

Equality and Human Rights Impact Assessment (EQIA) for Single Point of Contact

Date

V0.1

Name (policy/ procedure/ practice/ function)	Single point of contact equality and human rights impact assessment
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Team	Improving Access
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www.healthcareimprovementscotland.org

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1. Background

For all new or revised work, Healthcare Improvement Scotland has a legal requirement under the [Public Sector Equality Duty](#) to actively consider the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the [Equality Act 2010](#).
- Advance equality of opportunity between people who share a [protected characteristic](#) and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

Additionally:

- We give consideration to the principles of the [Fairer Scotland Duty](#) by aiming to reduce inequalities of outcome that are based on socio-economic disadvantage.
- If children up to the age of 18 are actually or potentially impacted, ensure you have undertaken a children's rights and wellbeing stage 1 assessment and carried out a stage 2 assessment if required. Guidance on Children's Rights and Wellbeing Impact Assessment (CRWIA) is available from the Scottish Government here: [Child rights and wellbeing impact assessment external guidance and templates - gov.scot \(www.gov.scot\)](#) The relevant templates are listed in section 9 at the end of this document.
- As the Children and Young People (Scotland) Act 2014 names Healthcare Improvement Scotland as a corporate parent, we must consider the needs of young people who have experienced care arrangements, and young people up to the age of 26 who are transitioning out of these arrangements.
- If the work will impact islands communities please follow the guidance from Scottish Government here: [Island communities impact assessments: guidance and toolkit - gov.scot \(www.gov.scot\)](#). Island communities are included within this impact assessment template.

This EQIA template is designed to guide teams through assessing the impact of their work. A team should begin this assessment as soon as they start planning a new piece of work or revising an existing piece of work. A team might use this template solely as a planning tool, or keep it as a live document to review and update as the work progresses.

When the work is completed this assessment should be published on the Healthcare Improvement Scotland EQIA page within a reasonable timeframe. Please ensure you have

deleted all the guidance and presented your document for public view. The EQIA for publication should be sent to: his.online@nhs.scot

2. EQIA overview

Use this section to provide details about the status (**new or existing**) of the work (which could be policy/practice/procedure/function) and provide an outline of the proposal including **aims** and **outcomes**. Please note all tables within this template are expandable.

Status	New <input checked="" type="checkbox"/>	Existing <input type="checkbox"/>
Aim	Healthcare Improvement Scotland will deliver a programme to help inform future Scottish Government (SG) policies to improve cancer care experience for the people across Scotland. We will do this by assessing the quality of Single Point of Contact (SPoC) on the cancer care experience and the high impact opportunities to spread to the wider system	
Intended Outcomes	<p>The objectives for 2024/25 will be to:</p> <ul style="list-style-type: none"> • Articulate the impact of SPoC services for patients, families and staff, using qualitative and quantitative data • Enable a better understanding of the quality of SPoC on the cancer care experience and the high impact opportunities of spread to the wider system • Collect, assess and share evidence that supports the design delivery and assurance of SPoC services 	

Is there specific relevance for children and young people?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
Are island communities included in the work?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>

3. Advancing equality

Provide details of how you think the work might impact **positively**, **negatively** or **neutrally** on people who share the characteristics listed below. This is about your judgement – you do not need to identify a positive, negative *and* neutral impact for every characteristic.

We are aiming to ensure we do not cause discrimination or miss an opportunity to ensure the diversity of intended beneficiaries enjoy the outcomes equitably.

It will be helpful to consider things like potential access issues, health inequalities or past experiences of discrimination that could be relevant to communities and that we can respond to / demonstrate awareness of somehow.

It will also be helpful to think about human rights and whether these will be impacted for any group. Our rights are described in the [Human Rights Act](#). Some groups are also protected by specific conventions, which are highlighted for your information in the relevant sections below.


There is no word count – you should include the information you think is relevant and proportionate. Please ensure the information you use is evidence based (e.g. articles, reports, engagement results, previous work). There is space at section 8 for you to record the evidence sources you use in your assessment. If you need a starting point for relevant equality-focussed evidence, see our Grey Literature Resource on the Equality and Diversity page.

General resources:

- <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2015-16-exploring-differences-cancer/pages/2/>
- <https://www.ncpes.co.uk/interactive-results/>

(Country/International)


(Type of article)

 Age	<p>Think about people from different age groups. Will the work affect specific age groups or in differential ways?</p> <p>If children up to the age of 18 are impacted, please complete the Children’s Rights and Wellbeing Impact Assessment (CRWIA) templates at the end of the document and follow the guidance here: <u>Child rights and wellbeing impact assessment external guidance and templates - gov.scot (www.gov.scot)</u></p>
Positive impact	
Negative impact	
Neutral impact	

Two factors were considered here: incidence and experience. On incidence, it is clear that the likelihood of developing cancer increases with age, with around 36% of new cases each year occurring in people aged 75 and over. Children and young people (0-24) account for less than 1% of new cancer cases, though incidence rates for these two age cohorts are showing the greatest increase in the UK since the 1990s[1]. Older people are also more likely to experience multimorbidity, which might cause a variety of complications when diagnosed with cancer[2].

Chambers et al, in their study using data from the National Cancer Registration and Analysis Service database and focusing on colorectal cancers in people aged 20 or over, that “Young adults comprised only a small proportion of new diagnoses of CRC but were more likely to present with advanced disease than older adults. Furthermore, they were more likely to present with distal tumours, supporting the findings of other smaller cohort studies that there may in fact be biological differences between young and older onset disease”[3]. While older people are significantly more likely to develop cancer, younger people face specific challenges of their own when diagnosed with cancer which should not be overlooked.

Experience of cancer can also differ according to age. In the Scottish cancer patient experience survey 2015-2016, the authors used those aged 75 and over as a reference group. They found that two questions were answered significantly more negatively than the reference group: the way they had been told they had cancer; and the length of time they had to wait when attending clinics/appointments. Their results showed that “those “aged 16 to 24 and 35 to 54 were more negative when asked how they would rate their care overall compared to those who were 75 and over”[4].

 Care Experience	<p>Think about children and young people up to the age of 26 who have experience of being in care. Care can include foster care/supported care, kinship care, residential care, or being looked after at home with the support of a supervision order.</p> <p>Healthcare Improvement Scotland is named as a corporate parent under the Children and Young People (Scotland) Act 2014. You can find information and working examples of what this means for us in our Children's Rights Report or by speaking to a member of our Children and Young People Working Group about our Corporate Parenting Action Plan.</p>
Positive impact	
Negative impact	
Neutral impact	

The available literature on any links between care experience and cancer is very limited. However, there is a significant amount of literature around overall worse socioeconomic and health outcomes for the care experienced. With clear links between these two factors and increased likelihood in the later development of cancer, we feel it is appropriate to discuss here.


A comprehensive summary of the outcomes of those in and leaving care is covered in 'Care leavers: A British affair' [5]. The authors state that due to material and social disadvantages and isolation, "Those in and leaving care are more likely to experience adverse physical and mental health outcomes such as premature mortality, drug abuse, depression, and anxiety". The authors then go on to discuss the negative effects experienced by children and young people when exposed to adverse living conditions, such as chronic health problems, including the increased likelihood of developing cancer.

[UK, narrative literature review] Those in and leaving care are more likely to experience adverse physical and mental health outcomes such as premature mortality, drug abuse, depression, and anxiety (Akister, Owens, & Goodyer, [2010](#); Hjern, Vinnerljung, & Lindblad, [2004](#); Kerker & Dore, [2006](#); Meltzer, Gatward, Corbin, Goodman, & Ford, [2003](#); National Audit Office, [2015](#); Pilowsky & Wu, [2006](#); Tarren-Sweeney, [2008](#); Tine & Mette, [2009](#)). Although some of this may be due to the characteristics of those entering care as 6% of children with disabilities are located within care facilities (Gordon, Parker, & Loughran, [2000](#)), most of this can be attributed to their exposure to material and social disadvantage and isolation prior to, during, and after leaving care.

