that the setting does not have an effect on the types of concerns raised. This is understandable as the assessor (the link officer) remains the same. Clinical guidelines[19] state that an HNA can be effectively led by a number of professions, including nurses, allied health professionals, social workers, generalists (such as link workers) and doctors.

The fact that the link officer is not clinically trained is a unique feature of the ICJ model of support. ICJ clients have identified that their non-clinical expertise is valued:

[18] Not everyone who decides to access support from ICJ has an HNA. Reasons can include not qualifying for a home visit as they reside out of Glasgow (but client can be offered telephone support and/or support in their area), the client has passed away, or it is not the right time for the client, if they are too unwell, for example.

[19] Department of Health (2010). The National Cancer Survivorship Initiative National Cancer Survivorship Initiative. London: The National Cancer Survivorship Initiative Vision.

'There is no scope in my treatment to engage with the medical professionals about things like my job and my family. That's maybe a good thing as they have their role. They're very pleasant but you're there and you can sense that there's people waiting. It's not the right format for that kind of thing. But they [ICJ] came out to see me and I was able to go into areas that previously I had felt awkward about'

(ICJ client, female).

Most people access support from ICJ when they are completing their treatment. Therefore, it is likely that their needs and concerns will change over time. For example, the post-treatment time can bring new concerns about side effects or emotional concerns relating to fear of reoccurrence[20]. For that reason, ICJ link officers continue to carry out new HNAs with their clients until they are satisfied that no further support is required. Individuals are reminded that they can contact ICJ again should they require any further assistance or support. A total of 14% of clients go on to have two or more HNAs as they have new concerns or support needs. This is a significant part of why ICJ is perceived as being beneficial, providing reassurance which helps people to manage uncertainty.

'I'm going for major surgery soon, but it's OK, I've got the help there if I need it. If anything crops up I can pick up the phone'

(ICJ Client, male).

[20] There is a great deal of literature written on this. For example: Ng, Z. X., et al., (2017). Breast cancer: exploring the facts and holistic needs during and beyond treatment. In Healthcare (Vol. 5, No. 2, p. 26).

Different Concerns for Different people

Characteristics and circumstances such as age, sex, cancer type and socioeconomic status can affect what people are concerned about. Therefore, we explored what the common concerns were for different groups of people and have highlighted some key differences in the table below:

	CHARACTERISTIC	CONCERNS
AGE	**Under 50**	Money/housing, worry, fatigue, **sleep problems, children**
	Over 50	Money/housing, fatigue, worry, **getting around, breathing difficulties**
SEX	**Male**	18% of men identify 'worry/fear/anxiety' as a concern
		Men rate 'work/education' as a high concern (7 out of 10)
	Female	27% of women identify 'worry/fear/anxiety' as a concern.
		Women rate 'contact/communication with healthcare staff' as a high level of concern (7 out 10)
	Both	Males and females are just as likely to identify 'money/housing' as a concern (62% of males and females)
SIMD	**SIMD1 top concerns**	**Money/housing,** worry/fear/anxiety, tiredness/fatigue, getting around, breathing
	SIMD5 top concerns	**Money/housing,** tiredness/fatigue, getting around, worry/fear/anxiety, transport/parking
CANCER STAGE	**Recently diagnosed**	**Money/housing,** getting around, transport/parking, breathing, tiredness/fatigue
	Receiving palliative care	**Money/housing,** worry/fear/anxiety, transport/parking, getting around, tiredness/fatigue

Table 3.2: Types of concerns for different groups of ICJ clients

RECOMMENDATION FOR SERVICE PROVIDERS

▪To be aware that financial concerns are a widespread issue irrespective of socioeconomic background and clinical circumstances.

▪Gender and age seem to affect the types of concerns raised. Future services may wish to consider gender/age related needs and preferences during evaluation.

What happens next?

Here is a summary of the supportive actions for the top five concerns of ICJ users.

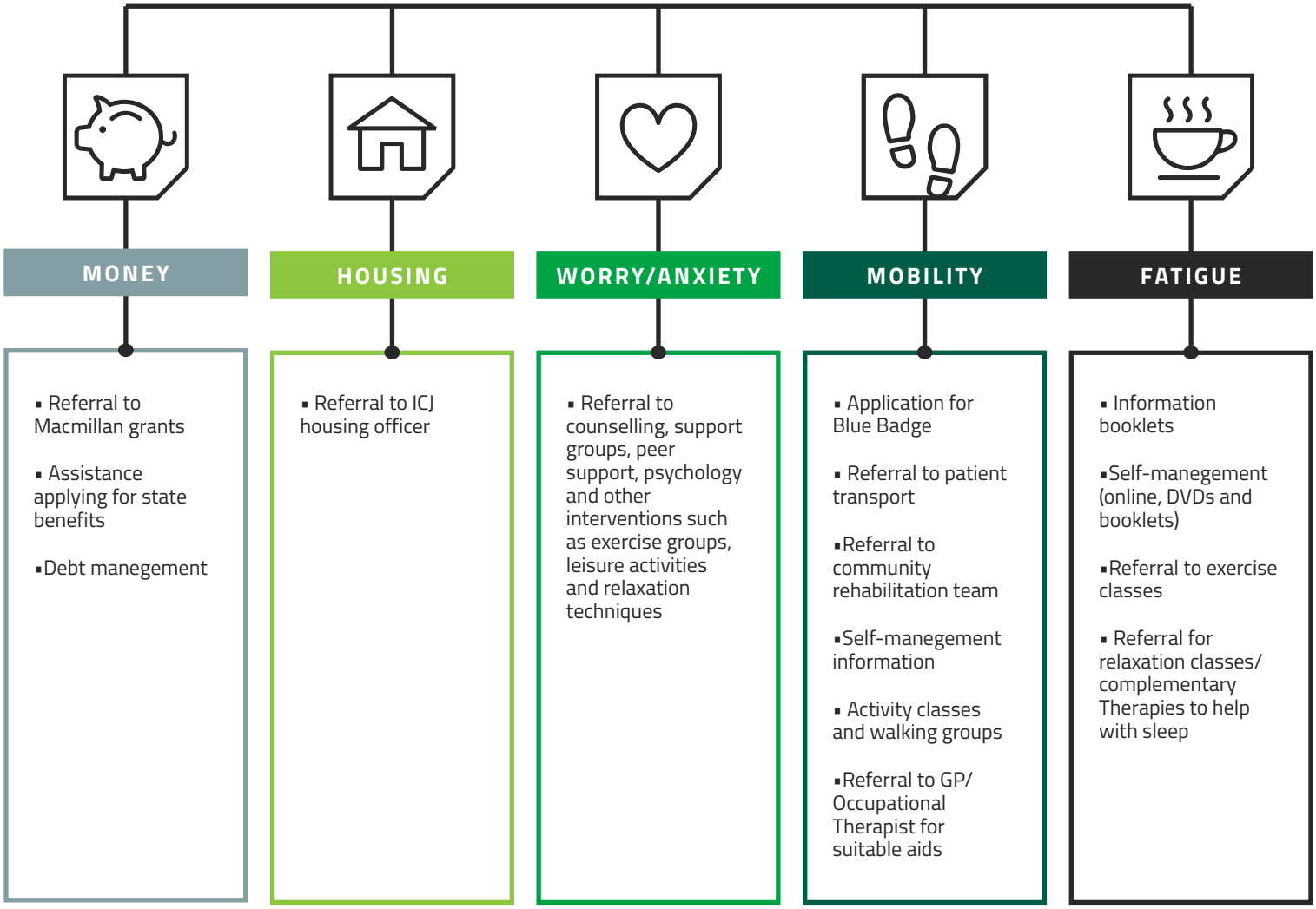


Table 4: Concerns and actions

ICJ link officers refer clients to a range of specialist and community-based support. Through discussion around what matters most to that individual, each HNA usually generates a combination of written support (such as self-management information booklets), actions that are led by the link officers (such as completing welfare benefits forms) and referral to organisations such as Maggie's and Cancer Support Scotland.

Where there was data available, 56% of people took up the referral. This is important – wider evidence on the implementation and impact of the HNA suggests that service uptake is key for the best outcomes. This moves the focus from the HNA as a means to an end to a focus on the impact of care after the assessment[21]. However, this data was not recorded for 25% of ICJ users, so we do not have a completely accurate picture of service uptake.

RECOMMENDATION FOR SERVICE PROVIDERS

▪We recommend that ICJ and future services collect data on the connection between HNA, service uptake and outcomes.

From the data available, 18% of people chose not to attend their referral. There will, of course, be different reasons for this, but ICJ's review process found that some people could not afford to travel to services or found it difficult logistically. Therefore, in August 2019, ICJ hired four volunteer drivers to enable clients to attend HNA appointments and organisations for support. Early anecdotal evidence suggests that clients value the opportunity to leave their home and engage with other people who are experiencing similar problems.

[21] Johnston L, Young, J & Campbell (2019) The implementation and impact of Holistic Needs Assessment for people affected by cancer: A systematic review and thematic synthesis of the literature. European Journal of Cancer Care

Improving Outcomes

Clients are asked to rate the severity of their concerns from 0 (no concern) to 10 (high concern) when they complete the HNA. When link officers review their cases, they ask clients to rate their concerns again, to understand if the support has been effective.

We analysed a selection of HNAs and found that overall mean severity of concern for 1142 ICJ clients is substantially reduced from 7.1 (out of 10) to 3.8 when the same person has two HNAs completed over time (average five months apart). This is a statistically significant drop[22], which means that it did not occur due to chance alone and is likely to be related to the support provided by ICJ. Previous research[23] on distress screening (using tools similar to the HNA concerns checklist used here) has found that identifying concerns or problems and getting support for them is associated with positive outcomes such as being better able to cope, lower levels of anxiety and depression, improved communication between the patient and the assessor, and feeling more confident and in control. ICJ clients reported similar outcomes.

'When they asked me again, my concerns were right down. I was much less stressed and worried as I had support with my finances and somewhere I could ask questions' (ICJ Client, male).

To understand this in greater detail we looked at how reducing someone's concerns may have an effect on their quality of life.

Measuring Health Status

To capture any improvements in quality of life in ICJ clients, we used a short questionnaire called the EQ-5D-3L measure[24]. It has two components. First, it measures health status across five dimensions – mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The respondent is asked to indicate if they have 'no problems', 'some problems' or 'extreme problems' on each of these. Scores range from 0 to 1, with a higher value representing a better quality of life.

