

Equality Human Rights and Fairer Scotland Duty Impact Assessment

Stage 2 Empowering People - Capturing their Views



Scottish Borders MacMillan Improving the Cancer Journey

Supporting the non-medical concerns of people newly diagnosed with cancer

Equality Human Rights and Fairer Scotland Impact Assessment Team

Role	Name	Job title	Date of IA Training
HSCP Joint Executive Team	Chirs Myers Lynne Huckerby	Director / Chief Officer, Borders HSCP Interim Director Acute, NHS Borders	
Responsible Officer	Simon Burt	General Manager Mental Health and Learning Disabilities Service	
Main Stakeholder (NHS Borders)	Laura Gibson	Project Manager Macmillan Improving the Cancer Journey	
Mains Stakeholder (SBC)	Claire Veitch	Local Area Coordination Service Team Manager	
Third/Independent Sector Rep	Ben Mudge	Engagement Manager, Macmillan	

Evidence Gathering (will also influence and support consultation/engagement/community empowerment events)

Evidence Type	Source	What does the evidence tell you about the protected characteristics affected?
What equalities information is routinely collected from people currently using the service or affected by the policy?	None	No data currently available s this is a new service for anyone diagnosed with cancer
Data on populations in need	National Data – Public Health Scotland & MacMillan (specifics to be added)	
Data on relevant protected characteristic	https://publichealthscotland.scot/publications/cancer-incidence-in-scotland/cancer-incidence-in-scotland-to-december-2021/ https://www.nature.com/articles/s41416-022-01718-5 https://www.cancerresearchuk.org/about-	<p>Age - Older people are more likely to be diagnosed with cancer than younger people. In 2021, ¾ of cancer diagnoses were in people aged 60 years and over</p> <p>Sex – more men than women are diagnosed with cancer overall, however in the 25-59 years age group the risk is higher for females than males. Some cancers are more prevalent in younger age groups e.g. cervical.</p> <p>Gender reassignment - the carcinogenicity of hormonal therapy in transgender people is an area of considerable concern. Concerns about cancer risk in transgender patients have been linked to sexually transmitted infections, increased exposure to well-known risk factors such as smoking and alcohol use, and the lack of adequate access to screening.</p> <p>Disability – if you have cancer, the law considers this a disability. This means people with cancer cannot be treated less favorably than other people because you have cancer or for reasons connected to the cancer. Disabled people are more disadvantaged in social determinants of health and therefore have high rates of risk factors for some types of cancer as they are more likely to smoke, be overweight and be physically inactive than people who are not disabled. Disabled people face barriers to obtaining</p>

	<p>cancer/coping/practically/the-disability-discrimination-act-equality-act-and-cancer</p> <p>https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045%2822%2900018-3/fulltext#:~:text=People%20with%20disabilities%20also%20have,individuals%20who%20are%20not%20disabled.</p> <p>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5868281/</p> <p>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8177048/</p>	<p>cancer care including inaccessible medical diagnostic equipment, ineffective communications accommodations and potentially biased attitudes among clinicians.</p> <p>Marriage and civil partnership – cancer can take a huge toll on relationships.</p> <p>Pregnancy and maternity – in pregnancy, there may be limitations to the treatment options for cancer, and pregnant women may have different support needs</p> <p>Race – the rates of some cancers vary by ethnicity. White people are more than twice as likely to get some types of cancer than people from Black, Asian or Mixed ethnic backgrounds. However, some cancer types are more common in Black people and some more common in Asian people.</p> <p>Religion or belief (including non belief) – being diagnosed with serious illnesses like cancer can cause people or their care givers to have doubts about their beliefs or religious values and cause much spiritual distress.</p>
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Data on service uptake/access	Not applicable – new service	Recommendation to capture from electronic Holistic Needs Assessment reporting & monitoring info Learning from other areas Screening uptake may be of relevance
Data on socio economic disadvantage	https://publichealthscotland.scot/publications/cancer-incidence-in-scotland/cancer-incidence-in-scotland-to-december-2021/	Socio-economic circumstance – cancer risk is greater with increasing deprivation. There are associations with stage of cancer diagnosis also for example, more women are diagnosed with breast cancer as deprivation category increases.
Research/literature evidence	As noted above	
Existing experiences of service information	Not applicable – new service	
Evidence of unmet need	Not applicable – new service	Recommendation to capture – electronic Holistic Needs Assessment reporting & monitoring info
Good practice guidelines	https://www.gov.scot/publications/national-cancer-strategy-scotland-2023-2033-equalities-records-impact-assessment/pages/4/	Cancer Strategy Scotland 2023-2033 – Equality Records Impact Assessment Chapter 4 – Assessing the impacts and identifying opportunities to promote equality sets out the protected characteristics that are impacted positively, negatively or no impact by the national Cancer Strategy – the impacts are all positive or no impact. We have used this to inform planning for our new local service as it is a key action within the associated Action Plan
Other – please specify	https://www.gov.scot/publications/equalities-impact-assessment-recovery-redesign-action-plan-cancer-services/	Cancer Services – Action Plan: Equalities Impact Assessment evaluates how the Cancer Recover Plan will affect individuals once impacted We have used this national document to identify inequality at a local level and actions to address these

