

## Integration Joint Board 15 December 2022

<b>Subject :</b>	<b>Improving the Cancer Journey</b>
<b>Purpose :</b>	<ul style="list-style-type: none"> <li>• Awareness</li> <li>• Approval</li> </ul>
<b>Recommendation :</b>	<p>The Integration Joint Board is asked to:</p> <ol style="list-style-type: none"> <li>1. Note the vision and aim for the Macmillan Improving Cancer Journey within North Ayrshire;</li> <li>2. Support the development and delivery model proposed;</li> <li>3. Approve the proposed governance and oversight arrangements and</li> <li>4. Issue a Direction to NHS Ayrshire &amp; Arran to recruit staff for Programme delivery.</li> </ol>

<b>Direction Required to Council, Health Board or Both</b>	Direction to :-	
	1. No Direction Required	
	2. North Ayrshire Council	
	3. NHS Ayrshire & Arran	x
	4. North Ayrshire Council and NHS Ayrshire & Arran	

<b>Glossary of Terms</b>	
NHS AA	NHS Ayrshire & Arran
HSCP	Health and Social Care Partnership
ICJ	Improving the Cancer Journey
PSF	Project Support Facilitator
HNA	Holistic Needs Assessment
TCAT	Transforming Care After Treatment

<b>1.</b>	<b>EXECUTIVE SUMMARY</b>
1.1	<p>This paper sets out the proposed arrangements and opportunities for partnership working between Macmillan Cancer Support and East, North &amp; South Ayrshire Health &amp; Social Care Partnerships (HSCPs) to deliver key objectives of the Scottish Cancer Plan and other Scottish Government strategies by implementing an Improving the Cancer Journey (ICJ) model to help better meet the needs of people affected by cancer from the point of diagnosis across Ayrshire and Arran.</p>

1.2	<p>This £1.1m programme will be delivered on a pan Ayrshire basis with an aim to develop and work with HSCPs in Ayrshire and Arran building on the learning from the two local Transforming Care After Treatment (TCAT) projects to provide holistic care solutions and improve the personalised experiences of all people affected by cancer. Together, Macmillan in partnership with East, North &amp; South Ayrshire HSCPs and working with local health providers, local authorities, third sector, communities and people affected by cancer and carers will combine our expertise with the aim of ensuring everyone diagnosed with cancer can easily access all the support they need as soon as they need it to enable them to live as well and as independently as possible. In addition, there will be scope to consider the learning from the work and its transferability to other long term conditions to support the longer term sustainability of the work.</p>
1.3	<p>NHS Ayrshire &amp; Arran (NHS AA) Health Board is the host for the pan Ayrshire led Programme which will be delivered via East Ayrshire HSCP as Lead HSCP for Primary Care with local delivery and governance arrangements in place.</p>
<b>2.</b>	<b>BACKGROUND</b>
2.1	<p>The first ICJ was developed in Glasgow in 2014, which was a UK first and won many awards for its innovative and inclusive approach. The ICJ has since been implemented across Scotland with ICJs in Ayrshire and Arran, Dumfries &amp; Galloway, Borders and Lanarkshire being considered more recently within 2022.</p>
2.2	<p>Macmillan Cancer Support (2020) report that with the significant advances in treatment, many people, 1 in every 2, are now surviving their cancer. It is projected that across Scotland by 2030 that 350,000 people will be living with a cancer diagnosis, however it doesn't necessarily mean that people will be living well. Projections show that 70% of people with cancer will also have at least one or more co-morbidity, with cancer now increasingly recognised as a long-term condition.</p> <p>The increasing incidence and prevalence of cancer is also having a wider impact not only with an increase in informal carers but also on children (i.e. young carers or children with parents with cancer) and employers/education.</p>
2.3	<p>Macmillan Cancer Support highlight that returning to normality for those affected by cancer is fraught with difficulties, as the consequences of the disease and treatment pathways not only impact on their physical condition, but also on their psychological, financial and social wellbeing that necessitates;</p> <ul style="list-style-type: none"> <li>• Support with mental health issues arising from their experience of cancer;</li> <li>• Help to make lifestyle choices to aid survival and prevention of secondary occurrences and</li> <li>• Assistance with returning to and/or enabling independent living (including self-management) and maintaining wellbeing (including employment) or to access welfare benefits, and end-of-life and bereavement support.</li> </ul>