The second part of the questionnaire asks the respondent to rate their overall health, from 0-100 on a visual analogue scale (VAS). Zero indicates the worst imaginable state of health and 100 is the best imaginable. This measure was chosen because it is used widely across the world – it is easy for individuals to use and has been validated in samples of people with cancer.

In 2018/19, a sample of 437 ICJ clients completed the EQ-5D during their initial visit with the ICJ link officer and again at their follow-up review. As reviews usually happen over the telephone, the link officer, through conversation, completed it for the individual on their behalf. The time between assessments ranged from 14 to 456 days, with an average of 117 days.

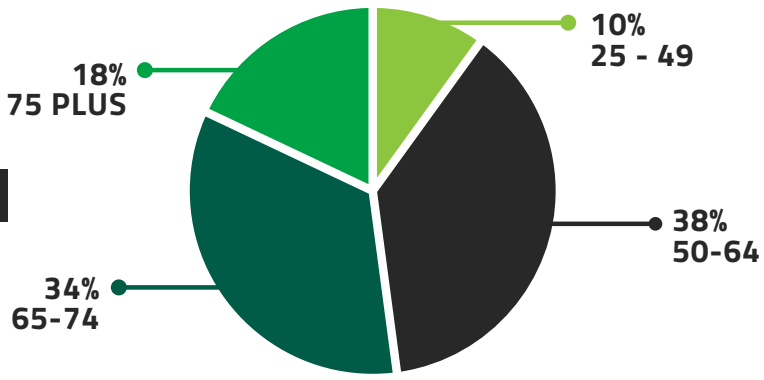
[22] Paired t(4454) = 64.68, P < 0.0001, a significant reduction of 3.31 (95% CI 3.21□3.41).

[23] Ehlers, S. L. et al. (2019). Screening for psychosocial distress among patients with cancer: implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship. Translational behavioral medicine, 9 (2), pp 282-291.

[24] To watch a short video that explains EQ-5D go to: https://vimeo.com/366207839

RESULTS

AGE



SEX

CANCER TYPE

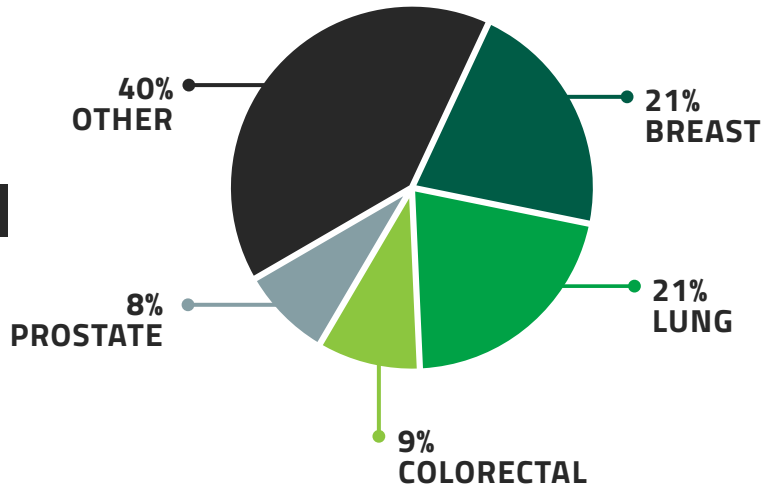


Figure 11: Participant characteristics

EQ-5D scores

	EQ-5D (0-1)	CHANGE IN SCORE	VAS (0-100)	CHANGE IN SCORE
TIME 1 BASELINE	0.45		49	
TIME 2 FOLLOW-UP	0.57	0.12	56	7

Increase in scores on both components of EQ-5D

It was a statistically significant increase which means it did not go up due to chance alone.

Table 5: EQ-5D scores

'I actually didn't realise I was as stressed about it as I was. I thought I was handling it quite well. And then when I actually had to put into words how I felt, and how I was dealing with it, I realised that I wasn't dealing with it well. I was frightened to speak too much about things for fear of upsetting my husband too much. So having an outlet by speaking to the ICJ people was great' (ICJ Client, female).

Between Time 1 and Time 2, which corresponds with the first HNA and then the review, there was an increase in EQ-5D scores indicating an improvement[25] in overall health status.

An increase of 0.12 is enough to be classed as a 'meaningful difference[26]' to cancer patients, something that has a positive and beneficial impact on the individual. Beyond the figures, we can consider what a meaningful difference is when we ask users, in their own words, to describe how ICJ has helped them.

'One of the things I hated was worrying about things. If someone can take some of those worries away then it makes such a difference to me. These kinds of things then help me physically, if you know what I mean, because I can concentrate on getting better which is all I wanted to do in my head anyway'

(ICJ Client, male).

EQ-5D Scores by Cancer Type

CANCER TYPE (n=number of people in sample)	EQ-5D SCORE TIME 1	EQ-5D SCORE TIME 2	DIFFERENCE
LUNG (n=99)	0.41	0.49	0.08
BREAST (n=90)	0.46	0.57	0.11
PROSTATE (n=40)	0.53	0.64	0.11
COLORECTAL (n=34)	0.43	0.55	0.12

Table 6: EQ-5D scores by cancer type

The range of EQ-5D scores amongst the different types of cancer shows how it affects people in different ways. Therefore, the clinical context must also be taken into account when interpreting quality of life. For example, in general, breast cancer patients go on to report a higher level of health status than lung cancer patients, which will be related to prognosis, symptoms and treatment side effects[27].

To put this into wider context, it has been estimated that the mean EQ-5D score for individuals with no medical problems is 0.85[28]. This difference highlights the burden associated with cancer for individuals accessing ICJ, at a point where they have considerable problems with their physical and emotional health. Therefore, the support and reassurance provided by ICJ is vital.

[25] ($t(330)=7.48$, $p<.001$) as was the increase in VAS of 7.81 ($t(330)=7.96$, $p<.001$)

[26] Coretti S, et al. (2014) The minimum clinically important difference for EQ-5D index: A critical review. Expert Review of Pharmacoeconomics and Outcomes Research.

[27] Pickard, A. S. et al. (2016). Using patient-reported outcomes to compare relative burden of cancer: EQ-5D and functional assessment of cancer therapy-general in 11 types of cancer. Clinical Therapeutics, 38 (4), pp 769-777.

[28] Szende et al (2014). Self-reported population health: An international perspective based on EQ-5D.search.

Focusing on the Different Domains

The EQ-5D measure assesses health status across five different domains. Focusing on how people scored their health across these domains reveals the factors that may cause the most or least difficulty to people and how these factors affect their overall quality of life.

On every domain, the number of people who had 'no problems' after support from ICJ rose at Time 2[29].

		NO PROBLEMS	SOME PROBLEMS	EXTREME PROBLEMS
ANXIETY/ DEPRESSION	TIME 1	22%	58%	19%
	TIME 2	36%	58%	5%
MOBILITY	TIME 1	22%	74%	3%
	TIME 2	26%	71%	2%
PAIN/ DISCOMFORT	TIME 1	24%	62%	12%
	TIME 2	28%	64%	6%
SELF-CARE	TIME 1	44%	52%	2%
	TIME 2	53%	42%	4%
USUAL ACTIVITIES	TIME 1	9%	74%	16%
	TIME 2	15%	70%	13%

Table 7: Percentage of people reporting problems/no problems across the different EQ-5D domains

[29] Percentages do not always add up to 100 due to rounding

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

MOBILITY
- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

SELF-CARE
- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

PAIN/DISCOMFORT
- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

ANXIETY/DEPRESSION
- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

On every domain at Time1 most people have problems

By Time2, the percentage of people reporting problems decreases

90% of the respondents had problems with usual activities at Time1

Anxiety/ depression had the biggest increase in 'no problems' between Time1 and Time2 (22% to 36%)

The fact that people report fewer problems across every domain shows that how they rate their overall health status improves between Time 1 and Time 2. The biggest fall was in the number of people who went from being 'moderately' or 'extremely' anxious or depressed at Time 1 to not being anxious or depressed at Time 2. Therefore, intervention from ICJ is having the biggest impact on this domain.

Despite these encouraging findings, a high proportion of people at Time 2 still report problems. In particular, 83% of the respondents still have problems with 'usual activities'. However, this is to be expected – despite reporting benefits in other areas, such as feeling less concerned with financial worries, factors such as prognosis, cancer type and stage will all have an impact on how people rate their health status.

Why is there an Improvement?

Between the two EQ-5D measures taken, individuals received support from ICJ, with discussion of needs and concerns and joint construction of a care plan with a link officer, who acted upon various routes to information and support.

It is reasonable to infer that engagement with ICJ contributed to the overall improvement in health in this sample. To explore this further we investigated if the mean HNA severity of concern was associated with the EQ-5D score.

EQ-5D AND HNA

HNA data and EQ-5D data was obtained and analysed for 332 individuals. Following intervention from ICJ, the mean HNA concern severity fell from 6.4 to 2.9. At the same time, the EQ-5D score rose from 0.45 to 0.57. Therefore, a reduction in overall HNA concern severity was associated with an overall improved health status in this sample of participants[30]. While we acknowledge that other factors may contribute to the improvement, such as completing treatment, that individuals can be helped in a statistical and personally meaningful way is a marker of success.

RECOMMENDATION FOR SERVICE PROVIDERS

- **New services may wish to consider embedding outcome measures into routine practice to help them to evidence and understand service impact.**

[30] Snowden, A Young, J & Savinc, J (2020) Meeting psychosocial needs to improve health. BMC Cancer, 20, pp 1-10. Open access: https://link.springer.com/content/pdf/10.1186/s12885-020-07022-w.pdf

section 3 SUMMARY

- **HNA is an established, effective and person-centred way of identifying and supporting individual concerns.**

- **The results provide robust evidence on the impact that holistic support can have on health outcomes.**

- **This sample had complex needs and most people lived in areas of high deprivation, with a poor cancer prognosis and with baseline levels of health status that were considerably lower than other cancer populations. This emphasises the importance of looking at the association between sociodemographic and clinical variables to understand the effect of supportive interventions.**

section 4: THE SERVICE LEVEL

System efficiency & effectiveness	Support based on need	Skilled workforce
Co-locating ICJ into the clinical setting	Focus on housing and finance	Link officer diary analysis

Figure 12: Section 4 evidence overview

At a time when the cancer workforce is facing increased demand, there is an urgent need to rethink how resources can be used efficiently without having a negative impact on patient care. Integrating health and social care is currently seen as the best way to deliver safe, effective, person-centred cancer care.

