PARTICIPATION IN CANCER RESEARCH IN BNSSG: A HEALTH EQUITY AUDIT. 2021

Under the Acute Provider Collaborative, BNSSG

A health equity audit of participation in cancer research at University Hospitals Bristol and Weston NHS Foundation Trust and North Bristol NHS Trust. Completed under the Provider Collaborative, with support from partners across the BNSSG *Healthier Together* Health and Care System and Research networks

Kathryn Hamilton
Kathryn.hamilton@nbt.nhs.uk; Kathryn.hamilton2@nhs.net

Health Equity Assessment Tool: Equity of access to cancer research. December 2021

Provider Collaborative project for University Hospitals Bristol and Weston and North Bristol Trust
Senior Sponsors of the provider collaborative: Mr Tim Whittlestone (North Bristol Trust Medical Director) and Paula Clarke (University Hospitals Bristol and Weston, Director of Strategy and Transformation)

Report main author: Dr K Hamilton, Public Health Registrar, North Bristol Trust
Kathryn.hamilton@nbt.nhs.uk or Kathryn.hamilton2@nhs.net

Report co-authors: Owen Ainsley, Diana Benton, Helen Lewis-White, Helen Winter, Sarah Hollier

Project team:

Owen Ainsley	ASR Programme Director
Kathryn Hamilton	Public Health Registrar, North Bristol Trust
Hazel Phillips	Chief Operating Officer, Bristol Biomedical Research Centre
Diana Benton	University Hospitals Bristol and Weston NHS Foundation Trust Deputy Director of Research and Innovation
Helen Lewis-White	North Bristol NHS Trust Deputy Director of Research and Innovation
Helen Winter	Clinical Director of Somerset, Wiltshire, Avon and Gloucestershire Cancer Alliance Group, and Medical Oncologist Bristol Cancer Institute
Sarah Hollier	Business Intelligence Manager (Population Health Management), NHS Bristol, North Somerset & South Gloucestershire CCG (Healthier Together)
Emily Eyles	University of Bristol, Applied Research Collaboration West England
Senior Sponsors	Tim Whittlestone (NBT), Paula Clarke (UHBW)

Executive summary

People from the most deprived communities have a 53% higher cancer mortality rate across all cancers compared to the people from the least deprived communities[1]. There is also national evidence that patients from deprived communities have lower participation rates in cancer research. Yet patients treated in research-intensive environments have better outcomes, and wider participation has benefits for healthcare organisations and produces more generalisable research. The Acute Provider Collaborative formalises collaboration between University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) and North Bristol NHS Trust (NBT) to meet the needs of the Bristol, North Somerset and South Gloucestershire (BNSSG) population and define Bristol as a centre of excellence for research. Under the Acute Provider Collaborative, leads from UHBW and NBT research and clinical services, supported by Public Health, undertook a health equity audit of the participation in Cancer Research at the Trusts to create a profile of people participating in cancer research. The hypothesis from national evidence, was that some social groups would be under-represented in research. Through comparing the research profile to people newly diagnosed, or living with, cancer in BNSSG we aimed to identify inequities, and use the published evidence-base to look at ways to address these.

The following are key findings for this health equity audit:

- Older adults (aged 70 or older, or aged 80 or older) are statistically significantly under-represented in cancer research

- Compared to the age profile of people newly diagnosed with cancer in BNSSG:
    - Adults aged 70 or older were 56% less likely to take part in research
    - Adults aged 80 or older were 77% less likely to take part in research

  pages 8-9

- People from an ethnic minority background may be under-represented in cancer research, but recording of ethnicity was poor, particularly for people presenting to NBT, so that meaningful assessment of ethnicity was challenging

  page 11

- People with cancer from the most deprived communities are statistically significantly under-represented in research in BNSSG when compared to the group newly diagnosed with cancer. They are also under-represented when compared to the group living with cancer, although this difference was not statistically significant

  page 12

- Compared to the deprivation profile of people newly diagnosed with cancer in BNSSG, the most deprived patients are 27% less likely to participate in research compared to the least deprived

  pages 12-17

[1] Cancer in the UK 2020: socio-economic deprivation. Available here

- People from the most deprived communities involved in cancer research are more likely to be younger, have one or more comorbidities, and have recently experienced an emergency admission than those from the least deprived backgrounds. Finally, they are more likely to be from Bristol, consistent with the BNSSG socioeconomic profile. Under-representation is likely multifactorial, including poorer long term cancer survival for people from the most deprived communities *page 12-17*

- Patients from outside BNSSG (18%) appear similar in profile to those recruited to research from within BNSSG, including for deprivation. Data on the expected number of patients who travel from out of area are not known. This is, however, reassuring that people from extremes of age and deprived communities are able to travel for research participation *page 18*

- There are some differences in the profile of people taking part in research between the two Trusts. Firstly, patients at UHBW were twice as likely to come from outside of BNSSG. In addition, due to available services, patients at UHBW were on average 8 years younger and had different cancer types *page 9*

- Data recording needs to improve for some factors crucial to assessing equity and cancer pathways. This includes:
  -ethnicity, particularly at North Bristol Trust
  -stage of cancer
  -Inclusion Health factors in Trust datasets: homeless people, Gypsy, Roma and Traveller community members, vulnerable migrants, people who leave prison and sex workers

The published evidence base shows that there are patient-level, clinician-level and system barriers and motivators to participation in research, some of which are more common for the under-represented groups described.

Action plan – Health Equity Assessment Toolkit

This health equity audit is a starting point and a call to action. It provides a platform to collaborate further using the Health Equity Assessment Toolkit[2] to develop an action plan.

