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# Improving the Cancer Journey

## *More than the Sum of its Parts*

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

**Glasgow**  
CITY COUNCIL

**Nhs**  
GG & C

**Wheatley  
Cordia  
&  
Other Charities**

**Macmillan  
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## Executive summary

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

Since inception in 2014 ICJ has seen 2413 people, 53% women and 47% men. The average age is 63.5 years but it ranges from 24 to 100 years old. Lung cancer is the biggest diagnostic category, followed by breast, prostate and bowel, with these four accounting for 50% of all users. Most (82%) individuals described their ethnicity as 'white'<sup>1</sup>, 54% had at least one co-morbidity and the vast majority were from the most deprived areas of Glasgow. Sixty-one per cent of ICJ service users come from the lowest SIMD<sup>2</sup> (SIMD 1). For comparison Glasgow City has 48% of its population in the bottom SIMD and Glasgow has more people in the most deprived areas than any other area in Scotland. ICJ is helping some of the most disadvantaged people in the country.

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

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

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

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

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<sup>1</sup> Including White Scottish, White Other British and White Irish

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

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

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

The previous report<sup>3</sup> identified the key components of success: strong leader, strong buy-in from all partners, a skilled workforce using a workable system. This analysis holds. What this report adds is the background machinations within the partner agencies and their motivations to make ICJ succeed. Readers looking to better understand the process to develop similar services should read chapter six in particular.

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

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

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<sup>3</sup> [https://www.macmillan.org.uk/\\_images/Glasgow-improving-the-cancer-journey-programme-summary\\_tcm9-301275.pdf](https://www.macmillan.org.uk/_images/Glasgow-improving-the-cancer-journey-programme-summary_tcm9-301275.pdf)

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

The Nine National Health and Wellbeing Outcomes provide a framework for improving integrated services in Scotland. ICJ aligns seamlessly with the principles of this framework by adopting a personal outcomes approach. Through the HNA the support provided to ICJ service users is based on their need. This recognises the multifaceted consequences to receiving and living with a cancer diagnosis allowing the individual to shape the care and support they receive. ICJ delivers across all nine Health and Wellbeing Outcomes<sup>4</sup>. For example, ICJ has a dedicated housing professional within the team who ensures people are prevented from homelessness and are supported to live in their own home independently and for longer. ICJ has so far prevented 26 people becoming homeless as a function of their cancer diagnosis. There is no doubt ICJ is having a significant positive impact across Glasgow consistent with the objectives of government policy.

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

## Recommendations and Next Steps

### 1. Continue to fund ICJ

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

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

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

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

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

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

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

There is a small window of opportunity to create a matched cohort in other Scottish cities so that service usage could be meaningfully compared between an ICJ and non-ICJ sample<sup>5</sup>. Permissions are in place to do this, and strict control should be placed on the parameters ‘time since diagnosis’ and deprivation category given these factors are so instrumental to quality of life.

## **4. Measure financial well-being**

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

## **5. Understand the carer experience**

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

## **6. Understand the impact of outreach**

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

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

## **7. Explore the prevalence and impact of signposting and referral**

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

## **8. Saving clinical time**

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

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

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

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