SYSTEM EFFICIENCY AND EFFECTIVENESS

Co-locating ICJ into the Clinical Setting

In 2016, ICJ link officers were placed at two lung outpatient clinics in hospitals in Glasgow. By 2019, people in Glasgow affected by cancer could get support from ICJ within a range of inpatient and outpatient hospital settings across the city and in the Prince and Princess of Wales hospice. In practical terms this meant that health professionals (nurses and doctors) worked alongside link officers for the first time. It was not known how this development would impact upon clinicians' working practices and the patient experience.

Data Collection

From June to September 2018, ten clinicians were asked for their views on ICJ[31]. Most (n=6) of the clinicians were from the lung team and the remainder were from breast, gastro-intestinal and head and neck specialisms. Eight were Cancer Nurse Specialists and two were medical oncologists. A semi-structured interview schedule was used to explore their motivations for working with the service, what difference (if any) it had made to their practice and what benefit the collaboration may have for patients. Interviews were audio recorded and then transcribed .

In September 2019, a survey based on the findings from these interviews was developed and distributed by email to 85 professionals who work in relevant hospitals within Glasgow and the Prince and Princess of Wales hospice. A total of 55 completed it, a 62% return rate.

Of the 55 participants, 34 said there was a link officer physically located in their workplace. The remaining professionals referred their patients to ICJ. The following section merges the findings from the interviews and the questionnaire to show the transformative impact that ICJ has had on clinical practice.

Sample

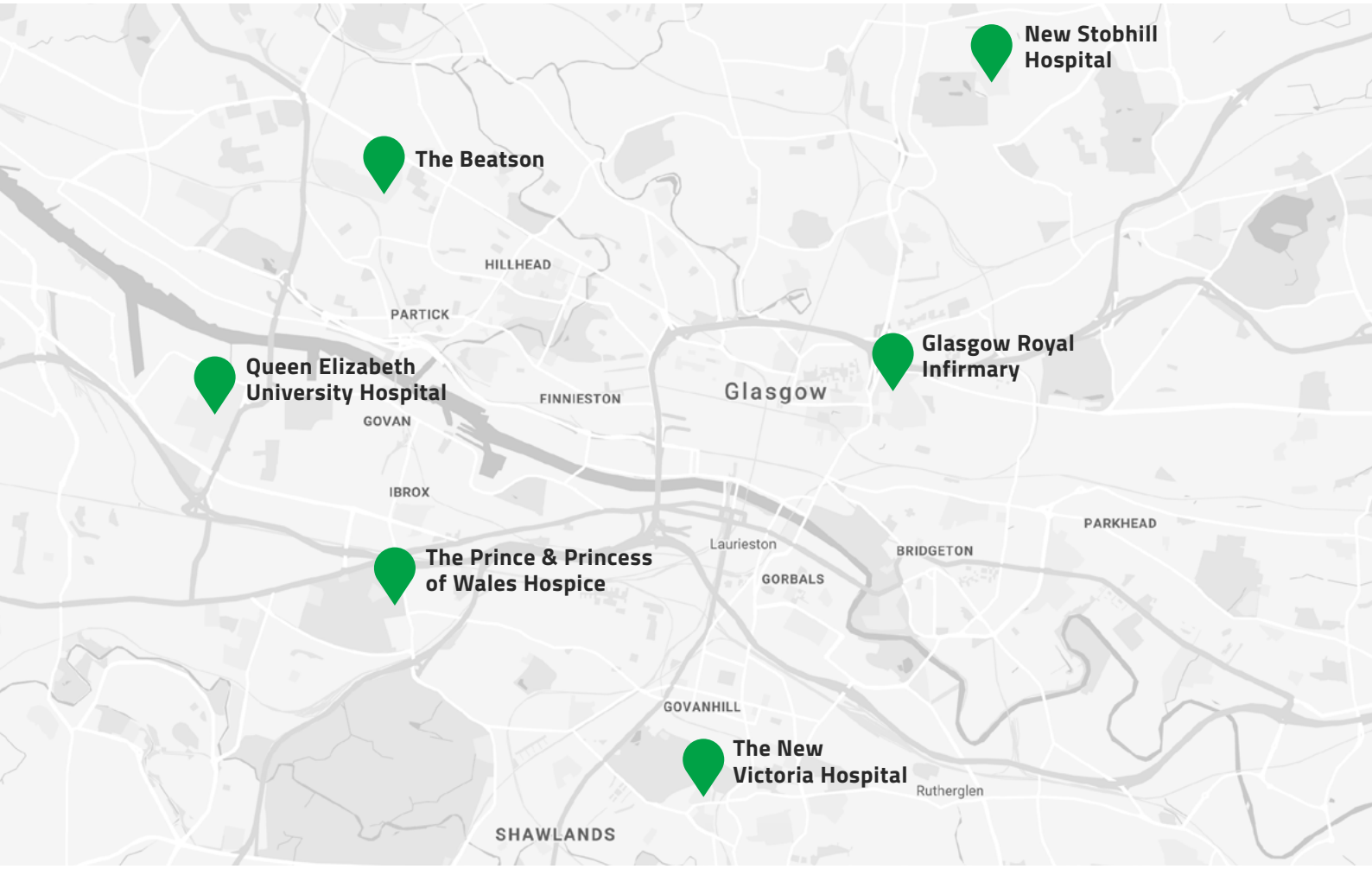
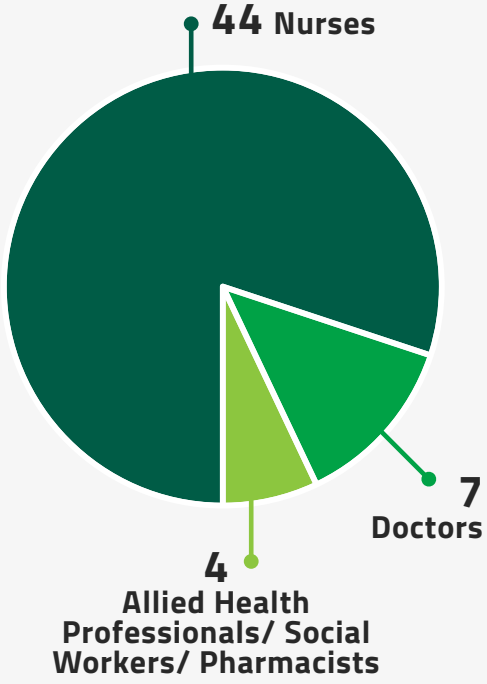


Figure 13: Clinical locations

[31] For further detail see: Young, J., & Snowden, A. (2020). AJ curve of interprofessional change: co-locating non-health partners in an oncology unit. British Journal of Nursing, 29(3), S10-S16.

PROFESSION



CANCER SPECIALISM

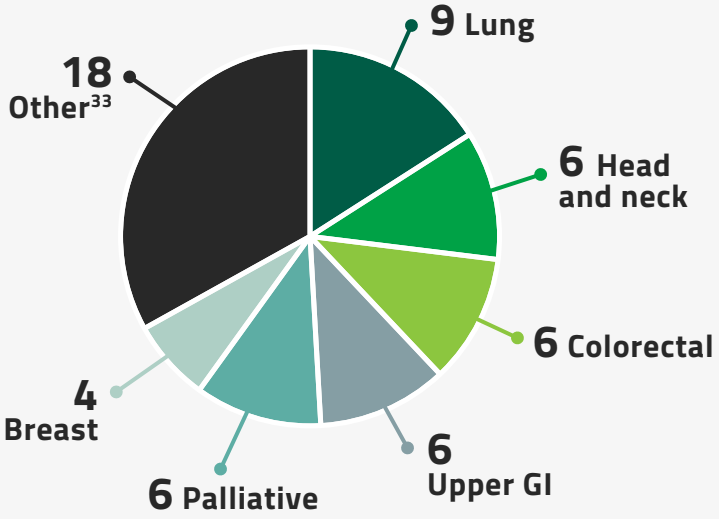


Figure 14: Participant characteristics

Implementing Change

When the clinicians were interviewed, they revealed that there was some hesitation about introducing a new service like ICJ to their patients. The clinicians described how patients can feel overwhelmed with the amount of information they receive at the point of diagnosis. Therefore, they wanted to shield their patients, particularly those with complex lives, from something that was unknown.

However, confidence to refer to ICJ developed once it became evident how much extra support the service could provide for their patients.

'It was just a confidence thing – I didn't want to promise something I hadn't experienced but then patients are coming back and saying can I get it for my friend and then you're seeing it, it gives you much more confidence to say I can sell this service'

(CNS, female).

[33] Others include bladder, haematology, urology, unknown primary, neurology, gynaecology.

When surveyed in 2019, the majority (72%) of participants disagreed that it was difficult to bring ICJ into conversation with their patients.

INITIALLY, IT WAS DIFFICULT TO BRING ICJ INTO CONVERSATIONS WITH PATIENTS	NUMBER OF RESPONDENTS
Strongly Agree	1
Agree	3
Neither Agree or Disagree	10
Disagree	25
Strongly Disagree	11

Implementing any change to practice can be difficult. It may feel like there is extra work to do if there are new processes to manage.

ICJ INITIALLY GENERATED MORE WORK FOR ME	NUMBER OF RESPONDENTS
Strongly Agree	0
Agree	2
Neither Agree or Disagree	17
Disagree	19
Strongly Disagree	12

We also asked if ICJ initially generated more work for the clinicians and 62% disagreed.

Confidence and trust developed among the professionals once it was understood and appreciated just how useful the service could be.

69% of clinicians stated that they 'always' or 'often' refer to ICJ

I REFER EVERYONE TO ICJ	NUMBER OF RESPONDENTS
Always	10
Often	24
Sometimes	12
Rarely	2
Never	1

However, it was recognised that not everyone may wish to use ICJ. Sometimes clinicians were unable to refer clients because they did not live in the Glasgow City local authority area.

It would be useful for the ICJ support to be extended to areas outside of greater Glasgow council. Many of our patients come from outside the Glasgow city council and therefore the service is not as easily available to them' (Doctor, female).

Nevertheless, ICJ still supports individuals, irrespective of where they live, as long as they are receiving care from a Glasgow hospital.

Improving the Experience

The collaboration between ICJ and health and social care professionals creates mechanisms to provide a more holistic experience for the patient. Link officers are experts in non-clinical matters – by integrating knowledge and skills across the professions, patients benefit from an increased range of care and support.

100% agreed that ICJ increases the range of support a patient can access

'They sort out all the things that can make for a stressful life. I often say in my job you can't change the outcome but you can change the experience. And I think that is how their job is too' (CNS, female).