Child and adolescent exposure to adverse living conditions is related to chronic health problems during both childhood and adolescence and later to adulthood even when adult socio-economic life circumstances are accounted for (Davey-Smith, Hart, Blane, &

Hole, [1998](#); Spencer, [2008](#)). This is especially the case for cardiovascular diseases, adult-onset diabetes, and respiratory disease, amongst others (Barker, Forsen, Uutela, Osmond, & Eriksson, [2001](#); Ebrahim, Montaner, & Lawlor, [2004](#); Kuh & Ben-Shilmo, [2003](#); Lawlor, Smith, & Ebrahim, [2004](#); Lynch & Davey-Smith, [2005](#); Maty, Lynch, Raghunathan, & Kaplan, [2008](#)). Moreover, findings from the collection of studies titled “Adverse Childhood Experiences Study” (ACES, e.g., Brown, Thacker, & Cohen, [2013](#)) highlight the implications of neglect and abuse on future health trajectories (see below for further specification).

he effects of abuse are related to one's future experience of disease, for example, pulmonary disease, cancer, liver disease, and autoimmune disease (Anda et al., [2008](#); Brown et al., [2013](#); Dong, Anda, Dube, Felitti, & Giles, [2003](#); Dube et al., [2009](#)); mental health illness, for example, depression, memory disturbances, and suicidality (Anda et al., [2007](#); Brown et al., [2007](#); Chapman et al., [2004](#); Dube et al., [2001](#)); and the use of health damaging substances (Dube et al., [2003](#); Hillis, Anda, Felitti, & Marchbanks, [2001](#); Strine et al., [2012](#)). <https://onlinelibrary.wiley.com/doi/full/10.1111/cfs.12421>

 Disability	<p>Think about people with sensory impairments, communication difficulties, learning disabilities, physical impairments, sensory impairments like sight or hearing loss, energy impairments, autism spectrum disorder, mental health conditions and cancer. Think also about Deaf users of British Sign Language. You might also consider unpaid carers here.</p> <p>Convention on the Rights of Person with Disabilities</p>
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative	
Neutral impact	

There is a significant amount of evidence around the links between disability

The new study, led by the Scottish Learning Disabilities Observatory and published in the BMJ Open, found that adults with learning disabilities had a higher incidence of metastatic cancer of unknown primary origin (cancer that has spread to other parts of the body), and three times as many died from cancer at this advanced stage compared to the general population. ([Source](#))

[UK, systematic review] Evidence suggests that people with a learning disability (PwLD) are less likely to attend cancer screening than the general population in the United Kingdom. Study found that women with a LD may not attend cancer screening due to fear, concerns over pain, and the potential influence of family carers and paid care workers. The review identified practical mechanisms which could help WwLD attend screening.

<https://onlinelibrary.wiley.com/doi/10.1002/pon.5311>

[UK, qual research] **Results** The findings illustrate that people with physical disabilities in England and Wales face a variety of barriers to accessing cancer services. The overall theme that emerged was that participants experienced a lack of attitudinal and institutional preparation both from healthcare professionals and healthcare facilities. This overall theme is illustrated through three subthemes: lack of acknowledgment of disability, unseeing disability and physical inaccessibility.

Conclusions As the population ages and increasing numbers of people live with cancer and disability, it is important to develop knowledge to respond to the needs of this population. The mere existence of services does not guarantee their usability. Services need to be

relevant, flexible, and accessible and offered in a respectful manner. It is important that healthcare professionals work towards inclusive healthcare provision, enabling the utilisation of services by all. Necessary steps to be taken include better communication between the various professionals and across the different teams involved in patients' care, raising awareness of how physical disability can affect or interact with cancer-related treatment and creating more accessible physical environments.

<https://bmjopen.bmj.com/content/9/6/e027555>

[UK case study article 2018] Evidence suggests that disabled people are less likely to be screened for cancer (e.g. Floud et al., 2017; Sakellariou & Rotarou, 2019). Discomfort, inaccessibility, lack of information, and cost have been found to act as barriers to accessing cancer services (Iezzoni, Kilbridge, & Park, 2010; Llewellyn, Balandin, Poulos, & McCarthy, 2011; Merten, Pomeranz, King, Moorhouse, & Wynn, 2015), and negative experiences might lead disabled women to skip screening procedures (Liu & Clark, 2008). Liu and Clarke (2008) found that disabled women were less likely to have mammography and Pap test explained to them compared to women without disabilities, and more likely to report problems with these procedures. Such barriers are linked to social disparities in cancer care, which arise from "adverse working and living conditions and inadequate health care (...) and discrimination" (Krieger, 2005:7). These barriers in access to cancer services and the ensuing inequities contradict several United Kingdom (UK) policy documents, such as Achieving World-Class Cancer Outcomes: a Strategy for England 2015-2020 (Independent Cancer Taskforce, 2015) and the Cancer Delivery Plan for Wales (Welsh Government, 2017), which both call for reducing inequalities in access to cancer services. These barriers also contravene the Equality Act (HM Government, 2010) and the Convention on the Rights of Persons with Disabilities (United Nations, 2006), which call for the elimination of barriers that affect disabled people's participation in social life.

When new symptoms started to appear, Claire described how her general practitioner attributed them to her pre-existing conditions. According to Claire, several healthcare professionals attributed the initial symptoms of ovarian cancer to the chronic conditions she was living with, leading to a 9-month delay from Claire noting the first symptoms of ovarian cancer to finally being diagnosed. In Claire's story, disability became an essentialising category, overshadowing any other possible explanation for her symptoms. Her own ability to know which symptoms related to her impairment did not appear to be listened to, exemplified in healthcare interactions where her explanation of her symptoms was dismissed. Ultimately, the interaction between her position as a disabled woman and the reported attitudes of healthcare professionals contributed to a long diagnostic delay.

Anna was a woman in her forties, living with multiple sclerosis. When she was diagnosed with breast cancer, it was decided she should undergo a mastectomy. As she was led to the operating theatre, she was told by the anaesthetist, for the first time, that nobody knew how anaesthesia would affect the progress of the multiple sclerosis. As it turned out, Anna came to in the recovery room to discover that she was paralysed and could not even speak. Lying down, unable to communicate with anyone, she was afraid that this might be a relapse

in the multiple sclerosis or, even worse, a permanent change. Anna described that it was only then, after the second time that a problem arose following anaesthesia, that the multiple sclerosis and cancer teams liaised with each other.

When, a few months later, he started having bowel problems, they experienced a lack of coordinated care to explore the reasons behind these issues. Linda reported insisting that these problems were not typical for him. On several occasions, professionals asked Robert about the kinds of symptoms he felt in his abdomen. Robert, of course, had no sensation in any part of his body below the chest. With the cancer team and the spinal injuries team not liaising, Linda and Robert were left in a very difficult situation, where they knew things were not right but did not know how to make them better. Eventually, it was found out that the fluid in Robert's abdomen was connected to a recurrence of the cancer, which eventually ruptured his bowel. Robert died of sepsis, which was diagnosed at a very late stage.

Matt was living simultaneously with the effects of a spinal injury and the after-effects of cancer treatment in a social environment that he found to be unresponsive to his needs. It was not any one of those things in isolation, but their cumulative effect that impacted on his experience of living with cancer; in other words, he was rendered as disabled through the cumulative embodiment of various types of discrimination, ranging from poor understanding of his needs to unemployment and poverty. As he said: 'the total becomes greater than the sum of its parts ... each little problem complicates the others'. Matt's story highlights the complexities and interacting factors related to pre-existing impairment and cancer. Even when access to cancer services in itself might not be challenging, there may be other factors affecting people's experiences, such as poverty.

We identified three specific pathways through which disability-based discrimination is embodied – normativity expectations, lack of disability-awareness and/or training, and discontinuity of care.

https://orca.cardiff.ac.uk/id/eprint/124370/3/CPH_FINAL_07_07%2BER.pdf

[uk, qual study] this study looked at healthcare workers experiences of supporting vulnerable people through cancer pathways. Participants were primarily focused on getting patients through treatment. The identification of vulnerability was an 'extra' complication and one that in practice was difficult to define/categorise. The participants appreciated the wider inclusion of family and friends to support vulnerable patients although they felt formalised health care was not particularly facilitative of this process. There were difficulties in achieving support for complex patient needs in the presence of a target driven culture. The difficulties of supporting vulnerable patients have been highlighted by the participants of this study. Within the narratives presented by participants, they appeared to position themselves as 'experts' within the drama who articulated the patient problem(s) and were tasked with finding effective solutions. There was an assumption from participants that they were responsible for providing 'holistic' care although from the stories of patient distress, it was unclear how they could possibly address those perceived needs or whether patients necessarily felt the participants were responsible for meeting them. <https://onlinelibrary.wiley.com/doi/10.1111/jocn.12583>

[UK, Original study] Testicular cancer patients who also have a learning disability (LD) have a one in nine chance of dying, compared to a one in 36 chance for [testicular cancer](#) patients without LD. This is because patients with LD are less likely to detect the disease at an earlier stage.

