Midlothian Integration Joint Board

Thursday 26th August, 2021

Improving the Cancer Journey- Service Update

Item number:	**Agenda number: 5.5**

Executive summary

Improving the Cancer Journey (ICJ) is a Macmillan-funded programme for the Lothians and brings investment of £295 000 into Midlothian. The service supports people's non clinical needs following a cancer diagnosis and is also open to carers.

In Midlothian, the funding has been used to secure two additional Practitioners to join Thistle's Wellbeing Service. In addition, a part-time Project Manager is employed and Along with the Programme Manager, supports the planning, implementation and service monitoring and evaluation.

The service went live in March 2021 and funding is secured for four years.

Board Members are asked to:

- Review the progress made to date
- Note the approach taken to align ICJ with an existing service in Midlothian
- Consider the monitoring and evaluation plans
- Consider the expectations for the service in the first year of operation

Report

Improving the Cancer Journey- Progress Update

1 Purpose

1.1 To share information with the IJB on progress made since going live in March 2021.

2 Recommendations

2.1 As a result of this report what are Members being asked to:-

- Review the progress made to date
- Note the approach taken to align ICJ with an existing service
- Consider the monitoring and evaluation plans
- Consider the expectations for the service in the first year of operation

3 Background and main report

3.1 Improving the Cancer Journey (ICJ) is included in Midlothian HSCP's Strategic Plan as part of the work to look at a range of long term conditions collectively. Governance is via the local Operational Group, Chaired by Fiona Huffer (Midlothian rep on the ICJ Programme Board), which reports into the Pan-Lothian Programme Board (Chaired by Morag Barrow).

3.2 Midlothian ICJ helps people access services which can support people to live well following a cancer diagnosis. This includes mitigating against financial consequences, managing symptoms such as fatigue and pain, help to navigate the wider systems, including accessing social care, housing and third sector services; as well as contributing to an individual's sense of feeling more 'in control' and improve overall wellbeing. Across the ICJ services in Scotland, fatigue, money, mobility and mental health (anxiety, low mood) are consistently the most common concerns raised. ICJ uses a model similar to the existing Wellbeing Service, focusing on 'what matters', supporting people to self-manage and directing into local services for support.

3.3 Public Health Scotland has provided data for Midlothian based on the 5 year period up to the end of 2017 of incidence (644 cancer diagnoses per 100 000), prevalence data (over 3000 people living with cancer) and mortality data (290 deaths per 100 000); with additional information in terms of age, deprivation, stage at diagnosis for the 6 most common cancers (lung, breast, colorectal, prostate, head and neck and skin).

3.4 Key Performance Indicators (KPIs) have been agreed by the ICJ Programme Board in terms of uptake, with the expectation that 40% of people with a new diagnosis of cancer will be referred into the service. For Midlothian, this equates to 212 people. In addition, people living with cancer and carers can also access the service. Work is also underway to set a KPI related to inequalities and the % of referrals coming from SIMD1 & 2 areas (the most deprived 40%).

3.5 Macmillan's Holistic Needs Assessment (HNA) captures quantitative data around:

- Demographics: age, gender, deprivation
- Health information: cancer type, pathway stage, co-morbidities
- Referral source
- Service user or carer
- Concerns: number, type and severity
- Actions taken: referrals, signposting, information

Going forward, we are working with partners and data will be sought to establish:

- Financial gains - e.g. Macmillan Grants, Benefits, Blue Badge
- Housing information- e.g. adaptations, avoidance of rent arrears and evictions
- Participation in physical activity programmes

Case Studies will be routinely sought to offer qualitative information and demonstrate personal outcomes (see Appendix 2). Questionnaires to service users and staff are also planned.

3.6 Between March-July 2021, 45 referrals have been received and the pace of referrals is increasing with 18 referrals received in July. These have come from a range of colleagues, including Clinical Nurse Specialists, primary care, social care and self-referrals (Public Health Scotland send an invitation letter out 6-8 weeks post diagnosis, inviting people to contact the service). It should be noted that the Midlothian team have also provided a service for people from East Lothian and Edinburgh until the ICJ teams were established in these areas (these teams went live at the start of August).

3.7 The majority of service users are women and are aged over 60, which mirrors uptake in other ICJ services. It should be noted that in addition, strong relationships are developing with the Gynae and Breast Teams. Conversely, the Urology Team have been slower to engage with, but are now starting to refer. This will be an area for monitoring and taking proactive steps to mitigate against any imbalance. As the service develops, a comparison will be made between ICJ service users and the actual populations to monitor service reach across the SIMD (deprivation) quintiles although the uptake so far in SIMD 1 and 2 is encouraging.

3.8 The main concerns have been fatigue, anxiety, uncertainty, nutrition and finances, with referrals onto a range of services including Macmillan Welfare Benefits, OT, Physio and Red Cross. See Appendix 1 for a summary.