REFERRING PATIENTS TO ICJ INCREASES THE RANGE OF SUPPORT A PATIENT CAN ACCESS	NUMBER OF RESPONDENTS
Strongly Agree	29
Agree	21
Neither Agree or Disagree	0
Disagree	0
Strongly Disagree	0

This additional support has had a major impact on the patient experience.

92% agreed that referring to ICJ improves the patient experience

REFERRING PATIENTS TO ICJ IMPROVES THE PATIENT EXPERIENCE	NUMBER OF RESPONDENTS
Strongly Agree	25
Agree	22
Neither Agree or Disagree	4
Disagree	0
Strongly Disagree	0

'If someone isn't supported practically, it has a psychological impact on them. And then it manifests itself physically and then you're dealing with someone who's really not in a good place and going downhill pretty fast. Whereas if they are supported in the community they're a lot happier, they feel supported' (CNS, female).

Supporting a client's needs across a range of domains can increase their confidence and ability to manage the physical and psychosocial consequences and lifestyle changes associated with cancer.

ICJ PROVIDES THE MECHANISMS TO HELP SUPPORT SELF-MANAGEMENT	NUMBER OF RESPONDENTS
Strongly Agree	18
Agree	16
Neither Agree or Disagree	16
Disagree	1
Strongly Disagree	0

66% agree that ICJ provides the mechanisms to help support self-management

A total of 31% did not agree or disagree with this statement. This suggests that the concept of self-management is broad and it may mean different things to different people. Nevertheless, feedback from the free text box supports the idea that support from ICJ alleviates worry and helps people to feel in control.

'ICJ has allowed me to refer patients for advice and support during a very anxious and stressful time for them. ICJ has allowed patients to access benefits or financial help that they may not otherwise have had. This alleviates a very common worry that many patients have' (CNS, female).

Freedom to Focus

The range, prevalence and complexity of patients' social and practical needs can be challenging. Health professionals do not have the expertise and time to adequately deal with non-clinical issues.

Before ICJ, 61% stated that they usually had to deal with social and clinical issues for their patients

BEFORE ICJ, I HAD TO DEAL WITH SOCIAL ISSUES AS WELL AS CLINICAL	NUMBER OF RESPONDENTS
Yes, often	16
Yes, most of the time	13
Yes, sometimes	13
Yes, rarely	3
No, never	2

'For instance finances. We would have completed the forms; we would have done it personally. We did it all in-house and I spent many a long night in the office filling in the paperwork so at least patients were getting some kind of service' (CNS, female).

This stretched the health professionals' workload to the limit. While they were providing some level of service it was recognised that it was not always ideal.

'When we did have to deal with the social issues it was very time-consuming and took us away from the clinical work. We didn't have the knowledge, so patients were getting a really raw, a really bad deal'

(CNS, female).

Since the collaboration with ICJ, the clinicians now feel that directing patients to the service for non-clinical support means that they can regain a clinical focus in their consultations.

This has had a positive impact on clinical time and efficiency.

'My clinical role is changing quite a lot. Linking with ICJ has given us the space to let this happen' (CNS, female).

70% agree that referring patients to ICJ saves them time

REFERRING TO ICJ SAVES ME TIME	NUMBER OF RESPONDENTS
Strongly Agree	21
Agree	15
Neither Agree or Disagree	15
Disagree	0
Strongly Disagree	0

67% agree that their time is used more efficiently now they can refer patients to ICJ for non-clinical support

MY TIME IS USED MORE EFFICIENTLY NOW I CAN REFER PATIENTS TO ICJ FOR NON-CLINICAL SUPPORT	NUMBER OF RESPONDENTS
Strongly Agree	19
Agree	14
Neither Agree or Disagree	13
Disagree	3
Strongly Disagree	0

'ICJ affords me a lot more time to deal with my clinical role which is increasing in workload secondary to the increasing number and complexity of treatments available' (CNS, female).

As workloads increase and budgets are tightened, health and social care systems need to develop innovative ways to provide the best support for patients. ICJ is a successful model of health and social care integration that increases the efficiency of the system and produces tangible benefits for patients.

'I had a patient recently who was still working when he was diagnosed with cancer. He had never claimed any pensions or benefits. He had the worry of his diagnosis and also that he could not pay his rent due to being off work. ICJ was able to help him claim a substantial amount of money. He now can concentrate on his cancer treatment without worrying about money. You can physically see the relief on this man' (CNS, female).

As a result of this collaboration with ICJ, several clinicians said there was a considerable contrast between the old and new ways of working. Being able to refocus on their clinical role had a positive impact on staff morale and wellbeing. Participants reported feeling less worried, less pressured and less guilty knowing they could easily refer patients for further support.

'I think because you feel that burden is taken off you and someone has taken it, you do feel overall we're doing a better job and we are better addressing the needs of the patient'

(CNS, female).

COLLABORATING WITH ICJ HAS IMPROVED STAFF MORALE/ JOB SATISFACTION	NUMBER OF RESPONDENTS
Strongly Agree	17
Agree	18
Neither Agree or Disagree	18
Disagree	0
Strongly Disagree	0

68% agreed that collaborating with ICJ has improved staff morale/job satisfaction

A number of the participants recognised this working relationship as positive – they were sharing information, respecting each other's contribution and working interdependently. ICJ has now become indispensable.

LOSING ICJ WOULD HAVE A NEGATIVE IMPACT ON SUPPORTIVE CANCER CARE IN GLASGOW	NUMBER OF RESPONDENTS
Strongly Agree	36
Agree	10
Neither Agree or Disagree	3
Disagree	0
Strongly Disagree	0

93% agree that losing ICJ would have a negative impact on supportive cancer care in Glasgow

Wider research conducted on the unmet needs of cancer patients suggests that these are often financial, emotional and practical[34]. There are different explanations for this, but one reason may be that patients might not feel it is appropriate within the health setting or they do not have the opportunity to raise these concerns. Furthermore, and crucially, health professionals do not have the appropriate skills to support these types of concerns, as they require specialist knowledge of systems and resources.

SUPPORT BASED ON NEED

Since our evaluation began, the main areas of concern identified by ICJ clients have remained the same. Practical, financial and emotional concerns are common for individuals across different cancer types, stages and socioeconomic backgrounds. Consequently, ICJ has made a considerable impact by providing information to patients and their families, simplifying the benefit application process, and ensuring that these concerns are supported, along with any other needs or concerns that are important to the individual.

[34] Soothill, K., et al. (2001). The significant unmet needs of cancer patients: probing psychosocial concerns. Supportive care in Cancer, 9(8), pp 597-605.

FINANCIAL SUPPORT

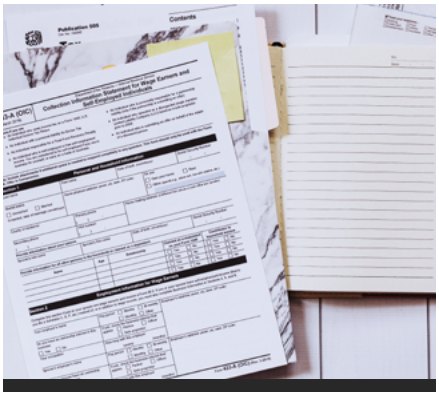
It is estimated that nine out of ten cancer patients suffer a financial loss because of their diagnosis (Macmillan Cancer Support, 2014) and financial distress can be a major predictor of poor quality of life[35].

The UK benefits system is designed to help people with state payments when they are ill. However, it can be difficult to navigate. Almost every ICJ client interviewed for this evaluation did not know that they were entitled to financial support or knew how to go about making a claim.

'I had no money coming in and I knew I was going to be out of the game for months. And the stress that I had, I was not used to applying for benefits and things like that. So it was really essential getting that at the time because we would have been left with nothing'

(ICJ client, male).

ICJ Actions and Outcomes



Identification	Problems	Support
4138 individuals have received financial support	Loss of income Transportation costs Higher fuel bills Debt Funeral costs	State payments Macmillan grants Debt manegement Fast track for those at end of life

Figure 15: Summary of financial support

From October 2014 to June 2020, 4,138 people received financial support from ICJ. The service has obtained £18.5 million for clients, highlighting how influential ICJ has been in terms of tackling cancer poverty and contributing to welfare reform in the city. This support included state benefits, grants, support with council tax and housing, assistance with fuel poverty, carer support and debt management. The most common sources of support were[36]:

[35] Hastert, T. A.,et al. (2018). Financial burden among older, long□term cancer survivors: Results from the LILAC study. Cancer medicine, 7(9), pp 4261-4272.

[36] See Appendix 5 for full description of the financial support. Overall numbers since then have increased but the most common types of financial support remain the same.

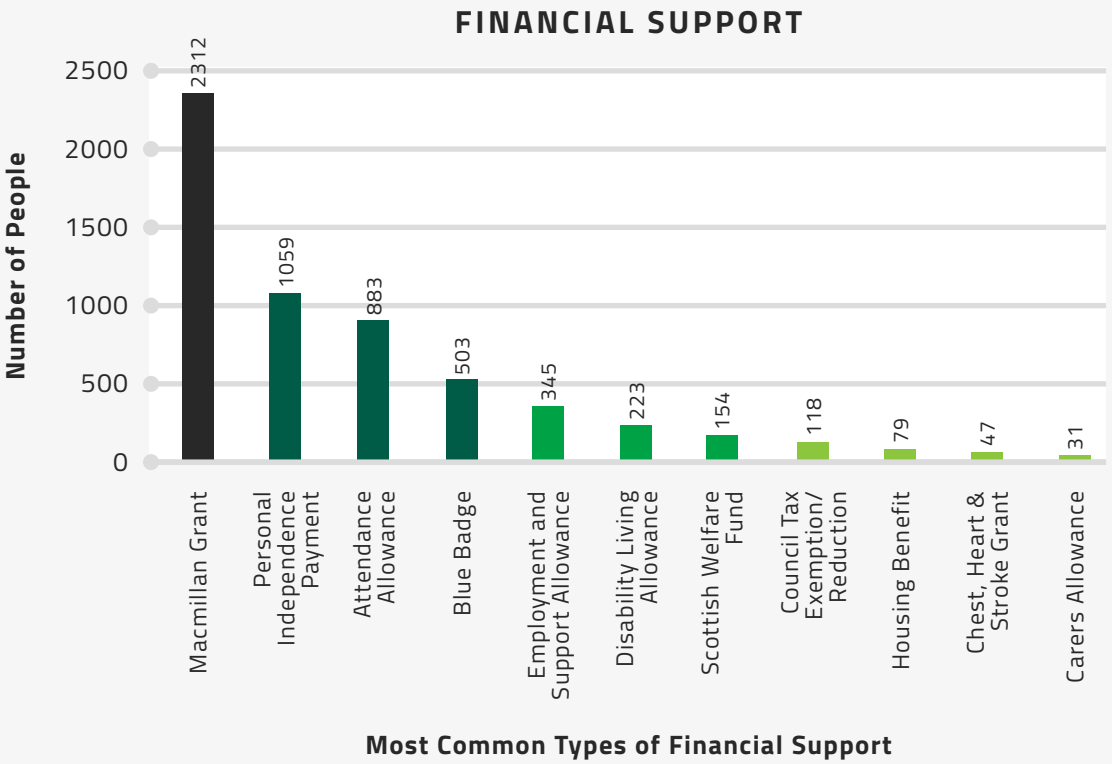


Figure 16: Range of financial support awarded to ICJ users

The average financial gain for these clients was £5,300. In individual cases this ranged from £25 for a Macmillan grant to £66,000 for an insurance pay-out. In 45% of cases the individual received £1000 or more.