<https://www.sciencedirect.com/science/article/abs/pii/S2588931118302165?via%3Dihub>

[UK, original research] This study provides large-scale evidence that women in England with disabilities are less likely to participate in free routine screening for breast and bowel cancer than women without disabilities. This is an important finding given the high prevalence of women living with a disability that causes substantial difficulty with day-to-day activities, estimated at 32% in the United Kingdom for women aged 60–64 years ([Department for Work and Pensions, 2014](#)), and the fact that both disability and cancer incidence increase with age. We found that participation in screening varied by type of disability and number of disabilities. There were greater disparities by disability status for breast screening than for bowel screening. In women with a disability, not having access to a car was associated with a further reduction in the likelihood of participating in breast screening, as it does for women in general ([Moser et al, 2009](#)), presumably because of the extra effort required to go to breast screening centres. These results provide the NHS screening programmes with objective evidence of inequity and the results may assist in the development of future policy.

<https://www.nature.com/articles/bjc2017331>



**Gender
Reassignment**

Think about trans / transgender people - anyone whose gender does not match the sex they were assigned at birth.

Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

Source

- One in four LGBT people (24 per cent) have witnessed discriminatory or negative remarks against LGBT people by healthcare staff.
- One in eight LGBT people (13 per cent) have received unequal treatment from healthcare staff because of their sexual orientation or gender identity.
- Almost two in five trans people (37 per cent) have avoided healthcare treatment for fear of discrimination.
- Nearly three in five trans people (59 per cent) have experienced healthcare staff having a lack of understanding of specific trans health needs.

Similar to the case in 2015, we found that often data sources can only provide evidence for broad overarching categories of people who share particular characteristics, such as people from ethnic minority groups or disabled people. These broad categories mask the variation in people's experiences. Other small groups such as **Gypsy/Travellers, transgender people, and disabled people with specific impairments** (for example, hearing or visual impairments) are rendered virtually 'invisible' by the lack of data. Small numbers mean national surveys will not be able to gather information for a sufficiently large enough sample to support robust analysis. [Source](#)

When accessing general healthcare services in the last year, two in five trans people (41 per cent) said healthcare staff lacked understanding of trans health needs. Seven per cent of trans people said they have been refused care because they are LGBT, while trying to access healthcare services in the last year. ([Source](#))

Beyond transitioning and pathologising the transgender experience, a large minority of transgender people believed their gender identity affected their health care experience negatively (EHRC Transgender Research Review). Issues included being placed on inappropriate hospital wards and the provision of medical treatment relevant to one's sex (e.g. transgender women being asked about their periods or given smear tests; and not being offered breast and prostate screening, as appropriate). A high percentage of transgender people (44 per cent) felt uncomfortable about being open about their gender identity with NHS staff (figures for Scotland, Stonewall Scotland, 2014). This compares with 22 per cent of LGB&T people as a whole. ([Source](#))

More sources:

<https://pmc.ncbi.nlm.nih.gov/articles/PMC7807311/>

<https://www.sciencedirect.com/science/article/pii/S1521690X24000630>

<https://www.bmj.com/content/365/bmj.l1652>

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10424092/>

<https://ascopubs.org/doi/10.1200/JCO.22.01857>

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/transgender>

<https://cmcanceralliance.nhs.uk/news/raising-awareness-how-cancer-affects-transgender-people>

<https://wessexcanceralliance.nhs.uk/tackling-inequalities-in-cancer-care/>

<https://www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people/nhs-population-screening-information-for-trans-people>

<https://www.nursingtimes.net/cancer/reducing-health-inequalities-and-cancer-risk-in-trans-and-non-binary-people-15-05-2023/>

https://www.canceracademy.nhs.uk/wp-content/uploads/2022/10/trans_awareness_factsheets.pdf

<https://news.cancerresearchuk.org/2021/07/26/improving-cancer-care-for-the-lgbtq-community/>

<https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-patient-experience-survey/>

[UK, review] it is difficult to assess the exact size of the transgender population in the UK, population surveys suggest a prevalence of between 0.2 and 0.6% in adults. Being transgender is often, although not always, associated with gender dysphoria, a potentially disabling condition in which the discordance between a person's natal sex (that assigned to them at birth) and gender identity results in distress, with high associated rates of self-harm, suicidality and functional impairment.


Re cancer screening - The best principle is to screen the target organ, not the gender.²

being invited or included in screening can provoke intense dysphoria for transgender people, which may make them reluctant or unable to participate.


Physicians from all fields should address transgender patients with acceptance, compassion and a non-judgemental approach. Formal education and training on gender identity and reassignment is needed for general practitioners, primary care trainees and clinicians from other specialties who will see an increasing number of such patients. Education can change attitudes for the better, overcome difficulty and confusion for patients and doctors alike. In the interim, innovative approaches are needed to bridge the gap in knowledge between specialist centres and primary care; specialist advice via telephone or email might be a simple but effective solution.

<https://pubmed.ncbi.nlm.nih.gov/28382847/>

[UK, article]

 Marriage & Civil Partnership	Are there any implications for people who are married or in a civil partnership?
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

Spousal bereavement? For cancer-related bereavement the rise in mental-health related healthcare utilisation is observable both before and during the first year after their loss (Guidin, Jensen, Zachariae, & Vedsted, [2012](#)). <https://onlinelibrary.wiley.com/doi/full/10.1002/hec.3573>

 Pregnancy & Maternity	Think about people who are pregnant, breast-feeding or who recently gave birth.
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

In 2022, 11.9% of expectant women were current smokers at the time of their antenatal booking appointment, this is decline on 14.6% in 2019. A further 13.3% were former smokers at the time of their first appointment, whilst 74.8% had never smoked.

This is a slight increase on 2019, when 12.1% of expectant women were former smokers, and 73.2% had never smoked.


Monitoring the BMI of expectant mothers is important because obesity in pregnancy is associated with an increased risk of a number of serious adverse outcomes, including miscarriage. There is also a higher caesarean section rate and lower breastfeeding rate in this group of women compared to those with a healthy BMI. There is even evidence to suggest that obesity may be a risk factor for maternal death. Increasing maternal age and deprivation are both known to be risk factors for a higher maternal BMI.

In Scotland the BMI of expectant mothers has gone up slightly in 2022 compared to 2019. Of women delivering, 2.3% were 'underweight' (compared to 2.8% in 2019). There was also a lower proportion of women with 'healthy' BMI (40.9% compared to 44.5%), a slightly larger proportion were 'overweight' (29.6% compared to 27.9%), and a slightly larger proportion were 'obese' (27.3% compared to 24.8%).