2.4	<p>Other key statistics reported by Macmillan Cancer Support (2020) suggest that 2 in 3 people living with cancer have practical or personal needs, 4 out of 5 have emotional needs, 83% of people living with cancer are impacted financially and 10,000 people are at risk of losing their home as a result of cancer. The 'Hidden at Home – the social care needs of people with cancer' Report revealed that 1 in 10 people with cancer in the UK say they are constantly or often left housebound due to a lack of support. Results from the 2016 Scottish Cancer Experience Survey revealed that nearly half of all the respondents (49%) who wanted it indicated that they received no information on financial assistance or benefits. These figures highlight that people affected by cancer have widespread needs that cannot be met solely by a medical model of care.</p>
2.5	<p>Macmillan Cancer Support also reported headline figures for Ayrshire and Arran which include a cancer incidence rate of approximately 645 per 100,000 equating to approximately 2,463 people within Ayrshire and Arran being diagnosed with cancer annually broken down to 785, 942 and 736 for East, North &amp; South Ayrshire respectively. In addition, the incidence of cancer is also anticipated to increase by 33% over the next 5-10 years. As well as a rising incidence of cancer, with more people now surviving their cancer diagnosis the prevalence of cancer will also be increasing. With a current prevalence of 3.8% of the population living with cancer it would be safe to assume that approximately 22,300 people are currently living with cancer across Ayrshire and Arran and this does not count the carers providing support.</p>
2.6	<p>Over the last few years Macmillan has invested significantly in Ayrshire and Arran across a number of different services including the TCAT programme, clinical services, welfare benefits, information &amp; support and Move More, with MoveMore implemented across our three HSCPs.</p>
<b>3.</b>	<b>PROPOSALS</b>
3.1	<p>It is proposed the Macmillan ICJ service across Ayrshire and Arran will be delivered by:</p> <ul style="list-style-type: none"> <li>• Utilising dedicated Project Support Facilitators (PSFs) to support delivery of the service;</li> <li>• Utilising local assets to assist with the signposting of ongoing referrals;</li> <li>• Ensuring cancer support is embedded in our three HSCPs strategic plans;</li> <li>• Accessing cancer services and associated clinical teams and wider support services;</li> <li>• Co-producing with service users and people affected by cancer. This will involve the development of an engagement plan to ensure those affected by cancer are able to influence local delivery of ICJ to ensure it meets their needs;</li> <li>• Ensuring income maximisation for service users with finance and housing services included in design;</li> <li>• Ensuring the ICJ is integrated within local health and social care systems;</li> <li>• Ensuring the electronic Holistic Needs Assessment system is utilised;</li> <li>• Reviewing current IT and other systems for case management and recording outcomes;</li> </ul>

	<ul style="list-style-type: none"> <li>• Supporting learning and development for the programme;</li> <li>• Supporting the attainment of the nine National Health &amp; Wellbeing outcomes and</li> <li>• Evaluating impact to inform future delivery.</li> </ul>
	<p>Following a detailed Option Appraisal process, which considered a wide range of implementation and delivery models, the model below was agreed at the ICJ Programme Board on 30 November 2022:</p> <p><b>Option 3: Develop into Community Connector/Links Practitioner/Worker Services</b></p> <p>This option meets the strategic aim of embedding the ICJ service into the community. Within Ayrshire HSCPs the Community Connector/Links Practitioner/Worker services are aligned to and delivered within GP practices, however they are managed within different services across the three locality areas:</p> <ul style="list-style-type: none"> <li>• North Ayrshire Community Links Workers as a local authority-based HSCP service</li> <li>• East Ayrshire Community Connectors within their Third Sector Interface (CVO EA)</li> <li>• South Ayrshire Community Links Practitioners as an NHS-based HSCP service</li> </ul> <p><b>Each of the IJBs are asked to support this approach to delivery.</b></p>
	<p>Oversight and management arrangements of the Programme have also been considered with wide engagement across the HSCPs, cancer support services and wider community services.</p> <p>It was agreed at the Programme Board on 30 November 2022 that the Programme Lead will work on a pan Ayrshire basis along with a Project Assistant to oversee the programme. The Ayrshire wide referral team will also be based centrally with the programme team, with the overall team linking closely with the Project Support Facilitators in each HSCP. As noted above, for North HSCP, the facilitators will be based within the communicator connector team (1.5wte).</p> <p>The Programme Board Terms of Reference are attached as Appendix 1. It has been agreed that a pan Ayrshire Operational Steering Group will also be established, Chaired by the Programme Lead.</p> <p><b>The IJB is asked to approve these arrangements.</b></p>
3.2	<u>Anticipated Outcomes</u>
	<ul style="list-style-type: none"> <li>• Improved access to, and increased uptake of, practical, emotional and financial support to those affected by a cancer diagnosis across North Ayrshire; this support is essential for wellbeing and quality of life;</li> <li>• Individuals affected by cancer will benefit from having an outlet to discuss their concerns, particularly those related to financial burdens and emotional worries</li> </ul>