Risks Identified	None	
Additional evidence required	None identified	

Consultation/Engagement/Community Empowerment Events

Event 1: Online survey open to the whole population and completed by people with a disability

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
March to April 2024	Online survey	119 responses including people with lived experience of cancer	Protected characteristics were not requested therefore unknown, however over 55% of respondents had experienced cancer themselves, which is recognized as a disability by the Disability Act, therefore disability is represented in the survey results.

***Attendance by category – including but not limited to: People using the service, people not using the service - currently, unpaid carers, paid carers, key stakeholders (organisation and job title)**

Views Expressed	Officer Response
The service might not reach all of those who would benefit from it “Admitting to needing more advice or support”	We will proactively offer the ICJ service to everyone newly diagnosed with cancer and will work closely with Cancer Services and other partners across the Borders to help us to identify people who the service should be offered to
People may not want the service straight away, but might need it later in their cancer journey “Your needs change throughout the journey”	We will offer the service from the point of diagnosis whilst ensuring that there are multiple opportunities for people to access the service throughout their cancer journey. For people who decline the service when it is first offered, they will

<p>"In reality, you cannot retain information at the time, being in shock at the diagnosis"</p>	<p>receive written information about ICJ and a service leaflet encouraging them to contact us at any point in the future.</p>
<p>Some people will be too unwell to travel to an appointment "Depending on condition on the day, flexibility of access has to be paramount" "Not wanting to leave the house as too unwell"</p> <p>Some people will be unable to travel to an appointment in another town "transport services are shocking yet all services are located in the central Borders" "it needs to be prepared to operate in small distant localities and not expect patients to travel to hospital"</p>	<p>We will have a variety of comfortable places to meet with people in their local community settings across the region and will enable them to choose where we meet with them. We will be flexible in rescheduling calls and appointment to meet their needs.</p>
<p>Some people will not be comfortable to meet in person "Having options like Teams or Zoom will make it much easier for people"</p> <p>Some people will prefer to meet in person "someone that could visit you at home" "Has to be face to face to be really useful – to easy to say I'm fine otherwise"</p> <p>Some people won't want to meet virtually "not everyone is online" "online is a good substitute but somehow not as satisfactory as in person in a small intimate venue within the local community"</p>	<p>We will offer a range of options for people to choose from, including face to face appointments in their own homes or community settings, online appointments and telephone appointments. We will take into consideration travel times, venue accessibility to ensure a range of appropriate options.</p>
<p>Letting everyone know about the service may be a challenge "lack of knowledge that the service exists and where/how to access it"</p>	<p>We will develop a Communications Plan to raise awareness of the service across the region and work with Borders Community Action to ensure that communications are appropriate for a range of audiences including in alternative formats. We will use a range of media to promote the service to reach as many people as possible.</p>

One person's support needs will be different from the next person's "Not necessarily knowing what they want, need or can get" "Getting folk to take the help as often people find it hard to open up or talk"	We will deliver a person centred service that enables people to access the support that's important to them. Using a Concerns Checklist will act as a prompt for people to think about things more widely that matters to them.
Some people will be unable to access digital tools and information "Not everyone is online"	We will have paper copies of all communications for those who do not wish to or are unable to access them digitally ensuring accessibility for all including people with learning disabilities. We will have an easy-read tools available for those with learning disabilities and large print for those with visual impairments.
Some people were concerned about the capacity of the service to support everyone who needs it "the lack of staff to cover a large geographic area" "Assurance that there is sufficient funding available and enough staff to fulfill demand" Some people were concerned that the short term funding would limit the service "can only be resolved by greater financial investment"	We will continue to work closely with the Health and Social Care Partnership and Macmillan to plan a sustainable service that has the capacity to reach everyone diagnosed with cancer and continuation beyond the funding period.