[Scotland, original research] The odds of having any cancer were higher in women who had an inter-pregnancy interval >3 years compared to those with no subsequent pregnancy. Older age at first pregnancy was associated with increased risk of breast and gastrointestinal cancer, and reduced risk of invasive cervical, carcinoma in situ of the cervix and respiratory cancer. <https://www.mdpi.com/2072-6694/13/15/3731>

[UK, population based descriptive study] All cases of breast cancer diagnosed first during pregnancy, between October 1, 2015, and September 30, 2017, were eligible, with 84 confirmed cases analyzed. The incidence was 5.4/100,000 maternities (95% CI 4.37, 6.70). Nine women (11%) had undergone *in vitro* fertilization (IVF), compared with an estimated 2.6% IVF pregnancies in the UK at that time. During pregnancy, 30 women (36%) underwent surgery and 37 women (44%) received chemotherapy. Three women had major maternal morbidity during pregnancy. Two women died and two perinatal deaths occurred. The incidence of breast cancer arising in pregnancy in the UK is similar to that reported in other countries. The higher proportion of IVF pregnancies among women diagnosed with breast

cancer during pregnancy needs further investigation, as it may not be entirely explained by relatively advanced maternal age. <https://openresearch.nihr.ac.uk/articles/4-40/v1>

 Race	<p>Think about people from the diversity of minority ethnic communities. This includes gypsy/travelers. Are there health inequalities or access barriers that should be considered and addressed?</p> <p>Convention on the Elimination of all forms of Racial Discrimination</p>
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

There isevidence base regarding the incidence of cancer for different ethnicities. In the United Kingdom studies have

Incidence

[UK, original study] South Asian women were diagnosed at a significantly younger age (mean age of 60.3 years) compared to women of White ethnicity (mean age of 66.9 years) with a mean difference of 6.6 years (95% CI 5.1 to 8.1, $p < 0.001$). <https://www.mdpi.com/2072-6694/13/23/6123>

[Scotland, population study] Ethnic minority populations in Scotland had lower incidence of cervical cancer compared to the White population between 2008 and 2017. <https://onlinelibrary.wiley.com/doi/10.1111/ecc.13441>

[UK, epid study] disease incidence within the population - Black children (RR = 1.18, 99% CI: 1.01–1.39), and amongst South Asians, Pakistani children (RR = 1.19, 99% CI: 1.02–1.39) appear to have an increased risk of all cancers. There is an increased risk of leukaemia in South Asians (RR = 1.31, 99% CI: 1.08–1.58), and of lymphoma in Black (RR = 1.72, 99% CI: 1.13–2.63) and South Asian children (RR = 1.51, 99% CI: 1.10–2.06). South Asians appear to have a decreased risk of CNS cancers (RR = 0.71, 99% CI: 0.54–0.95). <https://bmccancer.biomedcentral.com/articles/10.1186/s12885-017-3551-7>

[UK, original research] In this large primary care-based cohort, the incidence of prostate cancer in men with elevated PSA levels increases with increasing age, even when using age-adjusted thresholds, with Black men significantly more likely to be diagnosed compared to White or Asian men. <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-024-03283-5>

[uk original] The study included 15,506 cancer diagnoses from 2017 to 2022, with the highest incidence in skin, breast and urology cancers. Preliminary censoring adjustments reduced censored records from 86% to 60%. Factors such as age, ethnicity, frailty and comorbidities were associated with cancer risk. The analysis identified 22 relevant variables,

with comorbidities and ethnicity being prominent. The spatial distribution of the risk and cumulative risk of the cancer types revealed regional variations, with five clusters identified. Rural areas were the least affected by cancer and Barrow-in-Furness was the area with the highest cancer risk.

<https://www.medrxiv.org/content/10.1101/2024.02.24.24303312v1>

Barriers/challenges to accessing care

[UK, original research] Awareness of bowel cancer symptoms, risk factors and screening varies by ethnicity. One in three adults ($n = 722$; 29.7%) did not know there is a Bowel Cancer Screening Programme. Bowel screening awareness was particularly low among Afro-Caribbean and Somali adults (both p 's < 0.05).

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-10536-y>

[UK, original research] Ethnic minorities were more likely than White British to report barriers to help-seeking. South Asians reported the highest emotional barriers, such as lack of confidence to talk to the doctor, and practical barriers, such as worry about many other things. The Irish were more likely than the White British to report practical barriers, such as being too busy to visit a doctor. White British participants were more likely than any other ethnic group to report that they would feel worried about wasting the doctor's time. Overall, Black Africans had the lowest barriers. All differences were statistically significant ($P < 0.01$ level), after controlling for confounders. <https://www.nature.com/articles/bjc2016158>

[UK, original research] Insights into prevention and screening for Gypsies, Roma and Travellers ethnic minority groups. Most women participated in cervical and breast screening but few Gypsy/Traveller men would engage with bowel screening, which conflicted with community ideals of stoical masculinity. Roma participants described language barriers to screening.

[uk, original reseach] Research has shown that Gypsies and Travellers have worse health outcomes than other ethnic minorities and those living in similar socio-economic circumstances in the UK (Peters et al., [2009](#); van Cleemput & Parry, [2001](#)). This study found that Four superordinate themes were identified which influence access to health care and experience of cancer diagnosis, treatment and care. These are as follows: Stigma, Fatalism, Family and Healthcare Professionals.

Service providers' attitudes and skills can enable or discourage service use (Scheppers et al., [2006](#)). This study provided examples of what a good service looks like, mainly from tertiary care, where practitioners (nurses, doctors and third-sector workers) were described as forming relationships of trust with patients and their families and communicating clearly.

Health providers can be uncertain and apprehensive when responding to the needs of people from ethnic minorities (Fazil et al., [2015](#)), and their attitudes can be influenced by negative media stereotypes (Francis, [2013](#); van Cleemput, [2018](#)). Cultural competence training for health professionals is frequently recommended; however, a risk is

acknowledged that this can emphasise patient characteristics rather than service provider and system-level factors (Burt et al., [2016](#)).

System-level barriers to ethnic minorities' health service use include opening hours, appointments and waiting time, length of consultation, translation and referral (Scheppers et al., [2006](#)). Registration with a GP has been identified as problematic for Gypsy/Travellers due to discrimination (McFadden et al., [2018](#); van Cleemput, [2018](#)), but was not raised in this study. For people living precarious lives (characterised by demanding and inflexible work, poverty and insecure housing) difficulties in booking appointments, though shared by all, act disproportionately to discourage access to health services (Scheppers et al., [2006](#)).

Fazil et al., ([2015](#)) identified access to interpreters as the main area where service providers and policymakers fail to provide BME people with a basic quality of care. The need for language support extends to booking appointments and ringing for results as well as clinical interaction (Lehane & Campion, [2018](#)), activities which contribute to early cancer diagnosis and treatment.

Other

[Mixed, mostly US, review of systematic reviews] The positive effects on patient satisfaction and quality of life were often most significant in racial and ethnic minority populations, including indigenous populations,⁵⁷ and when navigation programs included culturally sensitive care as well as addressing logistical and practical barriers and providing counselling and emotional support.

<https://acsjournals.onlinelibrary.wiley.com/doi/10.3322/caac.21788>

[UK, article on communication re breast cancer] Eighty-six percent of the population was white British. Asians (Pakistani, Indian, Bangladeshi, and other) "groups" made up 7.5% of the population; black groups 3.4%; Chinese groups 0.7%; Arab groups 0.4%; and other groups 0.6%. This figure is expected to increase by 20%–30% in 2050. It is, therefore, important that a doctor working within the National Health Service in the UK, should be prepared to deal with patients who may have a different culture, faith, language, and set of beliefs. In this article, I have highlighted the various challenges/issues in communication with such patients, available resources, and recommendations of strategies to improve their care.

In the UK, 1 in 8 women will develop breast cancer at some time during their life with over 55,000 new invasive cancers diagnosed annually.⁴

Psychological outcomes – improved by better communication?

[39163](#)

[UK, original research] Focus of study was re attending colonoscopy but some interesting themes:

Theme four. Reliance on family and friends.

Many participants reported that they relied on friends and family when attending hospital appointments, and that the same was/would be true for attending colonoscopy. Participants relied on family and friends in a number of ways, including transport (getting to and from the hospital), translation services (interpreting the information materials, the nurses and doctors, etc.) and emotional support. While reliance on family and friends did not appear to be intrinsically linked to ethnicity, it was reported more frequently, and more prominently, by Black and South Asian participants.

Cultural attitudes and beliefs are also cited but in relation to colonoscopy

<https://onlinelibrary.wiley.com/doi/10.1002/pon.6123>

[UK, retrospective study of screening results] Interestingly, insights from breast cancer, cervical cancer and other benign screening populations highlight that belonging to an ethnic minority group is a risk for noncompliance [13-17]. Worryingly, research also shows that being a person of non-White ethnicity increases the risk of having a positive stool-based screening test (2.8% positive for gFOBT in the most diverse ethnic quintile versus 1.75% in the least diverse ethnic quintile in London) [8] and for developing CRC [18]. African Americans, Native Americans, Native Alaskans and Japanese minorities in particular are shown to have 12%–38% higher incidence and mortality rates from CRC compared with Whites [18]. There is still some controversy around the link between ethnicity and uptake, with some concern that the effect seen can be accounted for by differences in socioeconomic status [19, 20]. A review of the English BCSP from 2010 to 2015 did show an independent effect of ethnicity on gFOBT uptake; however, this was based on area-level rather than individual-level data [8].