	<p>they did not feel were appropriate to be addressed within a clinical setting, and so improving their experience of cancer;</p> <ul style="list-style-type: none"> <li>• Release of clinical time previously taken up with the non-clinical aspects of supporting those affected by cancer and</li> <li>• Development of a skilled workforce who acknowledge and work within their own competency to address the non-clinical needs of those affected by cancer.</li> </ul>
3.3	<p><u>Measuring Impact</u></p>
	<p>Work is currently underway with Macmillan Cancer Support and Edinburgh Napier University to develop a minimum dataset with which to measure the impact of ICJ within each local authority or health board area, and across Scotland.</p> <p>The ICJ across Ayrshire and Arran will contribute to this work and also consider any additional local requirements.</p>
<b>4.</b>	<p><b>IMPLICATIONS</b></p>
4.1	<p><u>Financial</u></p> <p>This programme work sits within Macmillan's Strategic Plan in Scotland and the Scottish Government's financial support for the Transforming Cancer Care Programme.</p> <p>£1.1 million has been agreed to support the development of an ICJ across Ayrshire and Arran over a minimum of three years utilising the robust approach that has been developed in Glasgow and with other ICJs. NHS AA will manage the flow of these funds.</p> <p>NHS AA finance representation is on the overarching Programme Board.</p>
4.2	<p><u>Human Resources</u></p> <p>The overall programme includes:</p> <ul style="list-style-type: none"> <li>• 1wte x Programme Manager (pan Ayrshire Lead)</li> <li>• 1wte x Project Assistant (pan Ayrshire)</li> <li>• It is anticipated that 4.5 WTE Support Facilitators will be required to fulfil the aims and objectives of the project across Ayrshire and Arran with 1.5 WTE being managed by NHS Ayrshire &amp; Arran/North Ayrshire HSCP.</li> </ul> <p>Further discussions are required to determine who will employ the Project Support Facilitators, but it is anticipated this will be NHS AA.</p> <p>HR and staff side are represented are included on the overarching Programme Board.</p>
4.3	<p><u>Legal</u></p> <p>There are no legal implications from this report.</p>