ICJ has expert knowledge in this area and can provide a fast and efficient route to financial support as well as supporting clients with any other concerns they may have. For example, financial and emotional concerns often go hand in hand. This holistic approach has reduced stress and worry, improved living conditions and enhanced the ability to cope.

It is important to recognise this impact against the wider backdrop of UK welfare reforms. In 2016, the responsibility for delivering benefits to people with long-term health problems and disabilities was devolved to the Scottish Government. The Scottish Government's Lessons Learned[37] paper outlines reflections on the process behind Social Security Scotland taking over claims from the Department of Work and Pensions and notes the challenges of Universal Credit and other UK Government programmes. Devolving these benefits to the Scottish Government has played a critical role in alleviating adverse consequences for people with long-term conditions.

'I was on sick pay so my wages were halved, so it was a big help as I had a mortgage to pay and funeral costs to plan for. They sorted out benefits and grants for me and I didn't need to make one phone call, they did everything. Absolutely everything. Absolutely amazing and any time you need anything you just need to give them a phone' (ICJ client, female).

[37] Scottish Government (2019) Devolved benefits: lessons learned [Access: https://www.gov.scot/publications/lessons-learned-delivery-devolved-benefits/]

HOUSING SUPPORT

ICJ employs a full-time housing officer who is seconded from the Wheatley Housing Group. If an individual identifies housing concerns during the HNA process, they are referred to the housing officer for extra support. Demand for housing support continues to rise and from September 2015 to June 2020 the officer supported 730 families with housing issues.

ICJ Actions and Outcomes

Identification	Problems	Support
730 individuals have identifies 'housing' as a concern	Difficulty with stairs Unsuitable housing (damp, cold) No housing following hospital discharge Threat of homelessness due to rent arrears	Rehoused to more suitable housing Move to sheltered housing Remain in home with adaptations Increased opportunity for intervention from services such as Cordia

Figure 17: Summary of housing support

Outcomes

'I don't know how the system works as I was in that flat for 25 years but I was sent a letter saying my application was unsuccessful as I didn't have enough points. But then she [housing officer] spoke to someone and sorted it'

(ICJ client, female).

- 136 clients have secured new registered social landlord tenancies or moved into sheltered accommodation.

- 22 clients have had adaptations fitted at home, such as stair lifts, walk in showers and handrails, to allow them to remain there longer.

- The housing officer's onward referrals include Social Work for Occupational Therapy assessment, telecare service and homecare service, housing associations, referrals to carers' service and referrals back to ICJ for further HNA assessment and/or welfare benefits advice. This shows an increase in communication and efficiency between services, with added benefits for the client.

• Clients are supported rapidly – this is crucial in circumstances where the client has a poor prognosis.

• Having dedicated expertise is important when systems are complex.

• Housing support can have a positive effect on wellbeing and enhance connections to the local community.

• Arneil Johnston's Housing Options evaluation[38] suggests that the average cost to the public sector if homelessness cannot be prevented is £10,000. The housing officer has prevented homelessness on 50 occasions. This adds further weight to the benefits gained by the public sector from having a housing officer to support ICJ clients (see Appendix 6 for full cost saving/ prevention for actions which support vulnerable people to remain in their own home).

'Without them [ICJ] there I don't know what I would have done. I honestly don't know. Gone to what George Square to sleep?' (ICJ client, male)

'I live alone and I feel so comfortable here in this flat. S [housing officer] went through the Scottish Welfare Fund and they supplied me with a washing machine, bed, fridge freezer, couch and they gave me the carpet because I couldn't have afforded any of this, I just have my state pension'

(ICJ client, male).

There is clear benefit to having dedicated expertise at hand. Addressing someone's social and practical needs means that they are likely to feel more in control and better able to manage their health[39]. In recognition of the positive impact that housing support has had on ICJ clients, learning from the ICJ model will be used in a programme for all Registered Social Landlords (RSLs) in Glasgow. This approach will allow the ICJ housing professional to have a specific focus on supporting patients as they are discharged from hospital.

[38] Arneil Johnston is a housing consultancy based in Scotland. Details about their evaluation can be found here: Glasgow City Council https://www.glasgow.gov.uk/CHttpHandler.ashx?id=19320&p=0

[39] Page, A. E., & Adler, N. E. (Eds.) (2008). Cancer care for the whole patient: Meeting psychosocial health needs. National Academies Press.

SKILLED WORKFORCE

One of the unique attributes of ICJ is that the HNA is handled by non-clinical link officers. Therefore, understanding their skills and how they approach the role is an essential element of the evaluation. Link officers come into ICJ with backgrounds in financial inclusion and city council processes. They then undergo a three-month training period where they are provided with information and support, for example, training on clinical factors, HNA and care planning, communication training, IT training and psychological issues in cancer.

In order to understand how they navigate the cancer system and implement their training, ICJ link officers were asked to make audio recordings of diary entries over five days. These were then transcribed and analysed.

Findings

Three themes were identified from the diary entries – 'adapting to the unpredictable', 'unique connections' and 'self-awareness'.

Adapting to the Unpredictable

Link officers support clients in the hospital ward, their homes, community venues, by telephone, in outpatient clinics, and in hospices. The link officers recognised that they needed to adapt to these different environments by tailoring their interactions and conversations. In particular, the hospital environment presents challenges that require the ability to be sensitive to the patient's needs and circumstances.

> 'It's quite difficult working at the hospital because there are lots of things going on for patients. They are really unwell, hence them being in hospital, so it can be really hard to have proper conversations with people when they are feeling that way. Trying to do HNA for some people can be very exhausting.'

Yet, the link officers have adapted. When asked to reflect on what went well in their day, the link officers valued these experiences and gained professional satisfaction from reaching out to those who needed help.

They described working well under pressure with competing demands on their time. Through adapting to the unpredictable elements of their role, the link officers can support their clients in a location of their choice. Interviews with ICJ clients show that they value this, particularly when they feel too ill to travel to an appointment.

> 'It's challenging but for me the best thing was helping that family and getting things in place and knowing they won't need to struggle alone.'

Unique Connections

The link officers described successful partnerships with professionals from a range of organisations and sectors. Through their connections to different agencies, they supported clients where others had been unable to do so.

'The visit went really well because the client is 93 and he isn't accepting any support, but he has agreed to get handrails and I sorted out home care for four days a week, so that was a success.'

Some of these connections were novel, highlighting how beneficial it is to bring the support to the individual rather than waiting for them to seek it out.

'My afternoon visit was with a man who lives on his own but in sheltered accommodation. So, I got to meet the warden. My client doesn't answer the phone, so I got the warden's number.'

By working with the warden, this client will now benefit from ICJ support. Persistence and pro-activity are two key qualities. This allows link officers to support patients and family members in a seamless and holistic manner.

'I visited someone who had a brain tumour, so it was quite a difficult interaction as he doesn't retain information very well. But he didn't want his family member to be in our meeting, so it was just the two of us. It was quite difficult to pin down things and really get to the bottom of what his concerns were. He didn't really identify any concerns and I don't really want to put concerns on someone, but I could see there were some issues around lack of money – he should be claiming because he has a terminal illness.'

Connections with Cancer Nurse Specialists are essential for the best patient care. This entry shows how mutually reliant the two professionals are on each other.

'I logged on and had an emergency request from a CNS asking if I can support her with a client. I spent the morning liaising with the nurse and I was able to arrange patient transport for her client who was getting radiotherapy to his skull and she was worried about how he would get home.'

However, for these relationships to thrive, the working environment needs to support both professions.

'The patient was eligible for DS1500[40] so I asked the consultant if he would complete it, but they didn't have any. I asked the ward staff but they didn't know what I was talking about. So, I had to go to another ward and get one and the consultant said she would complete it and I could pick it back up. But I had to explain I'm not based in the hospital.'

Self-awareness

A challenging part of the link officer's role is the ability to balance time between client appointments, work with other agencies, complete reviews, upload paperwork onto the system and respond to new referrals. This requires the ability to plan ahead and prioritise.

While all officers recognised this as an essential part of the role, it can be demanding. The pressure to complete outstanding work is a common difficulty for link officers. This is heightened when there is a surge of new referrals.

'It's a balancing act between prioritising what needs to be done today and realising what can wait.'

[40] This is a form that allows someone with a terminal illness to claim benefits more quickly.

‘If we have spare time we can catch up with paperwork and reviews but with referrals being so high at the moment, that’s not an option. So I’ve got a list of things to do on my next paperwork day that I may have caught up with today but wasn’t able to, so that’s a little bit challenging as well.’

When job demands are high they can develop into stressors. However, the link officers described supportive resources that helped them to manage these challenges. Self-awareness is critical. Knowing when to stop and seek support is a fundamental part of this role.