<https://onlinelibrary.wiley.com/doi/10.1111/codi.15682>

[UK, retrospective study of screening results] Using the White British population as the reference group, the odds of being less likely to participate in the BCSP in the West London CWHHE population were significant ($p < 0.05$) for all ethnic minority populations except for Asian Chinese (age-adjusted OR = 1.113, $p = 0.06$)

<https://onlinelibrary.wiley.com/doi/10.1111/codi.15682>

[UK, retrospective study of screening results] Barriers that result in noncompliance are complex but can be categorized broadly as patient-, system- and provider-related barriers. Patients from Black, Hispanic and Asian backgrounds report issues around embarrassment, not part of the culture, problems with psychosocial care, health information and their own ethnic remedies as being protective against cancer among reasons for poor compliance [32, 33]. The results of this study clearly demonstrate that those from all ethnic minority groups except Asian Chinese have a significantly poorer compliance with uptake of gFOBT screening compared with the White British majority. This is particularly true for those of Bangladeshi and Pakistani heritage who have compliance rates of less than 35%.

<https://onlinelibrary.wiley.com/doi/10.1111/codi.15682>

[UK, retrospective study of screening results] Interestingly, the Asian Chinese group had similar compliance rates to the White British group overall (Table 3) and on subanalysis by gender (Table 4). This finding was unexpected but was similar to the participation of the Chinese population in gFOBt screening in Scotland from 2007 to 2013, i.e. Chinese men and women had a similar risk of compliance to Scottish and Other White British men and women [42. <https://onlinelibrary.wiley.com/doi/10.1111/codi.15682>

[UK, original research with black community organisations] However, in the UK there is no reliable national data on patterns of cancer incidence, mortality and survival in black communities (Gordon-Dseagu, 2006, Department of Health, 2011).

As a result, black men appear reluctant to engage with cancer services.

Gaining a detailed understanding of the meaning of cancer and cancer-related issues from black men's perspectives helps us to understand why black men are less aware of cancer risk factors and early-detection services, as noted in previous studies (Waller et al., 2009). This understanding may also explain why, despite there being no evidence to suggest that black men have better or worse access to diagnostic services in the UK (Metcalfe et al., 2008), black men are less likely to attend early-detection services and often present late with symptoms (Austin et al., 2009, Department of Health, 2011).

Understanding the health beliefs of different minority groups is important for designing effective cancer-related services. Healthcare professionals need to be equipped with cultural competency skills. Understanding how illness and treatment are perceived by different minority groups is essential if service delivery is to effectively target different communities and cultures within our highly multi-cultural healthcare environment.

<https://www.sciencedirect.com/science/article/pii/S1462388916301508?via%3Dihub>


[UK descriptive study] Patients from a Black Afro/Caribbean background were diagnosed with CRC at a much younger age than the White British group (median age 67 compared with 72, $p < 0.001$). In multiple regression, ethnicity, deprivation and age were positive predictors of presenting with advanced tumour stage at time of diagnosis. Black patients were more likely to present with Stage IV tumours than white patients (OR 1.37, 95% CI 1.18–1.59, $p < 0.001$). <https://www.sciencedirect.com/science/article/abs/pii/S1877782117300152?via%3Dihub>

Respondents who were non-white were more negative than those who were white for 1 out of the 47 questions analysed. The question asked if the doctors and nurses asked them what name they preferred to be called by whilst in hospital. [Source](#)

<https://northerncanceralliance.nhs.uk/wp-content/uploads/2021/09/NHSE-Qualitative-report-Experiences-of-ethnic-minority-patients-in-England-2020-1.pdf>

Language barriers cited in a number of US studies. Systematic reviews show that in US PNs can help to address this barrier for non-English speaking patients.


<https://pubmed.ncbi.nlm.nih.gov/37245225/>

 Religion or Belief	Think about people who follow particular religions, or none. For example: Judaism, Islam, Sikhism, Christianity etc. Are there particular beliefs or practices that are assumed or that may be impacted?
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10530149/>

<https://www.sciencedirect.com/science/article/pii/S0277953608002384>

<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/EPEC-external-study-10.pdf> (2.3.3)

 Sex	<p>Think about any differences for women compared to men, or vice versa.</p> <p>Convention on the Elimination of all forms of Discrimination Against Women</p>
Positive impact	mailto:dawn.mcneil@stath.ac.uk
Negative impact	
Neutral impact	

Males were more positive than females for 19 out of the 47 questions analysed – around two fifths. No clear areas of care stood out within the analysis, with the significant responses appearing sporadically throughout the survey. The other 28 questions did not show any significant differences by gender.

Similar analysis carried out on the Scottish Inpatient Experience Survey [2] and various English Patient Experience Surveys (Inpatient, A&E, Outpatient & Primary Care Trusts) also showed males to be more positive than females about their care. [Source](#)

The EHRC Triennial Review¹⁴⁶ reports that men continue to experience more cancer-related deaths overall than women, although women have a higher rate in a number of age groups. In England and Wales in 2008, the overall cancer mortality rate for all ages was 206 per 100,000 for men and 150 per 100,000 for women. Overall cancer rates are far higher in Scotland for both men and women. In 2008, Scottish men had an overall cancer mortality rate of 309 per 100,000 and women had a slightly lower rate of 283 per 100,000. Although there is a higher number of cancer deaths in the over 65s, cancer causes a greater proportion of the deaths among younger people. Threequarters of cancer deaths (76%) occur in people aged 65 years and over, but cancer caused more than a third (36%) of all deaths in the under 65s in the UK in 2008, compared with 25% of all deaths in the over 65s. [Source](#)

The indicators included in the access to health services sub-domain are patient experience and unmet care needs. The 2023 gender equality score for this sub-domain is 100, consistent with the gender equality score of 99 in 2020.

The patient experience indicator looks at the percentage of women and men who describe the overall care provided by their GP practice as “excellent” or “good”.

The latest data shows that, in 2021/22, two-thirds of women (66.3%) and men (66.8%) viewed the care they received in this way. This is an overall reduction from the data used for this indicator in the 2020 Gender Equality Index; in 2017/18 over four fifths of both women (82.0%) and men (83.7%) viewed the care they received in this way. There remains a high gender equality score of 100 for this indicator, consistent with the score of 99 in 2023.

The **health risks** indicator of Scotland's Gender Equality Index is based on the percentage of adults with two or more health risk behaviours as measured in the Scottish Health Survey. These behaviours are:

- current smoker
- harmful drinking
- low physical activity
- obesity

The proportion of women with two or more risk behaviours in 2019 was 27.0% and the proportion of men was 29.0%, leading to a high gender equality score of 99 for this indicator. This is consistent with the 2020 Gender Equality Index in which the gender equality index for this indicator was 98.


([Source](#))

[Mixed, mostly US, review of systematic reviews] For example, Yang and colleagues⁸⁷ reported that patient navigation significantly increased adherence to cervical follow-up appointments within 12 months (OR, 3.23; 95% CI, 2.14–4.88; N = 2; n = 707), and >12 months (N = 1; n = 565).

<https://acsjournals.onlinelibrary.wiley.com/doi/10.3322/caac.21788>

[UK, Original study] In the United Kingdom, men have a 69% higher [mortality rate](#) and a 62% higher incidence rate for the major cancers, which should affect men and women equally. The rate of premature death is correspondingly high, with more than 37 000 additional years of life presumably lost for working-age men (15–64 yr) as a result of death from cancer. This pattern is repeated elsewhere but has received little attention.

<https://www.sciencedirect.com/science/article/abs/pii/S1569905610000485?via%3Dihub>

 Sexual Orientation	Think about people who are lesbian, gay or bi or who have another minority sexual orientation (e.g. are not heterosexual / straight). Are there health inequalities or access barriers that should be considered and addressed?
Positive impact	
Negative impact	
Neutral impact	

Those who did not identify as heterosexual were more negative than those who did for 1 out of the 47 questions analysed. The question asked whether hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.