4.4	<p><u>Equality/Socio-Economic</u></p> <p>As reported in the report of the evaluation of the ICJ in Glasgow in 2015, there is a link between socio-economic factors, negative health related behaviours and incidences of cancer.</p> <p>The prevalence of cancer primarily resides within populations with the highest deprivation and Ayrshire &amp; Arran has a number of areas (123 datazones), which would be regarded as being some of the most deprived in Scotland.</p> <p>Although deprivation is an important factor in outcomes for cancer patients, those affected by cancer can also experience a range of physical, emotional, and social, as well as financial concerns.</p>
4.5	<p><u>Risk</u></p> <p>There is a risk that the ICJ is not embedded within core services at the end of the Programme term which will affect the sustainability of the ICJ service across Ayrshire and Arran.</p> <p>Different approaches for training and resilience across services to embed the model will be explored and tested throughout the programme to mitigate this risk.</p>
4.6	<p><u>Community Wealth Building</u></p> <p>The development of an ICJ will create additional posts in North Ayrshire which will support the employability agenda. Additionally, there is the possibility of a future opportunity to enhance third sector delivery on the isle of Arran.</p>
4.7	<p><u>Key Priorities</u></p> <p>The ICJ Programme aims to:</p> <ul style="list-style-type: none"> <li>• Improve mental and physical health and wellbeing;</li> <li>• Tackle inequalities by providing “early and effective support” to those affected by a cancer diagnosis which are stated as ambitions within the North Ayrshire HSCP strategic plan and</li> <li>• develop self-care/self-management, coping skills and improve health literacy.</li> </ul>
5.	<p><b>CONSULTATION</b></p> <p>The content and proposals within this paper have been explored in detail with the Programme Board on 30 November 2022.</p> <p>An engagement plan has also been developed and is currently being implemented to allow those affected by cancer, as well as wider group, to influence the local delivery of the ICJ. This is being taken forward by the Macmillan Programme Lead with support from local organisations such as Ayrshire Cancer Support, and the Macmillan Engagement Officer.</p>

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Appendices

- Appendix 1, Macmillan ICJ (A&A) Programme Board Terms of Reference

## Appendix 1: ICJ (A&A) Programme Board Terms of Reference



### Macmillan Improving the Cancer Journey (Ayrshire & Arran) Programme Board

#### Terms of Reference

##### 1. Purpose and Role of Group

The Macmillan Improving Cancer Journey (ICJ) Programme Board (Ayrshire and Arran) will oversee the direction, development and delivery of the programme, ensuring that the desired outcomes and benefits are achieved.

##### 2. Responsibilities of Group

The ICJ (A&A) Programme Board is responsible for:

- Providing overall strategy and direction of the ICJ, including ensuring any changes in the internal and external environment that present opportunities for the project are considered
- Ensuring coherent development and delivery of programme plans and service model, authorising any significant changes
- Directing resources within respective organisations that are required to deliver organisational and cultural changes
- Providing financial governance of the project
- Monitoring and reviewing performance and quality
- Project communications and engagement strategy and plans
- Risk and issue management, with authority for the day-to-day management of risks and issues being delegated to the ICJ (A&A) Operational Steering Group
- Ensuring the sustainability of the programme
- Championing and advocating for the project both internally and externally.

##### 3. Principles of Working

The ICJ (A&A) Programme Board will:

- Maintain focus on the strategic goals and objectives, achieving positive impact for all stakeholders



- Ensure that the programme is based on the best available evidence and good practice
- Embrace co-production, working alongside people affected by cancer
- Work collaboratively across the partnerships and beyond, building a strong coalition for change

#### **4. Chairperson**

The chair of the group will be Vick Campbell, Head of Primary & Urgent Care Services, NHS Ayrshire & Arran.

#### **5. Membership**

The membership of the ICJ (A&A) Programme Board is as follows:

- Strategic Partnership Manager, Macmillan Cancer Support
- Senior Manager, Primary Care Services, East Ayrshire HSCP
- Partnership Lead, East Ayrshire Health & Social Care Partnership
- Partnership Lead, North Ayrshire Health & Social Care Partnership
- Partnership Lead, South Ayrshire Health & Social Care Partnership
- Third Sector Interface Representative
- Clinical Nurse Consultant, NHS Ayrshire & Arran
- General Practitioner
- NHS Ayrshire & Arran Finance Representative
- NHS Ayrshire & Arran O&HRD Representative
- Staff side representation
- HMP Kilmarnock Representative
- Macmillan Programme Lead, ICJ, NHS Ayrshire & Arran

Deputies can be nominated where members are not able to attend. The presence of a deputy will be included in the calculation of a quorum.

Additional members may be required to attend as requested by the group for specific areas as the ICJ progresses.

#### **6. Quorum**

To be quorate the meeting requires to have six members present.

#### **7. Meetings**

The ICJ (A&A) Programme Board will meet six weekly during the early implementation stage, which may reduce to quarterly after the early implementation phase.

The agenda for each meeting will be agreed in advance and the agenda and papers for each meeting will be circulated at least five working days before the date of the meeting.