



<p><b>Meeting of East Renfrewshire Health and Social Care Partnership</b></p> <p><b>Held on</b></p>	<p>Integration Joint Board</p> <p>1 February 2023</p>
<p><b>Agenda Item</b></p>	<p>11</p>
<p><b>Title</b></p>	<p>Macmillan Improving Cancer Journey &amp; East Renfrewshire Health and Social Care Partnership</p>
<p><b>Summary</b></p> <p>This report provides an overview the Macmillan Improving the Cancer Journey (MICJ). The programme will be delivered in partnership with Macmillan and the HSCP.</p>	
<p><b>Presented by</b></p>	<p>Craig Menzies, Locality Manager</p>
<p><b>Action required</b></p> <p>The Integration Joint Board is asked to note the report.</p>	
<p><b>Directions</b></p> <p><input checked="" type="checkbox"/> No Directions Required</p> <p><input type="checkbox"/> Directions to East Renfrewshire Council (ERC)</p> <p><input type="checkbox"/> Directions to NHS Greater Glasgow and Clyde (NHSGGC)</p> <p><input type="checkbox"/> Directions to both ERC and NHSGGC</p>	<p><b>Implications</b></p> <p><input type="checkbox"/> Finance                      <input type="checkbox"/> Risk</p> <p><input type="checkbox"/> Policy                              <input type="checkbox"/> Legal</p> <p><input type="checkbox"/> Workforce                        <input type="checkbox"/> Infrastructure</p> <p><input type="checkbox"/> Equalities                         <input type="checkbox"/> Fairer Scotland Duty</p>

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## EAST RENFREWSHIRE INTEGRATION JOINT BOARD

1 February 2023

Report by Chief Officer

### MACMILLAN IMPROVING CANCER JOURNEY & EAST RENFREWSHIRE HEALTH AND SOCIAL CARE PARTNERSHIP

#### **PURPOSE OF REPORT**

1. This report provides an overview the Macmillan Improving the Cancer Journey (MICJ). The programme will be delivered in partnership with Macmillan and the HSCP.

#### **RECOMMENDATION**

2. The Integration Joint Board is asked to note the report.

#### **BACKGROUND**

3. Macmillan Improving the Cancer Journey (MICJ) is funded and supported by Macmillan Cancer Support (Scotland) and the Scottish Government, designed to deliver key objectives of the Scottish Cancer Plan and other Scottish Government strategies. The proposed partnership will offer support to anyone affected by cancer across East Renfrewshire, by offering a Holistic Needs Assessment (HNA) to help identify and address all physical, psychological, social, financial and practical needs.

#### **REPORT**

4. Together in partnership, Macmillan and East Renfrewshire Health and Social Care Partnership will work with local health providers, the local authority, third sector, communities and people affected by cancer (including family members and carers), with the aim of ensuring everyone affected by cancer can easily access the support they need as soon as they need it to enable them to live as well and as independently as possible.
5. The Glasgow model (initially launched in 2015), which is being scaled up and implemented across Scotland, demonstrated significant impact on, and reach to those people affected by cancer from the most deprived areas. This includes increasing financial gains, improvement in quality of life, providing a dynamic response to housing issues and a focus on preventative health.
6. The evaluation report (Executive Summary) is attached at Appendix 1 for information.

#### Cancer in East Renfrewshire

7. East Renfrewshire has a cancer incidence rate of approximately 590 per 100,000, equating to approximately 540 people being diagnosed with cancer annually. The incidence of

cancer is also anticipated to increase by 33% over the next 5-10 years. There were 2,888 cancers (excluding non-melanoma skin cancer) diagnosed in East Renfrewshire in the five years from 2016 to 2020. These were evenly split across genders. Across the two localities, Eastwood has the most diagnoses of cancer with 74.4% of cases compared to Barrhead with 25.6%.

8. At the end of 2019, 3,853 people in East Renfrewshire were living with a diagnosis of cancer and had been diagnosed within the previous 20 years. This equates to 4.01% of the population. This is higher than the national figure of 3.74%. It would be safe to assume that people living with cancer is expected to rise to circa 5900 by 2030. This number is increased significantly when you begin to consider the support needs of loved ones associated with a cancer diagnosis. Cancer mortality is consistently considerably lower in East Renfrewshire than it is in Scotland, with 46 fewer deaths per 100,000 occurring in 2018-20. The most common types of cancer in East Renfrewshire for both sexes combined (in order) were, female breast cancer, prostate cancer, lung cancer, colorectal cancer, malignant melanoma of the skin and kidney. These 6 cancers account for two thirds of all cancer diagnoses in the East Renfrewshire area.