[Source](#)

Cancer. Compared with heterosexual men, gay men were more likely to develop anal and prostate cancer (EHRC Sexual Orientation Research Review). Compared with heterosexual women, lesbians and bisexual women were more likely to develop breast cancer, but less likely to develop cervical cancer (EHRC Sexual Orientation Research Review). At the same time lesbians were less likely than heterosexual women to conduct breast self-examination (Fish and Wilkinson, 2003, referred to in the EHRC Sexual Orientation Research Review). Lesbians and bisexual women had their own specific sexual health needs, but there was a general lack of recognition of these (EHRC Sexual Orientation Research Review). In part, this stemmed from lack of recognition of the high percentage who had had sex with men (and so were subject to STIs through heterosexual sex) and also lack of knowledge (including amongst health professionals) of the transmission of STIs through lesbian sex. As a consequence, lesbians and bisexual women were less likely than heterosexual women to be screened for STIs or to have a cervical smear, leaving them at greater risk of cervical cancer and damage from STIs (EHRC Sexual Orientation Research Review). Lesbians and bisexual women expressed some confusion, about their risks of STI and also of cervical cancer, and also the actions they should take (Fish and Bewley, 2010 99). This was identified to largely be due to the information they had received, or indeed a lack of information.

More recently, in their survey of LGB&T and heterosexual people in Scotland, Stonewall Scotland (2014) found evidence of greater dissatisfaction with some health services amongst LGB&T people compared with heterosexual people. In particular, nine per cent of LGB&T people who had been to their GP in the last year (compared with two per cent of heterosexual people) rated their experience as poor or extremely poor. This rose to 17 per cent for LGB&T people aged 18-24.

[Source](#)

[UK review] The risk of transgender and non-binary people developing certain cancers is increased as a result of discrimination, inadequate health information and poor access to specialist screening clinics or health professionals who are trained to provide transgender

healthcare. Gender dysphoria, high-risk behaviours, viral infections and the effects of some gender-affirming treatments can also increase cancer risk among these communities. Nurses report poor knowledge of transgender healthcare needs and cancer risks; more education and ongoing awareness training are needed to improve transgender and non-binary patients' experiences and outcomes. Stonewall's (2018) report revealed that 62% of trans people had experienced a lack of understanding of specific trans health needs among health staff. This was supported by international studies on the attitudes and knowledge of health professionals treating LGBTQ+ adults with cancer, in which participants reported a lack of knowledge of these patients' specific healthcare needs and a desire for more education (Sutter et al, 2021; Berner et al, 2020). Nurses providing cancer care to TNB patients also face the challenge of managing the emotional impact of a cancer diagnosis. TNB people may already experience considerable social and psychological stressors, and a cancer diagnosis can exacerbate this; individuals who already experience anxiety and/or depression may struggle to cope. To identify and meet patients' holistic needs, nurses must be aware of any additional factors that may affect the individual's ability to come to terms with a cancer diagnosis.

Treatment

Some patients may be assessed and treated in gendered healthcare settings. As an example, people who were AFAB and have health conditions affecting the vagina or nearby pelvic area may be seen at a 'women's health' or gynaecology clinic, while people who were AMAB and have conditions affecting the prostate, testicles or penis may receive an appointment at a 'male' urology clinic. This can be upsetting and embarrassing for TNB patients, who are already trying to cope with a cancer diagnosis and its impact. This can also be difficult for nurses: without adequate guidance, they may struggle to support these patients, particularly if it is not possible to treat them in an environment in which they feel comfortable.

Nurses have a responsibility to maintain their knowledge and skills to ensure they deliver effective, non-discriminatory care (NMC, 2018). They should receive regular education updates on the healthcare needs of gender minority communities (Royal College of Nursing, 2020). Being able to recognise TNB-specific concerns is essential for nurses providing cancer care; Box 1 lists educational resources to improve LGBTQ+ patients' outcomes. **Signposting to appropriate information and support (Box 2) is also vital.** This knowledge improves nurses' confidence and creates more positive interactions with, and outcomes for, TNB patients (Carlström et al, 2021).

Cancer information

- Supporting and advocating for LGBTIQ+ people affected by cancer (Live Through This)
- Transgender and non-binary people and cancer (Macmillan Cancer Support)
- Trans women and prostate cancer (Prostate Cancer UK)
- Info for the transgender, non-binary and intersex communities (The Eve Appeal)
- Transgender people and breast cancer (Breast Cancer Now)
- Ovarian cancer information for transgender, intersex and non-binary people (Ovacome)

Health information leaflets need to have inclusive language.

TransPlus's UK Cancer and Transition Service (UCATS) is a new service for TNB communities; it works with TNB people and all health professionals involved in their cancer and gender-affirming care, aiming to provide clinical advice and enable patients to make the choices that are best for them. UCATS offers virtual appointments to review both gender and cancer care, with the option to include all of the multidisciplinary team involved in the patient's care. It can also signpost or refer to other services, including therapists, psychosexual counselling or fertility preservation clinics. All health professionals involved in the patient's care can refer to UCATS, and patients can also self-refer.

<https://www.nursingtimes.net/cancer/reducing-health-inequalities-and-cancer-risk-in-trans-and-non-binary-people-15-05-2023/>

[UK, Qual study] a growing body of evidence suggests that gay men may experience additional or unique challenges following a cancer diagnosis (Blank, [2005](#)). Results from quantitative studies carried out in the United States of America (USA), comparing prostate cancer treatment side effects, showed significant differences between heterosexual and gay men in terms of gay men's sexual functioning following anti-androgen treatment (Motofei, Rowland, Popa, Kreienkamp, & Paunica, [2011](#)) and poorer physical, sexual and psychosocial functioning following surgery (Latini, [2011](#)). Other side effects including pain during anal sex and specific issues relating to ejaculation and libido loss have also been reported (Lee et al., [2015](#)).

It is also important that healthcare providers are knowledgeable about the issues that may be relevant to gay men in order to signpost them to appropriate services, such as peer support groups. Traditional and familial support networks for gay men following prostate cancer treatment may be limited compared to those of heterosexual men, given that gay men are far less likely to have a regular partner than heterosexual men as they age, and are four times less likely to have children (Department of Health (DOH), [2005](#)). Therefore, healthcare providers are regarded as key sources of support for men in this patient group.

2.8 Information needs

During the diagnosis phase, participants wanted information about the implications of prostate cancer for gay men, but they found that this was not available. Participants perceived that they were poorly informed due to a lack of information directly relevant to gay men in the educational material provided within clinics and online. Participants frequently turned to the internet in the hope of finding information that made reference to gay men and what they may need to know or ask their healthcare providers. There was also a lack of information for gay men about resuming sex following a transperineal biopsy. Although leaflets included advice about when it was safe to resume sex following the procedure, men were unsure whether this only applied to those who engaged in vaginal intercourse.

Men who discovered prostate cancer support groups in their local area tended to have strong opinions about the structure and purpose of such groups and were unanimous in their view that they were not suitable for their needs. Most participants conveyed a strong sense of "*not belonging*" and were frustrated at the reluctance of group members to initiate discussions about common issues to affect all men with prostate cancer, regardless of their sexual orientation.

Due to the lack of routine sexual orientation monitoring in health settings across Europe and the United States, the responsibility for raising issues concerning sexuality is ambiguous.

Participants in this study would have liked healthcare professionals to raise the issue of sexuality. However, most felt that it was their responsibility to initiate a conversation about their sexual orientation, and were uncertain how this information would be received. Given that a large proportion of gay men choose not to disclose their sexuality to healthcare providers in general (Stonewall, [2012](#)), the findings from this study suggest that gay men consider sexual orientation to be a relevant factor following a diagnosis of prostate cancer, and have a need to understand how it may impact on every aspect of their cancer journey. Participants perceived that healthcare professionals had limited, or no, knowledge about sexual orientation, or about the potential impact of cancer treatment on gay men. Information about procedures, treatments and treatment side effects were presented from a heteronormative perspective.

LGBT organisations, for example, Stonewall are constantly developing information and training materials to support healthcare staff and sexual minority patients. Health messages and policies that promote non-discrimination and confidentiality in relation to sexual orientation could be displayed in clinical settings such as waiting rooms to promote inclusiveness and acknowledge diversity.