‘It was an emotional appointment, so after that I took some down time and composed myself, then spoke to my colleague just to offload.’

section 4 SUMMARY

- **Integrating ICJ link officers into the clinical setting has reduced the burden on clinicians, provided mechanisms for a more holistic experience for the patient, and strengthened the working relationship between the two professions.**

- **This evaluation shows the importance of connecting health with wider social concerns. Unless asked, it is unlikely that patients will raise concerns about housing or money at clinical consultations, so it can become a major unmet need.**

- **ICJ obtained a substantial amount of financial help for those who needed it, with associated improvements in wellbeing. Of note is that, irrespective of demographic background, finances are a top concern for ICJ users.**

- **Link officers complete induction training and receive ongoing learning and development from partner agencies. This has equipped them with the skills and professionalism to manage varied and complex cases.**

section 5: THE CULTURAL LEVEL

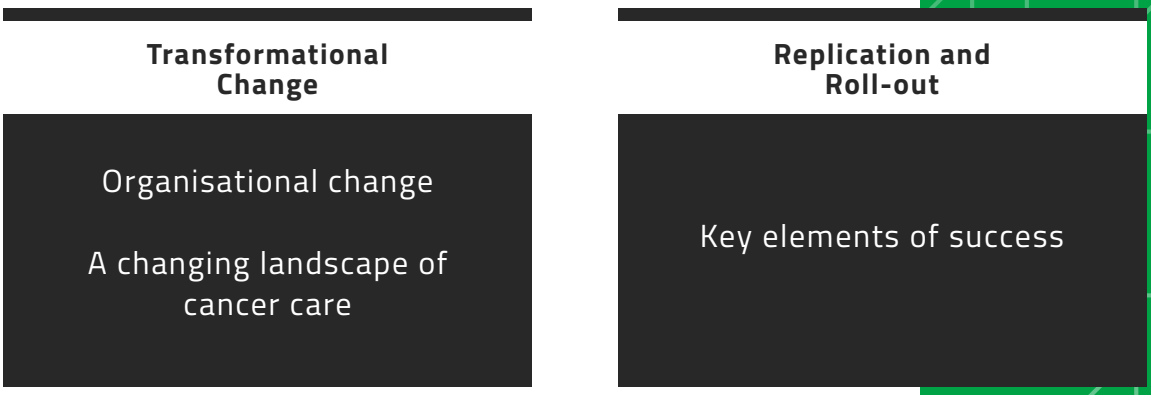


Figure 18: Section 5 evidence overview

One of the key aims of ICJ was to improve care by joining up support across organisations where appropriate. This approach recognises that, following a cancer diagnosis, people will connect with an array of different professions and services. For ICJ to deliver a seamless service across these different pathways required a change in attitudes and behaviours from those professionals who have a responsibility for treatment, support, information and advice to people affected by cancer. This was far from easy and required collaboration across disciplines and sectors. This section of the report will summarise the key milestones that led to this transformative change.

Testing the Concept

In 2014, ICJ commissioned the University of St Andrews to provide recommendations for the future of the programme in Glasgow. Interviews with senior managers from across different sectors who were involved in the inception and development of ICJ identified the importance of strategic leadership, overcoming differences in organisational culture and measuring outcomes. Subsequently, ICJ then commissioned further research with NHS Greater Glasgow & Clyde to test the idea of conducting HNAs in a community setting. After consulting with a group of people affected by cancer, it was noted that there was unanimous support for non-clinical professionals to carry out the HNA. This evidence helped to alleviate concerns raised by some health professionals at the time over which professions are most suited to conduct an HNA.

Listening to the patient voice

The ICJ patient reference group is a vital part of ICJ delivery. Significant decisions around the wording of the letter of invitation and initiatives on patient transport have come from ICJ users. The aim is to ensure that decisions are not 'top-down' with little regard to their impact on the individual, but to foster a culture that identifies gaps in knowledge and processes. It was agreed at the ICJ board meeting in October 2019 that the patient reference group will play a more active part in shaping service development.

Buy-in and Alignment

System-wide change requires wider stakeholders to be committed to it and share goals and values[41]. Two years into our evaluation[42] (2017), we recognised that the commitment of senior leaders on the ICJ board was a critical component for ICJ's success.

'I think it's an outstanding model of integration in relation to strategic planning, in relation to governance, in relation to delivery, in relation to realising it's not exclusively the remit of specialist organisations to deliver a wider wellbeing outcome'

(Glasgow City Health and Social Care Partnership).

The multidisciplinary background of the ICJ partners meant that organisational barriers were dismantled in order to work to the common goal of improving the patient experience.

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

(Wheatley Housing Group).

Given these common goals, ICJ's approach aligns to a number of strategic priorities across government and the care sector. At its heart is the desire to deliver effective and transformational services and improved outcomes for people who use health and social care.

[41] Swanson RC et al. (2012) Rethinking health systems strengthening: key systems thinking tools and strategies for transformational change. Health Policy Plan 27(Supp 4) pp 54–61.

[42] Edinburgh Napier University 2017 ICJ Evaluation report

ORGANISATION	STRATEGY	APPROACH	ALIGNMENT TO ICJ
The Scottish Government Riaghaltas na h-Alba	Realistic Medicine.	A focus on the person to understand their needs, preferences, expectations and values.	HNA and care planning to ensure that support is tailored and aligned to all the clinical and non-clinical circumstances going on in that person's life.
	9 Health and Wellbeing Outcomes.	What health and social care partners want to achieve through integration.	ICJ delivers across all nine outcomes[43].
	Cancer Strategy (2016).	Ethos underpinning this policy is the shift from 'what is the matter with you?' to 'what matters to you?'.	ICJ named in the cancer strategy as a successful example of how an integrated approach to care can improve outcomes.
Glasgow City HSCP Health and Social Care Partnership	(Strategic Plan 2019-2022).	Particular synergy with 'shifting the balance of care' and 'enabling independent living for longer'.	ICJ was included in the HSCP strategic plan for commitment to partnership working underpinned by shared values to support people affected by cancer.
			Partnership with housing to allow people with complex needs to live in their homes and communities for as long as possible.
			Access to financial support to reduce the poverty associated with a cancer diagnosis.
			Plans to increase the involvement of the ICJ patient reference group to keep future learning and development user focused.
			Addressing issues related to loneliness and isolation by developing a volunteer model to support clients to engage with community services, if they wish.

[43] See Edinburgh Napier University Evaluation report (2018) for more detail on this.

ORGANISATION	STRATEGY	APPROACH	ALIGNMENT TO ICJ
NHS Health Scotland	A Fairer Healthier Scotland 2017-2022.	Recognise the need to address the social detriments of health.	ICJ supports a majority of people with socioeconomic challenges. By considering the link between socioeconomics and health, ICJ is committed to ensuring that challenges such as poor mental wellbeing, diet and physical inactivity are considered when making decisions around referral and support.

Table 8: Strategic alignment

Integration - Strategic Planning

The Public Bodies (Joint Working) Act 2014 requires health boards and local authorities to work together to agree a model of integration to deliver quality, sustainable care services. The Act places a duty on the Integration Joint Board (IJB) to develop a strategic plan for their areas and chosen localities. Plans are then reviewed by the Ministerial Strategic Group (MSG) for Health and Community, which advises the Scottish Government on progress towards health and social care integration. The latest paper (January 2020) from the MSG stated:

'As policy ambitions begin to take shape we would expect that these revised plans demonstrate progress with embedding integration, evidence maturing relationships, developing priorities and articulating future ambitions... our expectation is that every plan identifies the total resource available across health and social care for each care group, including carers.' [44]

The expectation is that plans will continue to improve and develop. ICJ has been held up as an exemplar of integrated care and can show progress in terms of shifting the balance of care and 'whole system working' in terms of aligning to the National Health and Wellbeing Outcomes. For that reason, we suggest that the ICJ model may play a role in helping IJBs plan strategically.

[44] Overview of Strategic Commissioning https://www.gov.scot/publications/ministerial-strategic-group-for-health-and-community-care-papers-january-2020/

RECOMMENDATION FOR SERVICE PROVIDERS

- **To consider the ICJ model of support for strategic planning and commissioning.**

A Changing Landscape of Cancer Care

Often the barriers to applying personalised care are not moral or ethical ones. The challenge is how to implement and practise these principles. If we focus on the impact of ICJ on clinical practice, the commitment and collaboration across hospitals, outpatient clinics and from individual clinicians is noteworthy. Senior clinicians who were willing to have ICJ within their clinics should be recognised as playing a major part in bringing ICJ into clinical practice and driving organisational change forward.

'We made the decision to very much include ICJ as part of the team, so it felt to be a routine package of care that we offer everyone. I was very determined that it was seen as a coordinated, synchronised package'

(Senior Oncologist).

In addition, continuously measuring patient experience data is crucial for showing effectiveness and applying personalised care. This included our evaluation but ICJ should also be commended for its approach to internal evaluation. It ensured that the service was tailored to need by drawing on insight and expertise from its patient reference group, its own evaluation questionnaire, and analysis of routinely collected data in order to listen to and understand what ICJ clients valued. Widening access to ICJ, extending housing support and developing patient transport to help tackle loneliness and isolation are just some key areas where ICJ has taken a system-based approach to make positive changes to cancer care.

A major breakthrough was recognition from the Scottish Government that ICJ is an example of excellent practice after it was referenced in the government's 2016 cancer strategy, Beating Cancer: Ambition and Action.

In conjunction with ICJ, the Transforming Care after Treatment (TCAT) programme was also being delivered across Scotland, aspiring to reshape the care system to support the growing number of people with cancer, both now and in the future. Findings from an independent evaluation of TCAT emphasised that the planning and delivery of care should not wait until after treatment but should be a linked part of the patient's entire care pathway. The evaluation emphasised that the future delivery of HNAs and care plans must be applied to the whole cancer journey, the whole recovery package and the whole person[45].

[45] Edinburgh Napier University (2018) https://www.macmillan.org.uk/_images/ENU-TCAT-Programme-Evaluation-Wrap-Around-Bulletin-November-2018_tcm9-343325.pdf

'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'

(Scottish Government, 2016:48).

Transforming Cancer Care

In combination, ICJ and TCAT have been held up as 'gold standard' exemplars of good practice. Joint working across the organisations has enabled a more appropriate and efficient use of staff resources and ultimately improved coordinated care and greater access to services for people affected by cancer in Scotland. Demonstrating that this is a viable way to care for and support people has created the conditions for new programmes to flourish.

Subsequently, in 2019 it was announced that a new £18 million partnership will make Scotland the first country in the UK to offer cancer patients guaranteed emotional, practical and financial advice. The Scottish Government and Macmillan Cancer Support will invest £9 million each to ensure that everyone diagnosed with cancer has a dedicated support worker through the Transforming Cancer Care (TCC) programme. TCC will also support the embedding of new approaches to surveillance, reduce unnecessary care reviews, promote pre/rehabilitation and enable shared decision-making with people affected by cancer.

REPLICATION AND ROLL-OUT

The ICJ leadership has been dynamic in sharing the service's success. Since 2016, ICJ has been launched in Dundee, Fife, West Dunbartonshire and Renfrewshire. Plans are also in place for a phased pan-Lothian development in 2020. ICJ was also approached by local authorities in Wales and Belfast, who have now launched their services. Importantly, the roll-out of ICJ to other areas means that more people who require it can get support.