Event 2: Survey of people with a learning difficulty

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
May 2024	Paper survey distributed to 20 members of Borders Care Voice's Local Citizens Panel	1 completed response received 4 incomplete responses received	Disability

	for Adults with Learning Disability and their Carers		
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Views Expressed	Officer Response
Included in Event 1 above	Included in Event 1 above

Event 3: Ukrainian survey

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
May to June 2024	Online survey - Ukrainian	Although our survey was cascaded to Ukrainian people through SBC colleagues and the mass media, the survey received 0 responses	Race

Views Expressed	Officer Response
n/a	n/a

Event 4: Polish Survey

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
May 2024	Online survey	Although our survey was cascaded to Polish people through SBC colleagues and the mass media, the survey received 0 responses	Race

Views Expressed	Officer Response
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n/a	n/a
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Event 5: Women who have experienced domestic abuse

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
May 2024	Online workshop	3 attendees who had experience of domestic abuse plus group facilitator	Gender

Views Expressed	Officer Response
Opening hours of 9am to 5pm might be difficult for women with children or women who work Mon-Fri 9am to 5pm	We will offer a range of options for people to choose from, including face to face appointments in their own homes or community settings, online appointments and telephone appointments
Impact of controlling behavior from abusive partners which might restrict access to support services like ICJ	<p>We will proactively offer the ICJ service to everyone newly diagnosed with cancer</p> <p>We will offer the service from the point of diagnosis whilst ensuring that there are multiple opportunities for people to access the service throughout their cancer journey, enabling women to access at the time that is right for them</p> <p>We will have a variety of comfortable places to meet with people in community settings across the region to ensure that women have an option that works for them</p> <p>We will offer a range of options for people to choose from, including face to face appointments in their own homes or community settings, online appointments and telephone appointments</p> <p>We will deliver a person-centred service that enables people to access the support that's important to them</p>

Event 6: People with mental health problems

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
29/04/24	Community Centre in Duns and Hawick – open sessions for people with experience of mental ill health, carers and people with learning disabilities	1 attendee who experiences mental ill health	Disability

Views Expressed	Officer Response
“GP surgeries should be aware and tell people about the ICJ service”	We will develop a Communications Plan to raise awareness of the service across the region and consult Borders Community Action to ensure our mediums are accessible and suitable for all#
“Consider how people will find out ICJ is there”	We will proactively offer the ICJ service to everyone newly diagnosed with cancer
“Finance including transport and travel”	We will offer a range of options for people to choose from, including face to face appointments in their own homes or community settings, online appointments and telephone appointments

Event 7: People who are neurodiverse

Date	Venue	Number of People in attendance by category*	Protected Characteristics Represented
May 2024	Galashiels	6 attendees	Disability

Views Expressed	Officer Response
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<p>Accessibility of service</p> <p>“understanding my individual needs as a neurodivergent person”</p>	<p>We will offer a range of options for people to choose from, including face to face appointments in their own homes or community settings, online appointments and telephone appointments</p> <p>We will promote that the service is suitable for people who are neurodiverse and will work with local groups and forums such as Borders Additional Needs to progress this</p> <p>We will provide opportunities through our evaluation forms to encourage continuous feedback from people to ensure that we identify opportunities to improve access to ICJ</p>
<p>Adaptations might be needed for written / electronic materials</p> <p>“sometimes the way things look on a mobile phone, like the colours, make it hard to understand”</p>	<p>We will have paper copies of all communications for those who do not wish to or are unable to access them digitally and will work with Borders Additional Needs Group to develop materials that are accessible</p> <p>Macmillan has recently developed an ‘easy-read’ version of the Concerns Checklist and we will use this to support people who prefer an accessible version</p>
<p>Assessment is a term that puts people off</p> <p>“if you’ve had a bad experience with an assessment, the language you use might put people off”</p>	<p>ICJ staff will use appropriate language in delivering a person-centered service to ensure that we describe the tools and processes that we use to identify what matters to someone and work with them to agree how best to support them.</p> <p>The staff will be flexible and adapt their approach to meet the individual needs of each person that they support and will seek feedback from individuals to ensure continued improvement.</p>

Please note that we also attempted the following:

Arabic survey – though we paid for the survey to be translated, it was not possible to put it on to the survey platform or Microsoft Forms as Arabic writes right to left

An event with LGBTQ+ people – although there was initial interest, there was no response to follow up contact

There are no current encampments within the Borders so unable to engage with Gypsy Travellers