<https://onlinelibrary-wiley-com.knowledge.idm.oclc.org/doi/full/10.1111/ecc.12923>

[UK retrospective/descriptive study 2017] A diagnosis of cancer in the past 5 years was more commonly reported by male General Practice Patient Survey responders who endorsed gay or bisexual orientation compared with heterosexual men (odds ratio [OR], 1.31; 95% CI, 1.15 to 1.49; $P < .001$) without evidence of a difference between lesbian or bisexual compared with heterosexual women (OR, 1.14; 95% CI, 0.94 to 1.37; $P = .19$). For most common and rarer cancer sites (30 of 33 in women, 28 of 32 in men), the odds of specific cancer site diagnosis among Cancer Patient Experience Survey respondents seemed to be independent of sexual orientation; however, there were notable differences in infection-related (HIV and human papillomavirus [HPV]) cancers. Gay or bisexual men were over-represented among men with Kaposi's sarcoma (OR, 48.2; 95% CI, 22.0 to 105.6), anal (OR, 15.5; 95% CI, 11.0 to 21.9), and penile cancer (OR, 1.8; 95% CI, 0.9 to 3.7). Lesbian or bisexual women were over-represented among women with oropharyngeal cancer (OR, 3.2; 95% CI, 1.7 to 6.0).

<https://ascopubs.org/doi/10.1200/JCO.2017.72.5465>

[UK, Qual study] – experiences of gay men following diagnosis of prostate cancer. Participants wanted, and expected, candid discussions with healthcare professionals, about how prostate cancer could affect their lives, sexual function, and how to access culturally relevant support before and after treatment. Participants perceived that their healthcare team had little knowledge about their needs, and if, or how, their experience differed due to their sexual orientation. Information provided was perceived as being misplaced or informed by heteronormative assumptions. Consideration should be given to requesting sexual orientation when recording patient information, if patients are willing to disclose. Training should be provided for healthcare professionals to enable them to provide information and support that is culturally relevant at all stages of the consultation.

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/ecc.12923>

 Socio-economic	<p>Think about people living on low incomes and / or in deprived areas. Consider this as a cross-cutting issue since people from some protected characteristic groups are more likely than the general population to experience poverty.</p>
<p>Positive impact</p>	<p>mailto:dawn.mcneil@stath.ac.uk</p> <p>The four key themes regarding patient needs addressed by improved navigation supports are emotional, practical and informational, family, and other complex needs (Lorhan et al., 2014).</p>
<p>Negative impact</p>	
<p>Neutral impact</p>	

Employment status, using those who work full time as the reference group, was a significant factor for 11 out of the 47 questions analysed – almost a quarter. All but one of these questions were more positive for those not working full time compared to those who were. Respondents who were retired were most likely to be more positive – this being the case for 8 of the questions compared to the other categories who were more positive for two questions each.

Social deprivation:

Survey respondents were assigned to one of five categories of even size, or quintiles, based on the SIMD ranking of their postcode. Those in the first quintile, SIMD 1, are in the most deprived 20 per cent of datazones and those in the last quintile, SIMD 5, are in the least deprived 20 per cent of datazones.

Of the six questions showing a significant difference, only one was more negative. When asked about the length of time they had to wait before their first appointment with a hospital doctor people living in less deprived areas (SIMD 3, 4 and 5) were more negative than those in SIMD 1.

The other five questions were more positive for those in at least one of the other quintiles when compared to those in SIMD 1:

- Overall rating of administration of care – SIMD 2;
- Whether they understood the explanation of what was wrong – SIMD 5;
- Whether their GP was given enough information about their condition and the treatment they had received at the hospital – SIMD 4 & 5;
- How often they got answers they could understand when they had important questions to ask their CNS – SIMD 2, 4 & 5;
- Whether groups of doctors and nurses talked in front of them as if they weren't there – SIMD 2, 4 & 5;

In general, people living in less deprived areas were more positive about their care.

[Source for the above](#)

Poor diet is a leading risk factor for ill health internationally¹ and has been linked to a range of comorbidities including diabetes, cardiovascular disease, hypertension and certain cancers^{2,3}. The risk of such conditions can be reduced by improvements in the nutritional content of diets (increasing fibre, fruit and vegetable intake⁴, decreasing salt, fats and sugar⁵) and overall reductions in elevated body mass⁶.

Evidence is suggestive of varying impacts of the pandemic on diet and physical activity, with both positive and less beneficial behaviour adopted by individuals in response to their own and national circumstances, sometimes interchangeably⁷. Several reports have also highlighted the negative impact on food insecurity and the widening of existing inequalities with an 89% increase in demand for emergency food parcels in the UK in April 2020 compared with the same period in 2019 and foodbank demand more than doubling during the same period⁸.

Research has shown that more than 1 in 20 adult cancer cases are linked to excess weight in the UK making obesity possibly the second largest preventable cause of cancer. ([Source](#))

[US, Review] - https://ascopubs.org/doi/pdfdirect/10.1200/EDBK_100026

“multilevel barriers to cancer care, including transportation problems, inability to speak English, lack of insurance, financial concerns, lack of social support, lack of information about patient care resources, and poor patient-provider communication 27... The services that the patient navigators may provide include assistance with transportation, interpretation, applying for insurance, filling out medical forms, scheduling and coordinating appointments, providing emotional and psychosocial support (especially during uncertainties of diagnostic procedures and treatment), providing education about treatment and follow-up, and community-based resources (Table 1).²⁸ The provision of these services addresses inherent inequities in access to cancer care and may influence disparities in cancer outcomes.”

[Scotland, original research] Deprivation is associated with differential breast cancer incidence trends for screen-detected oestrogen receptor positive tumours. Deprivation is associated with higher mortality for select tumour subtypes. Disparities by socio-economic status (SES) in BC incidence are complex and involve risk factor differences including race/ethnicity, access to healthcare and differences in the predisposition to different tumour types. <https://link.springer.com/article/10.1007/s10549-022-06632-1>

The 2017 Macmillan Cancer Support-NHS report Deprivation and Survival from Breast Cancer in Scotland found that people with breast cancer in the most deprived areas of Scotland were 89% more likely to die from the disease than those in the least deprived areas. A Tumour stage seemed to explain some of the deprivation-associated survival gap in breast cancer, and therefore this might be amenable to early diagnosis initiatives. However, further analysis showed that even when all potential explanatory factors (see the Methods brief for further details) were added to the model, there remained some variation across the deprivation groups in survival from breast cancer. The remaining unexplained variation is likely to be due to deprivation-linked factors not accounted for in the model (such as smoking status), measurement error, and a range of other issues, such as differing expectations of health services and support.. https://www.macmillan.org.uk/images/Breast-Cancer-Survival-and-Deprivation-Brief_tcm9-308828.pdf

[Scotland, original research] In this study of nearly 4000 Scottish women diagnosed with a primary BC from 2007 and 2008, we found no evidence of socioeconomic disparities in IBR at 5 or 10 years for patients with ER+ tumours. <https://breast-cancer-research.biomedcentral.com/articles/10.1186/s13058-023-01704-6>

[Original Scottish research] The proportion with 2 or more diseases increases with higher deprivation and was more than twice as high in the most versus least deprived SIMD quintile (5 vs. 2%). Likewise, there was an educational gradient, with those with no education having higher multimorbidity. Those who were living in social rented housing or not paying rent had higher multimorbidity than private renters or house owners... The average disease trajectory of an individual in the most-deprived SIMD quintile is comparable with that for an individual

5 years older in the least-deprived SIMD quintile, which persists after adjustment for individual education (model 3). At age 40, those in the most-deprived quintile are already starting to see sharp accumulation of conditions with age, whereas 40 year-olds in the least-deprived quintile have flat trajectories.

<https://academic.oup.com/eurpub/article/34/4/696/7644332#476837951>

LS NOTE: Potential area for consideration with this group is access to tech for telehealth

https://www.macmillan.org.uk/_images/ISD%20Macmillan%20Deprivation%20Survival%20Technical%20Report_FINAL_tcm9-308832.pdf

[UK, original research] Hazard ratio of death was consistently higher in the most deprived group than the least deprived for both colon and rectal cancer

<https://jech.bmj.com/content/75/12/1155>

[UK, not peer reviewed] Intersectional study. Breast cancer care experience categorised by age, ethnicity, and sexual orientation in their intersection with deprivation status.

Results Poorer breast cancer care experience was mostly reported by the most deprived younger and minoritised ethnic groups. Similar findings were observed in adjusted multivariable analyses. Younger respondents were less likely than older patients to rate their care favourably. Pakistani, Indian, Chinese, and Black African women were less likely than White British women to rate their care favourably. Respondents from the most socioeconomic deprived backgrounds were less likely than the most affluent ones to rate their care favourably.