Elements of success: 'How to succeed like ICJ'.

As new areas launch similar services, it is vital that previous learning is absorbed into their development and delivery. The purpose of this evaluation is to understand if, how and why ICJ improved outcomes for people affected by cancer. To answer these questions we interviewed 28 ICJ service users, surveyed 800 more, and analysed routine data on all users (just under 8000). We also interviewed ten health professionals and surveyed 55, interviewed 12 key stakeholders, observed all the link officers in action and analysed 90 link officer diary entries. We led community workshops, presented at Integrated Joint Boards and discussed our findings at international conferences and through peer review publications. We have drawn together all of this evidence to understand the many moving parts of ICJ – uptake, concerns, care plans, support and signposting, referral pathways, joint working issues, barriers and benefits to users and wider stakeholders.

In 2016[46], we identified four key elements that we considered vital to the success of ICJ –a skilled workforce using an optimal process, with strong buy-in from all partners, all pulled together by an exceptional leader. In 2020, we would add a fifth element, evaluation. Section 6 summarises some key elements of self-evaluation important for future services to consider.

'So when I turned up at the start and said, this is what I think and these are my ideas, and they were like, how do you know that is what people want? But from there I started an NHS engagement group with oncologists, CNS, psychology and health improvement. And I worked with them for the next year and we commissioned some research to go back out and ask people what they thought. About the concept of it, will it improve your cancer journey, and it was unanimous about people saying it would'

(Sandra McDermott)

The first four elements summarise the vision, skill and day-to-day requirements for success. ICJ has the essential 'buy-in' from partners across health, social care and the third sector. Likewise, skilled practitioners have translated the principles of ICJ into practice by systematically supporting those in need through the use of Holistic Needs Assessment and supportive care planning.

Figure 19: Five elements of transferable success

[46] Snowden, A., & Young, J. (2016). Evaluation of Improving Cancer Journeys. London. Retrieved from http://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html

'It started off as Improving the Cancer Journey but it's now just referred to as ICJ. It's become part of the structure because it's so trusted and part of the system. I was meeting people who I've never had any contact with and they were like, "Oh yes, ICJ, I've heard all about it". So, it's just seen as part of the support package for people with cancer. That's about changing a culture' (Sandra McDermott).

'We kept information on who is supported, what are their needs, how they have been met and, importantly, what the impact has been. So we didn't wait until four years in and say how we are going to demonstrate impact. We have kept data and have constantly challenged what data we have and is it enough' (Sandra McDermott).

However, we sincerely doubt that ICJ would have been as successful without visionary and robust leadership. ICJ Programme Manager Sandra McDermott[47] has been instrumental in taking ICJ from an idea to a service that has supported almost 8000 people. Her dedication, motivation and passion for ensuring that no one slips through the cracks has been the driving force. Her previous experience in addressing inequalities at a strategic level has been entirely transferable to this programme and Sandra and her management team have collectively shaped ICJ into the award-winning service it is today.

ICJ will no doubt develop in new and exciting ways under new leadership, but in acknowledging the building blocks of success, Sandra's ambition and leadership should be recognised and lauded. For example, this evaluation in part came from her recognition that metrics must be embedded into service delivery – this is why we included it as the fifth element of transferable success. To be successful, any venture needs to show its success against a set of agreed parameters. This is not a new idea, but often one that gets side-lined as budgets tighten. Sandra has always recognised the value of independent evaluation and we would urge future ICJ ventures to systematically self-evaluate at the very least.

[47] Until August 2020

'The staff are empowered and enabled to go and make decisions on behalf of someone without having to come back and ask for permission. So, fundamentally, they have been key to the success, getting the right people and actually being able to say, what does that person need? And not being constrained by what their boundaries can be. Their boundary is to support that person and their family with cancer. And if they don't know to go and open doors, and if they need support, come back and we will help them to open them'

(Sandra McDermott).

section 5 SUMMARY

- **For ICJ to deliver a seamless service across different sectors required a change in attitudes and behaviours.**

- **The multidisciplinary background of the ICJ partners meant that organisational barriers were dismantled in order to work to the common goal of improving the patient experience.**

- **ICJ's approach aligns to a number of strategic priorities across government and the care sector. The impetus is the desire to deliver effective and transformational services and improved outcomes for people who use health and social care.**

- **We identified key elements vital to the success of ICJ –a skilled workforce, strong buy-in from all partners, the HNA process, an excellent leader and evaluation.**

section 6: LOOKING FORWARD

One of our aims was to conclude this evaluation with a 'legacy' of knowledge and skills which we could share with the ICJ team to enable them to self-evaluate their service once we had finished. By embedding rigorous and meaningful evaluation metrics into routine practice we can help ensure that decisions around service developments and future roll-out are based on the evidence.

Supported self-evaluation

ICJ routinely collects data on how people use the service, as detailed in Section 3. Analysis of it has been a vital part of this evaluation. However, the data is in multiple places in different formats, so it can be laborious to combine and analyse. To address this, Edinburgh Napier University worked with the ICJ team to build a dashboard/interface app for combining the data.

Goals included:

- Ability to merge several datasets, such as client information, referrals to ICJ, HNA and plan data, reviews, additional actions and referrals to services
- To report on linked results across the various data fields
- Create a dashboard view of top-level results by date
- Ability to monitor link officer caseloads over time
- Serve as a template for other areas adopting the ICJ model

Prototype Screenshots

Below is an example of the prototype in development. It uses made up data to protect anonymity but shows how the team will be able to filter for different information (left hand column), making reporting and analysis much less time-consuming.

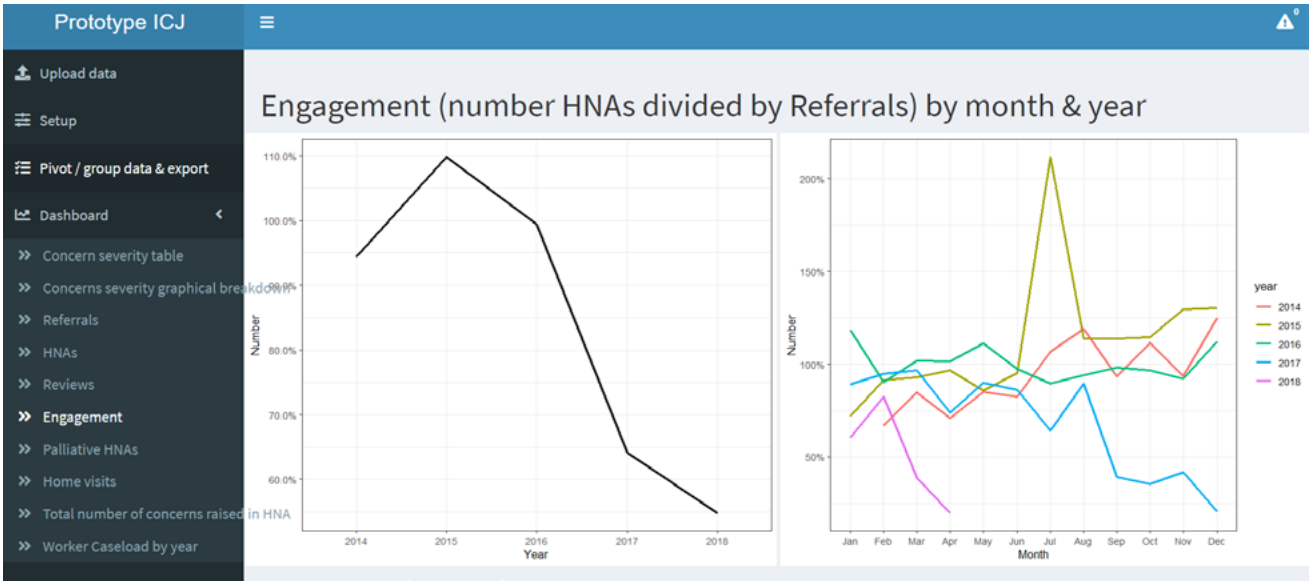


Figure 20: Example of dashboard view in prototype interface[48]

Recommendations for Analysis

Over ICJ's lifetime, the project has grown organically along with data collection and storage methods. The main challenge for the analyst was to reconstruct individual journeys from the data. The data was stored in a number of databases, with each representing different elements of engagement with the service – for example, inward referrals, personal details, HNA and plan, review, onward referrals, outcomes of onward referrals, and additional actions. An understanding of how the records relate to each other is understood by the link workers but they are inaccessible to the analyst because of the way the data is stored[49].

RECOMMENDATION FOR SERVICE PROVIDERS

▪ To think of ICJ usage in terms of episodes and to design data collection and storage around this idea. An episode comprises the steps along a client's journey and how they relate to each other. This needs an additional identifier linking each HNA to all of its associated plans, reviews, additional actions, and onward referrals so that the person's journey can be accurately understood from the records.

▪ Consider the use of eHNA to be a solution to shared information across health and social care.

[48] All data is made up for purpose of illustration. No real data is presented here.

[49] The eHNA mitigates some of these issues by creating time-stamped, easily accessible online records of HNAs completed. However, a wider issue to consider is the way that each service records their data. For example, how many times services complete HNAs with their clients can vary across the country which makes comparisons difficult.

EXTENDING THE MODEL

Holistic needs assessment and care planning supports people who need help due to illnesses such as cancer. But it is recognised that this approach can and should be extended to other health conditions.

The treatment and management of long-term conditions such as diabetes, stroke, asthma, arthritis and chronic obstructive pulmonary disease is a priority for health systems across the world. What is more, demographic changes and longer life expectancy mean that an increasing number of people have more than one health condition. In Scotland, 42% of the population has at least one long-term condition and 23% have two or more[50].

Co-occurring diseases (comorbidities) are more common among deprived populations, especially mental health problems, and there is evidence that the number of conditions can be a better indicator of a patient's use of health service resources than the specific diseases[51]. Personalised care planning for people with conditions such as diabetes, mental health problems, heart failure and asthma can lead to better physical and psychological health, ability to self-manage, and better health behaviours. It has also been suggested that care planning can be particularly effective when it includes record sharing, care-coordination, review, and the integration of the personalised care planning process into routine care[52] – all of which are features of the ICJ approach.

To that end, Glasgow City Council (GCC) has put forward a business case to extend the ICJ model of care to people with other long-term conditions, the ethos being that professionals and patients/families should come together to identify support needs, make goals, take action and monitor progress through review. Research is needed to understand what parts of the ICJ model can be transferred to other health conditions and which cannot, what works for people, and under what circumstances.