## CONSULTATION AND PARTNERSHIP WORKING

9. Corporate governance will come from senior representation within East Renfrewshire HSCP and Macmillan Cancer Support. A programme Lead has been identified within the partnership and initial scoping and partner inductions underway.
10. Membership of an East Renfrewshire MICJ board and Project Group meeting cohorts have been agreed and met twice to date. A user involvement group will also be established. The MICJ programme aligns with the East Renfrewshire HSCP Strategy 2022-2025. Existing HSCP governance structures will be utilised to further disseminate, review and challenge strategic development and delivery of the programme and will include regular visibility across IJB and Primary Care Forums.

## IMPLICATIONS OF THE PROPOSALS

### Finance

11. Macmillan will fund the development for a minimum of three years to the value of £320,000. The HSCP will host the service, and provide strategic leadership and governance of the development and implementation of the service.

Item	Description	Budget
Salary Costs	0.2 WTE Programme Lead 1.5 WTE Macmillan Wellbeing Advisors 0.4 WTE Business Support	£272,544
Non Salary Costs	IT Equipment User Engagement Evaluation Travel Expenses	47,456
	<b>Total Investment</b>	<b>£320,000</b>
	<b>Investment Period</b>	<b>36 months</b>

12. There are no implications in relation to policy, workforce, risk, legal, infrastructure or equalities.

## **DIRECTIONS**

13. There are no directions arising from this report.

## **CONCLUSIONS**

14. Building on learning from MICJ in the other partnerships within NHS Greater Glasgow and Clyde, MICJ provides a framework and evidence base to support improving patient outcomes and experience.
15. Macmillan ICJ in East Renfrewshire sets out to:
  - Invite all with a cancer diagnosis in East Renfrewshire to complete a Holistic Needs Assessment (HNA) and develop an individual care plan that includes carers and family members.
  - Provide the dedicated support of a named 'Link Worker' to everyone in East Renfrewshire with a cancer diagnosis, and to his or her carer or family.
  - Facilitate the delivery of effective and integrated Health and Social Care support solutions, based on their needs.
  - Demonstrate through outcomes the case for longer term sustainability of the service and the potential model for personalised care for other long term conditions.

## **RECOMMENDATIONS**

16. The Integration Joint Board is asked to note the report.

## **REPORT AUTHOR AND PERSON TO CONTACT**

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12 January 2023

Chief Officer, IJB: Julie Murray

## **BACKGROUND PAPERS**

Evaluation of Macmillan Improving the Cancer Journey – September 2020 Final Report  
<https://www.napier.ac.uk/~media/worktribe/output-2710068/evaluation-of-improving-the-cancer-journey-final-report.pdf>

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# EVALUATION OF IMPROVING THE CANCER JOURNEY

September 2020 - Final Report  
Executive Summary

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CANCER SUPPORT

Edinburgh Napier  
UNIVERSITY



# 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.

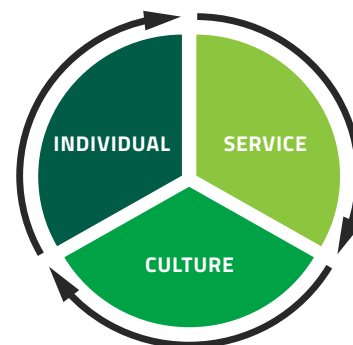
**Since its inception in February 2014 to June 2020 the service has supported 7587 individuals and families.**

## 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<sup>1</sup> 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.



5 YEARS OF ICJ

<sup>1</sup> 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 always 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.

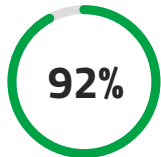


*Perceived benefits of ICJ*

## 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.



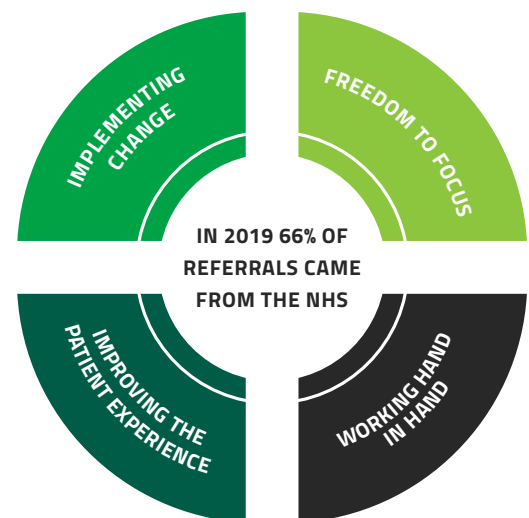
**70%** who agreed that referral to ICJ saves them time.



**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’<sup>2</sup>, 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<sup>3</sup>. 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.

<sup>2</sup> For example; <https://www.nhsconfed.org/-/media/Confederation/Files/Wales-Confed/WNHSC-Briefing-Seamless-services-to-improve-outcomes-for-people.pdf>

<sup>3</sup> <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<sup>4</sup>.**

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.

<sup>4</sup> <https://www.gov.scot/policies/illnesses-and-long-term-conditions/>

# EVALUATION OF IMPROVING THE CANCER JOURNEY

September 2020 - Final Report

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