3.9 The person-centred approach of ICJ will help develop understanding of the needs of people affected by cancer and as well as common themes, it will be important to highlight areas where there are specific issues and possible gaps in service provision. An example of this is from younger service users who have highlighted particular difficulties relating to work, money and family.

3.10 As the service develops, the intention is to develop a deeper understanding of the work in terms of common ground and the differences between ICJ and the Wellbeing Service and options for sustainability once the Macmillan funding concludes.

4 Policy Implications

4.1 The service can contribute in terms of (i) tackling inequalities; (ii) early intervention; (iii) the integration and co-ordination of care; (iv) supporting people with a long term condition and (v) managing resources effectively.

5 Directions

5.1 Improving the Cancer Journey contributes towards:

DIRECTION 19: PUBLIC HEALTH
The importance of shifting the emphasis of our services towards prevention and early intervention along with the need to redouble our efforts to tackle inequalities.

DIRECTION 5: Primary Care Improvement Plan - Link Workers
The ICJ Practitioners join the existing Wellbeing Service which operates in all Midlothian GP Practices.

6 Equalities Implications

6.1 An Integrated Impact Assessment was undertaken in February 2021 and a number of actions were identified to mitigate against identified concerns.

7 Resource Implications

7.1 While Macmillan funding is in place, there are no funding implications, but an exit strategy is required. This, in part depends on the monitoring and evaluation of the service as well as the IJB's plans for the Wellbeing Service.

8 Risk

8.1 None

9 Involving people

9.1 There is service user representation at the Programme Board and on Midlothian's Operational Group. The Project Team are developing opportunities for people affected by cancer including:

- Having experiences listened to
- Shaping the local ICJ service and telling us 'what matters'

- Supporting key areas of service delivery, e.g. digital inclusion agenda, returning to face to face assessments
- Identifying gaps in our plans/with services
- Providing support to take part in activities, e.g. formal group membership
- Feedback on plans and if they have used ICJ, tell us what they thought about the service

In Midlothian, a group of 5 people with lived experience of cancer have met, supported by colleagues from Macmillan and the Midlothian ICJ team. They wish to be a peer-led group. Themes include

- Everyone's experience with cancer is unique
- Loneliness - even when surrounded by family and friends
- Not wanting to burden family and friends with worries and concerns
- The value of peer support and how natural connections are made
- Importance of practical help (often not available)
- Opportunities for the group to inform health professionals learning
- Value of local support in Midlothian
- A peer led network would have great local knowledge of support available
- Online meeting may create greater accessibility for some people – not having to travel

9.2 The ICJ project team have established a Lothian-wide Forum that will bring together a group of people from across the four HSCP areas with lived experience of cancer, including family members and carers. This forum will meet quarterly and help inform and support the development of ICJ.

10 Background Papers

10.1 None

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DATE	6th August 2021

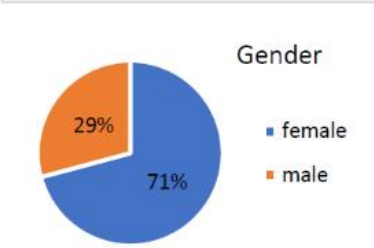
Appendices:

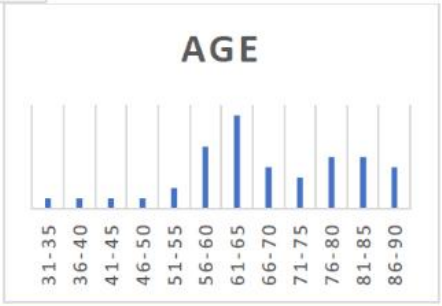
Appendix 1: Service Report
Appendix 2: Case Study

Appendix 1: Service Summary: Midlothian ICJ: March-July 2021

Referrals and demographics

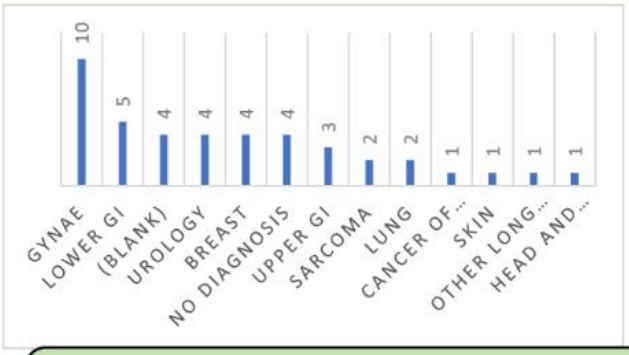
Comments
Broad range of referral sources including Clinical Nurse Specialists, GPs, Primary Care Mental Health Team, Wellbeing and Social Care
Age range 33-90 years – with 71% over 60 years old

