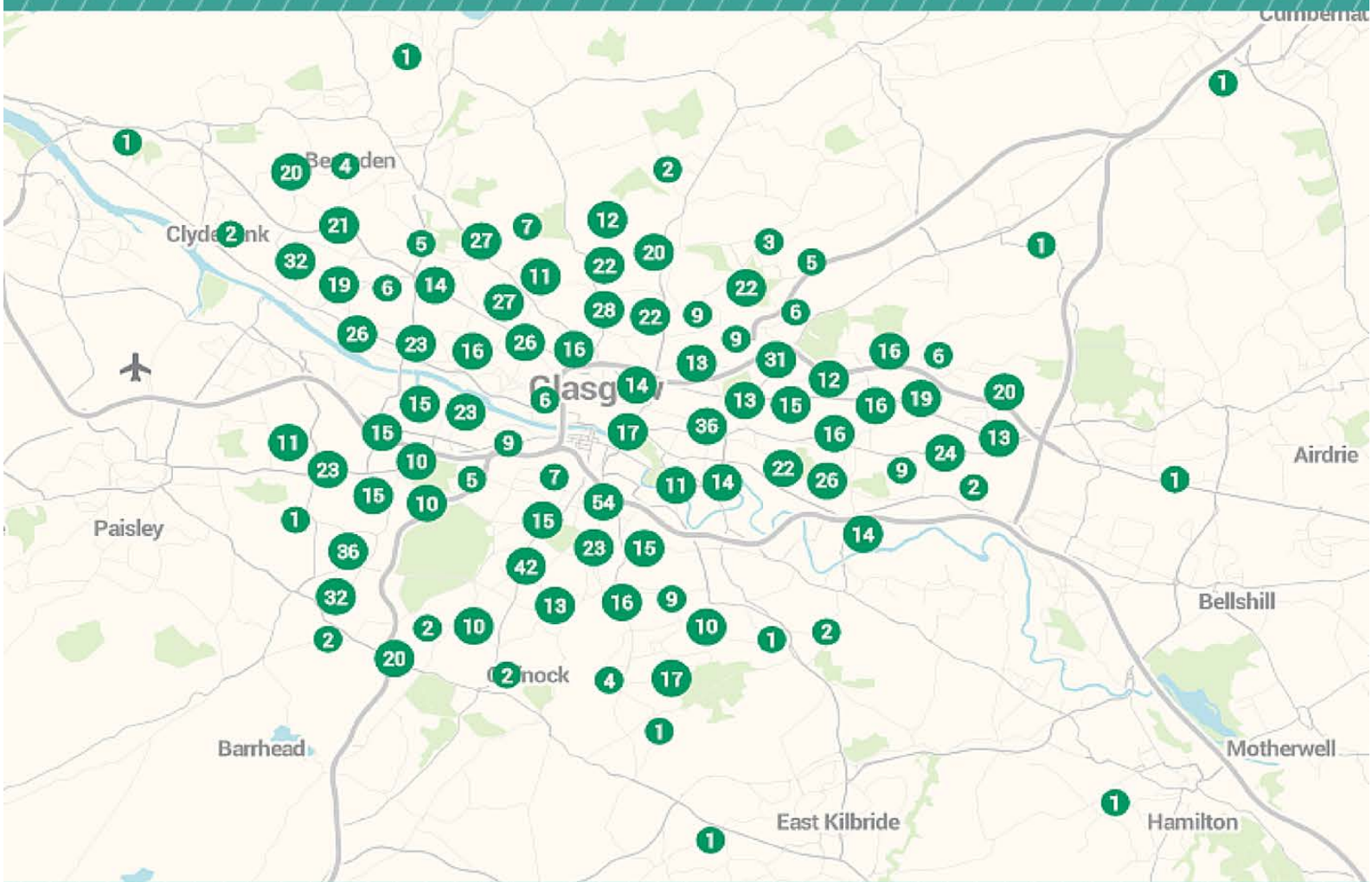
Evaluation of Glasgow Improving the Cancer Journey Programme



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WE ARE MACMILLAN. CANCER SUPPORT

Improving Your Cancer Journey

This is a brief summary of the full report which is also available on the Macmillan Cancer Support website.

Background

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

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

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

> *"The Improving the Cancer Journey experience in Glasgow is an example of how an integrated approach to health and social care can lead to an improvement in quality of life, person-led post-treatment rehabilitation and ability to self-manage."*
>
> (p48, 2016, Scottish Government. Beating Cancer, Ambition and Action)

[1] http://awards.themj.co.uk/winners

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

Aim

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

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

Method

This question is considered from three different perspectives, the:

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

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

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

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

		Logic model outcomes		
		Short Term	*Medium Term*	*Long Term*
Perspective	*Individual*	?	?	?
	Service	?	?	?
	Culture	?	?	?

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

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

Results

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

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

Individual level

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

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

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

These top concerns are different from a comparable study of 5000 assessments where a nurse carried out the holistic needs assessment.[2] The major concern for ICJ was money or housing, representing 8.15% all concerns identified. This is compared

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

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

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

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

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

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

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

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

Taking these two aspects together shows that those in greatest need are extremely satisfied with the care they receive from ICJ and report improvements in key target areas such as isolation, quality of life and capacity to take control of their care where

necessary. The nature and range of the referrals illustrate extensive networks and effective joint working. Integrating these results into the logic model shows that the following goals are already being met:

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

Service level

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

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

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

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

Cultural level

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

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

All of this activity is recognized at national level as **excellent practice**[3].

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

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

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

Discussion

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

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

1. *Strong leadership*

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

2. *Strong buy in*

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

3. *Highly skilled workforce*

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

4. *A workable process.*

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

Conclusion

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

Recommendations

ICJ leaders should:

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

ICJ link officers should:

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

ICJ partners should:

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

Evaluators should:

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

Macmillan should:

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

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