Conclusion There is evidence of inequity in overall cancer care experience among female breast cancer patients in England, particularly among women living at the specific intersection of age, ethnicity and socioeconomic position. Future research is necessary to understand the mechanisms underlying breast cancer inequities. Policymakers, commissioners, and providers should consider the existence of multiple forms of marginalization to inform improvement initiatives targeting patients at higher risk of vulnerability.

<https://www.medrxiv.org/content/10.1101/2023.12.13.23299922v1>

[UK, original study] Smoking-related cancer PAFs in England are 2.2 times larger in the most deprived quintile compared to the least deprived quintile (from 9.7% to 21.1%). If everyone had the same smoking prevalence as the least deprived quintile, 20% of the deprivation gap in cancer incidence could have been prevented. If nobody smoked, 61% of the deprivation gap could have been prevented.

<https://www.medrxiv.org/content/10.1101/2022.02.11.22270853v1>

[UK, longitudinal study] – study looked at cancer incidence and survival. Disparities were greatest for survival: Among 5016 patients diagnosed with CRC aged 50+, probability of death from all-causes was lower among those with a degree, compared to no degree and higher among those employed in manual occupations, compared to non-manual occupations and among those living in social-rented housing, compared to owner-occupiers. Individual indicators of SES were also associated with probability of death from CRC. Those living in the most deprived areas had a higher probability of death (from all-causes and CRC) compared to those in the least deprived areas.

<https://www.sciencedirect.com/science/article/pii/S0277953623004951?via%3Dihub>


[UK, retrospective study of screening results] Previous work has shown that socioeconomic status in London, measured using the English indices of deprivation, is significantly associated with poor compliance [24]. The multivariate analysis here confirms the independent role of ethnicity, irrespective of socioeconomic status, on poor compliance in London. <https://onlinelibrary.wiley.com/doi/10.1111/codi.15682>

[UK descriptive study] Social deprivation was also a predictor of Stage IV cancer presentation, with the most deprived group (Quintile 5) 1.26 times more likely to be diagnosed with Stage IV cancer compared with the most affluent group (CI 1.13–1.40, $p < 0.001$). Sub-group analyses demonstrated that Black & Affluent patients were still at greater risk of Stage IV CRC than their White & Affluent counterparts (OR 1.24, 95% CI 1.11–1.45, $p = 0.023$).

<https://www.sciencedirect.com/science/article/abs/pii/S1877782117300152?via%3Dihub>

[uk] Colon cancer patients diagnosed through emergency presentation had the highest number of hospital emergency admissions than all the other routes to diagnosis, especially in the last 7 months before diagnosis. Most deprived patients had an overall higher rate and higher probability of HEA but fewer conditions associated with it. Findings point to higher use of emergency services for non-specific symptoms and conditions in the most deprived patients, preceding colon cancer diagnosis. Health system barriers may be a shared factor of socio-economic inequalities in EP and HEAs. Repeated use of emergency services by most deprived patients with abdominal/pelvic pain two years prior to definitive cancer diagnosis, suggests delays on the pathway to cancer diagnosis. Often, delays in cancer diagnosis are attributed to delays in seeking help due to lack of symptom awareness, limiting beliefs [33], underestimation of the seriousness of symptoms or increased comorbidities [34,35,36,37]. Whilst not minimising the impact of those factors, our study showed that there may be system-level factors that contribute to delays in diagnosis [38]. The extent to which the patient-related or the system-related factors account for EP with colorectal cancer is debatable and may vary by socio-demographic characteristics.

<https://www.nature.com/articles/s41416-024-02688-6>

 Island communities	Think about people living on the Scottish islands. Does the work cover the islands as well as the mainland? What might be different for island communities?
Positive impact	
Negative impact	
Neutral impact	

Potentially relevant: Scottish cancer patient experience survey urban/rural experience

[Source](#)

<https://www.sciencedirect.com/science/article/pii/S1353829223001764?via%3Dihub>


LS NOTE_ I THINK WE NEED TO EXPAND OUR SEARCH BEYOND UK eg Miller, J. "Cancer patient navigation needs assessment: Project report." *Alberta Cancer Board: Medical Affairs and Community Oncology Division, Internal Document* (2006).

[LS NOTE: Potential area for consideration with this group is telehealth](#)

4. Overcoming negative impacts

Where it has been identified that the work has potential to adversely affect people who share one of the characteristics noted, or you think there are certain things you will need to do to ensure all relevant groups benefit equitably, provide details of what you will do to improve outcomes.

Protected characteristic		Actions	Person responsible
All characteristics			
	Age		
	Care experience		
	Disability		
	Gender reassignment		
	Marriage/civil partnership		
	Pregnancy and maternity		
	Race		
	Religion or belief		
	Sex		
	Sexual orientation		
	Socio-economic		

Protected characteristic		Actions	Person responsible
	Island communities		

5. Impact rating

Considering what you said in sections 3 and 4, provide an impact rating based on the degree to which the work may negatively impact on people who share one of the noted characteristics.

Impact Rating Key



Low

There is little or no evidence that some people are (or could be) differently affected by the work.






Medium










There is some evidence that people are (or could be) differently affected by the work.



High

There is substantial evidence that people are (or could be) differently affected by the work.

Protected Characteristic		Low	Medium	High
	Age			
	Care Experience			
	Disability			

Protected Characteristic		Low	Medium	High
	Gender reassignment			
	Marriage/Civil Partnership			
	Pregnancy & Maternity			
	Race			
	Religion or Belief			
	Sex			
	Sexual Orientation			
	Socio-economic			
	Island communities			

6. Stakeholder collaboration

Provide details of stakeholder collaboration and consultation.

Our [Equality, Inclusion and Human Rights Team](#) can help you identify relevant national or local groups.

Name and job title	Organisation / Team	Contact details

7. Monitor and review

Regular reviews ensure that policy, procedure and practice is kept up to date, and meets the requirements of current equality legislation. Where a negative impact has been identified and remedial actions are being implemented, the person leading the work should define a timescale for review.


Identified issue	Person responsible	Review date

8. Evidence and research

Please detail the evidence you used as part of this assessment. This will help others understand what you have considered. You might use journal articles, reports / resources from organisations or testimony from people you have engaged in the work. You can attach lists if this is helpful.



Have you linked in with the [Knowledge Management Team](#) in the Evidence Directorate or the [EEvIT team](#)? Have you looked at our Guide to [Grey Literature](#)? This signposts reputable sources of equality-focused data that are publically available.

Please only list or attach information that was used in this assessment.

Evidence & Research	

9. Further assessment templates

If you need to carry out a Children's Rights and Wellbeing Impact Assessment, please follow the Scottish Government Guidance and use the below templates.

Stage 1 assessment (screening)	 CRWIA stage 1 screening template.doc
Stage 2 assessment (full)	 CRWIA stage 2 full assessment template.

10. EQIA sign off

Please ensure the project lead is satisfied with the assessment and that you retain a copy for your records.



If you need any advice on completing this form, or any aspect of the Equality Impact Assessment process, please contact the Equality, Inclusion and Human Rights Manager rosie.tyler-greig@nhs.scot

Project Lead	
Sign-Off Date	mailto:dawn.mcneil@stath.ac.uk

You can read and download this document from our website.
We are happy to consider requests for other languages or
formats.
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1. Cancer incidence by age Cancer Research UK, 2 Redman Place, London, E20 1JQ2022 [updated 26 May 2022. Available from: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age>.
2. Ribe E, Cezard GI, Marshall A, Keenan K. Younger but sicker? Cohort trends in disease accumulation among middle-aged and older adults in Scotland using health-linked data from the Scottish Longitudinal Study. *Eur J Public Health*. 2024;34(4):696-703.
3. Chambers AC, Dixon SW, White P, Thomas MG, Williams AC, Messenger DE. Factors associated with advanced colorectal cancer differ between young and older adults in England: a population-based cohort study. *Colorectal Dis*. 2020;22(12):2087-97.
4. Division HaSCA. Scottish Cancer Patient Experience Survey 2015/16: Exploring Differences in Cancer Patient Experiences. Scottish Government; 2017.
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