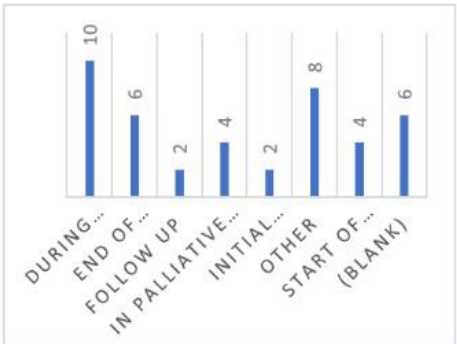




SIMD	ICJ	Midlothian Population
1	7%	8%
2	53%	34%
3	33%	24%
4	7%	21%
5	0%	14%

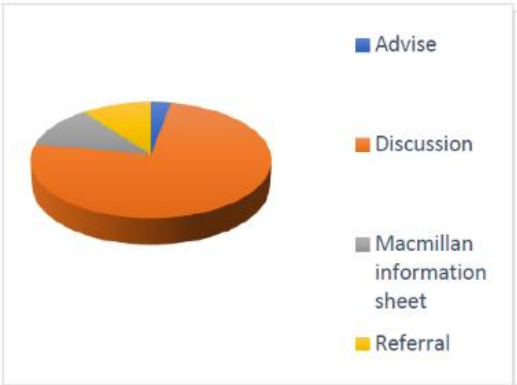
Diagnosis and Pathway stage

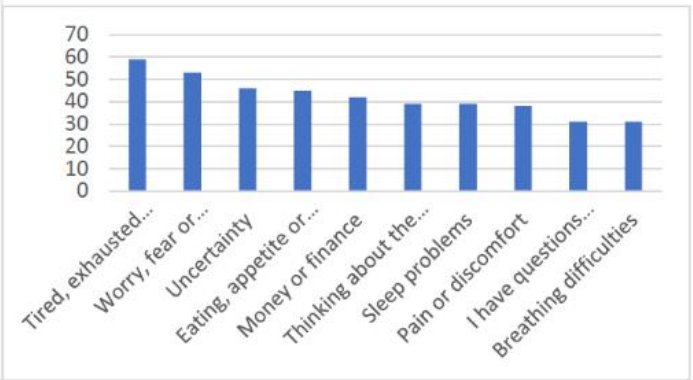




Comments: Good links developing with CNS colleagues. 4 carers have been referred to the service (No diagnosis category). Majority of people are 'in treatment'. Significant number palliative

Concerns and Actions





Comments: Practitioners have made referrals to: Housing; OT; Physio; Macmillan Welfare Rights; Red Cross; Dial a ride; Ranger service

Reflections and Learning

Practitioners noticing for the people referred who are having treatment - support has been around practical issues and has involved actioning referrals on – e.g. referral to OT for aids, housing issues.

Gaps in support – support for shopping if person is unable shop online – practitioners investigating further.

Challenge of telephone conversations with older people how to include carers where appropriate to help get the full picture while ensuring the support is centred around the person.

Appendix 2: Midlothian ICJ Case Study

Two years ago **B** was diagnosed with a recurrence of breast cancer and told she had a terminal diagnosis, which she says has preoccupied her mind, but she now tries to focus on living. She is currently about to start another course of chemotherapy.

B's top concerns from her Health Needs Assessment (HNA) and initial appointment

- Concerns about treatment and the future.
- Family live away and only able to see on a screen – concerned about how they were copying with her illness
- Independence – she has always looked after other people – she is now concerned about having to rely on others
- Fatigue – Struggling to cook meals because of fatigue caused by chemotherapy
- Worry fear and anxiety – treatment may stop

Support from ICJ
B has received an initial telephone appointment and follow up calls on a fortnightly basis over the last few weeks. Support from ICJ focussed on what **B** was already doing that was helping and the difference it made. Support also focussed on:

Fatigue and energy management
B started to monitor her eating, trying to eat small amounts more regularly and has found that she is able to eat a bit more. She is pacing her activities and making sure she plans her days so not to overdo things on the days she feels better but making sure she does a little each day.

Concerns about treatment and the future
Support from the ICJ has helped **B** reflect on questions she needed to ask the CNS and the GP. Support helped **B** to start to think about where she would like to stay – exploring her options to stay local or move to be nearer family.

Referrals on
Midlothian Ranger services; transport when unable to get to chemotherapy appointment; Connect to support IT skills for accessing online classes

What difference has appointment with ICJ made?
'Having local support in Midlothian I can contact when needed is really helpful'.

'Appointments have encouraged me to keep doing the things I was doing and also given me ideas about other things that might help'.

'It has helped me talk about things I didn't always want to talk to family and friends about – helped me off load and feel better'.

'It has also helped me explore my choices rather than telling me what to do'.