It would be reasonably straightforward to create a database as described above, and it should be part of the process at the beginning. Trying to do it retrospectively would probably be prohibitively expensive and time-consuming. We believe that it would be wise to move forward at pace while the conditions and motivations are there[53].

RECOMMENDATION FOR EVALUATION

- **We recommend that GCC begins with a pilot programme to test delivery, process and impact.**

[50] https://www.gov.scot/policies/illnesses-and-long-term-conditions/

[51] Barnett K, et al. (2012). Research paper. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet online

[52] Coulter, A., et al., (2015). Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews.(3).

[53] This final report was competed during the Covid-19 outbreak. Hopefully the motivation and conditions will prevail afterwards.

CORONAVIRUS challenges and opportunities

In March 2020, ICJ staff were able operate services from home and HNAs were conducted over the telephone. The main difficulty was making onward referrals as a lot of organisations were temporarily closed or restricted. However, through social media and communicating with partner agencies, the team was able to make it known that people could still access support from ICJ. As a result, the outbreak has been a catalyst for two new opportunities.

• Personal Independence Payment and Attendance Allowance applications were usually done on paper and returned by post. As mail rooms were closed, ICJ worked with the Department of Work and Pensions to accept online applications with reduced verification needed for DS1500 (last six to 12 months of life) cases. This shift in working has potential long term benefits after the lockdown eases.
• ICJ supported Glasgow City Council (until the end of July) to triage assessments for 'shielding' cases. This demonstrates the utility of the model beyond cancer.

In general, these are very complex times. The pandemic will have a profound and broad impact on patients' and carers' mental health, family responsibilities, finances and social networks. Health and social care systems are likely to be disrupted for a long time. In light of this, consideration should be given to ICJ clients being able to report more and/or different types of concerns than previously. That the service was able to offer holistic support during a time of disruption will be extremely valuable.

REPORT CONCLUSION

ICJ is the first cancer service of its kind in the UK. A multidisciplinary team of professionals came together to support people affected by cancer in a personalised and proactive manner. By listening to what people need and value, ICJ link officers refer and direct their clients to community-based support and also provide routes to specialist expertise. ICJ is perceived to be beneficial because it offers one-to-one, tailored and essential support and information at any point during the cancer journey.

ICJ is now an integral part of cancer care in Glasgow. It should be remembered as a working example of a model of integration that was recognised 50 years ago – to offer the best care, professionals, patients and families should come together to listen to what matters, identify and support needs, make goals, implement actions and then monitor and help through follow up and review.

APPENDICES

Appendix 1: Overall Referral Sources

These figures are from January 2015 to January 2020.

ICJ REFERRALS (05.02.14 - 18.01.20)	TOTALS	%
NHS	4106	55
NHS Letters	765	10
Long Term Conditions Macmillan	435	6
Glasgow Libraries	366	5
Friend/Family/Carer	1114	15
Hospices	279	4
GCC ALEOs & Partners	176	2
Other Agencies/Third Sector	161	2
Other Local Authorities	37	0
TOTALS	**7439**	**100**

Appendix 2: Link Officer Induction Checklist

WEEK ONE	ARRANGED (TICK)	COMPLETED (DATE)
Colleagues to be given an overview of roles and responsibilities.		
Introduction to 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 the Clinical Advisor.		
Start to carry out HNAs supported by the Clinical Advisor (minimum of six).		
Have a Care First support session with the Development Officer.		
Complete a case study.		
Have a one-to-one meeting with the Service Delivery Manager.		

WITHIN THREE MONTHS	ARRANGED (TICK)	COMPLETED (DATE)
Go out on visits independently (minimum of six per week).		
Weekly joint visits with Clinical Advisor (minimum of one 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.		

Appendix 3: HNA

National Cancer Survivorship Initiative – Your Holistic Needs Assessement 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.

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Appendix 4: All Evaluation Methods

QUANTITATIVE

MEASURE	RATIONALE
ICJ routine data	Description of service users/ICJ process/ HNA process and outcomes.
Questionnaire measuring: Quality of Life Patient Activation Social Support.	To measure these outcomes in ICJ clients and non-ICJ clients to determine differences.
HNA and Distress Thermometer (DT) Correlation.	To determine if the HNA and DT are comparable instruments for detecting concerns.
Analysis of wider health service usage.	To compare use of other health services in users of ICJ and in matched controls (non-ICJ users).
Clinician questionnaire.	To investigate the impact of ICJ on clinical practice in a larger sample.

QUALITATIVE

MEASURE	RATIONALE
Semi-structured interviews with ICJ users.	To analyse the perceived benefits of ICJ and to understand more about the process of identifying concerns and receiving support.
Semi-structured interviews with cancer professionals.	To analyse the impact of ICJ on clinical practice.
Link officer observation.	To understand the process of ICJ service delivery.
Semi-structured interviews with stakeholders from partner organisations.	To explore key successes from the stakeholder perspective.

Appendix 5: Financial Gains

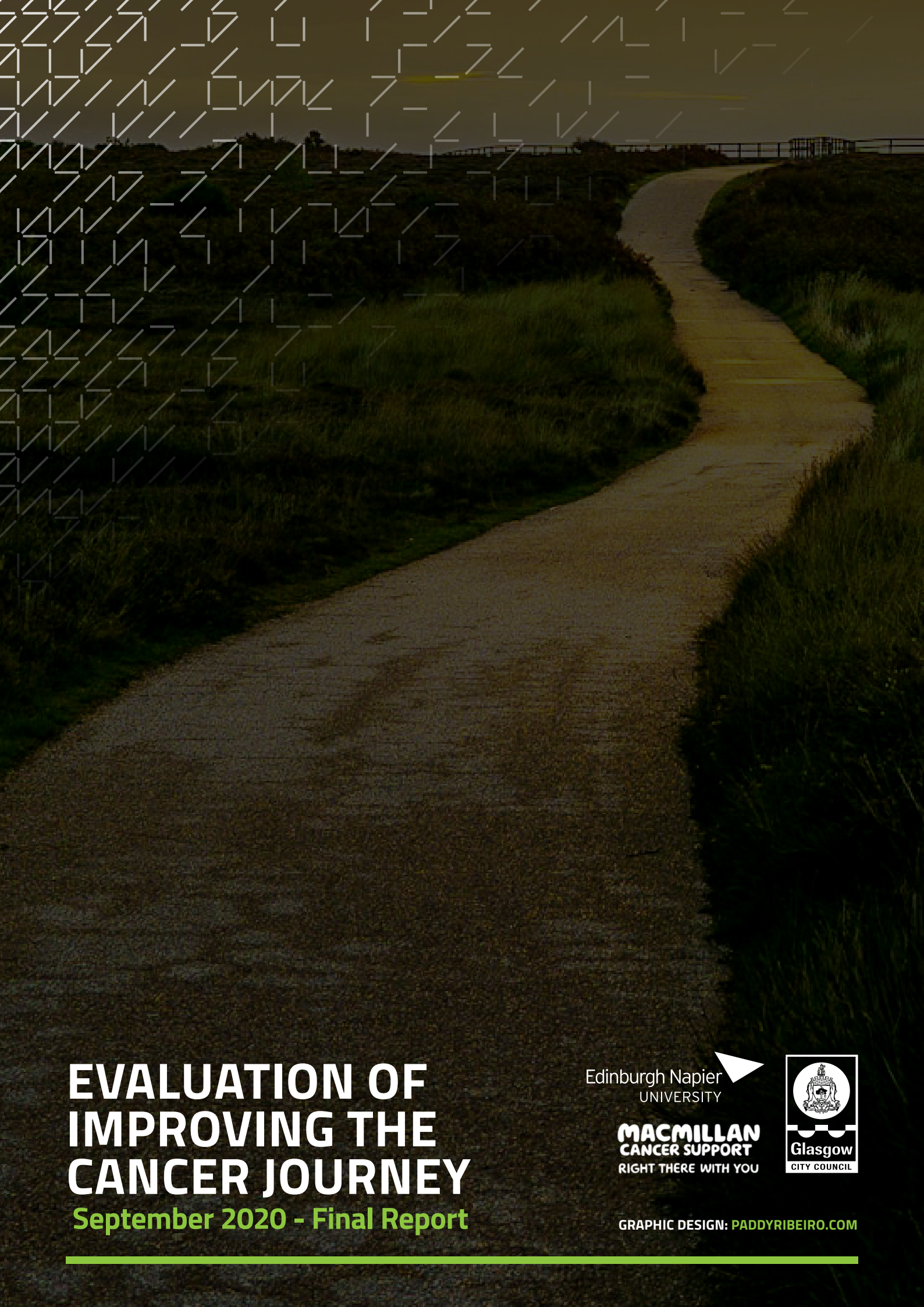
Full list of all sources of financial support for ICJ clients.

- Additional Room Allowance
- Attendance Allowance
- Blue Badge application
- Bus pass
- Carers Allowance
- Child Benefit
- Chest, Heart and Stroke grant
- Community Care grant
- Council tax reduction
- Debt written off
- Discretionary housing payment
- Disability Living Allowance
- Employment and Support Allowance
- Fuel poverty, Glasgow Lord Provost Fund
- G-Heat fund
- Housing Benefit
- Macmillan grant
- Pension Credit
- Personal Independence Payment
- Roy Castle Fund
- Scottish Welfare Fund
- Severe Disablement Allowance
- Universal Credit
- Working Tax Credit

Appendix 6: Arneil Johnston Evaluation of Housing Options matrix

CRITERIA USING ARNEIL JOHNSTON EVALUATION OF HOUSING OPTIONS MATRIX	NUMBER OF ICJ CLIENTS	PUBLIC RESOURCE SAVINGS AS PER CASE ALIGNED TO ARNEIL JOHNSTON EVALUATION OF HOUSING OPTIONS	TOTAL
Customers threatened with homelessness	50	£10,000	£500,000
Customers who were homeless	19	£10,284 (average cost if homelessness persists)	£195,396
Customers with no underlying needs	151	£1,286	£194,186
Customers with low level underlying needs (one need)	298	£4,349	£1,296,002
Customers with underlying needs (two needs)	155	£8,773	£1,359,815
Customers with complex underlying needs (three or more needs)	57	£10,005	£570,285
TOTALS	**730**		**£4,115,684**

See: https://www.glasgow.gov.uk/CHttpHandler.ashx?id=19320&p=0 for further information on the Arneil Johnston evaluation. Note this work was not done as part of the Edinburgh Napier University evaluation.



EVALUATION OF IMPROVING THE CANCER JOURNEY

September 2020 - Final Report

Edinburgh Napier UNIVERSITY

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