The following recommended actions are needed to further understand these inequities and review our research recruitment pathways, as well as improve our ability to do further Health Equity work. Please see the recommendation section for fuller details.

1. **To improve and target healthcare systems' data recording and sharing to ensure assessment of equity in our services is facilitated. Specifically, the recording of ethnicity and cancer stage must be prioritised**

[2]Health Equity Assessment Toolkit. Available here

2. **To embed the involvement of patients and carers in the whole research process to improve access and explore their views in increasing equity or barriers to research**

3. **To enable and facilitate effective clinical conversations around cancer research**

4. **To provide information about research and clinical trials alongside all other information given to patients accessing healthcare, in accessible, relevant forms**

5. **To review the research delivery methods, particularly with respect to practical and emotional support for patients, with the knowledge that older patients and those from more deprived backgrounds are currently under-represented locally**

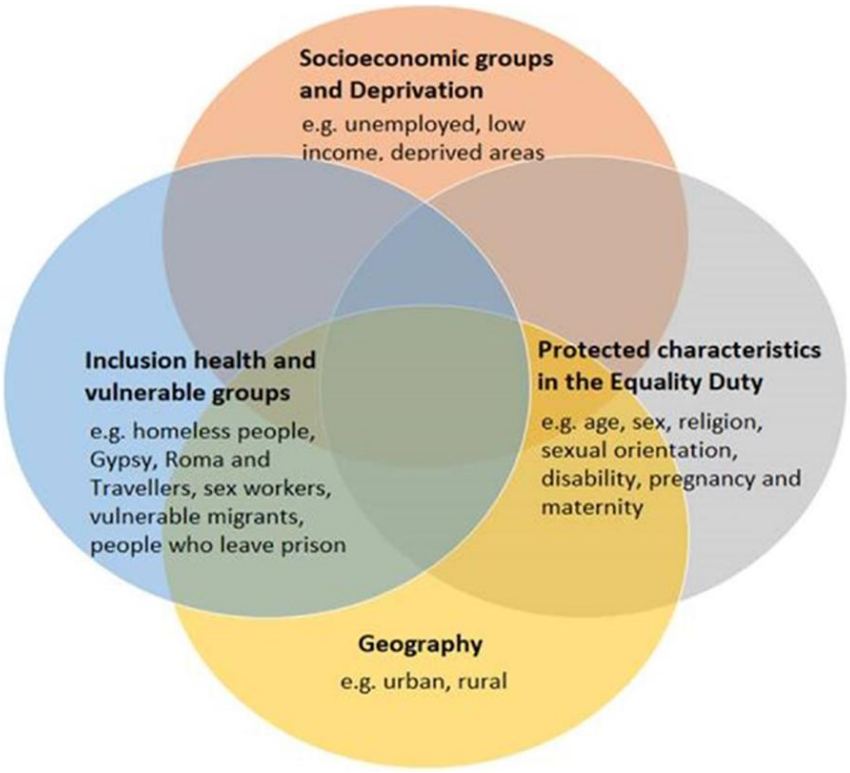
6. **To explore novel out-ward looking approaches to address inequities**

Background – access to research, health inequalities and cancer

Health inequalities are unfair and avoidable differences in health across the population. As of 2015 to 2017, across the *Healthier Together* (BNSSG) population the total gap in life expectancy between the most and least deprived communities was 7.5 years for males, and 6.7 years for females. It is estimated that cancer contributes 1.3 years for males and 1.6 years for females of this gap[3]. Patients from the most deprived communities are more likely to develop cancer, present at a later stage or as an emergency, have worse healthcare experiences and ultimately poorer outcomes[4]. In England there is a 53% gap in all-cancer mortality rate between the least and the most deprived communities[2]. The NHS Long Term Plan aims to "dramatically improve how we diagnose and treat cancer"[5]. This means prioritisation of reducing cancer rates, and improving cancer outcomes in our most deprived communities is an important part of reducing health inequalities.

It is important to consider other factors alongside socioeconomic deprivation when looking at health inequalities, including those listed in the Equality Act 2010 and "Inclusion Health" groups who are often underserved by traditional models of healthcare.

Figure 1. Patient characteristics for inclusion in Health Equity work[6]



It is part of the NHS constitution that patients have a right to access clinical research[7]. There is also a growing body of evidence that those who are treated in research-intensive environments or involved in research have better clinical outcomes[8][9].

[3] Health Inequalities Across Healthier Together. Phase 1: A Health Inequalities Profile. 2021
[4] Cancer in the UK 2020: socio-economic deprivation. Available here
[5] NHS Long Term Plan. Areas of Work. Cancer. Available here
[6] Health Equity Assessment Toolkit. Available here

Other benefits for the patient from participation in research include:

- Earlier access to new treatments
- Playing an active role in their own healthcare
- Opportunities for more frequent interaction with medical professionals
- Better access to information, and potentially support/resources
- Knowledge that you are helping others in the future

Organisational benefits of high levels of research participation:

- Higher levels of patient and staff satisfaction[10]
- Ability to recruit and retain high quality research aware staff
- Increased research income
- Wider reputational benefits for the research-active organisations and partners
- Cost savings in some cases

Unfortunately, national evidence shows that whilst the public are highly supportive of research within the NHS[11], access to research is not equitable. People from deprived communities for instance received half the number of referrals to phase 1 clinical trials in a national study[12]. There is evidence that clinicians' consultations around research recruitment differ with different social groups[13]. Research eligibility criteria can also be restrictive, for instance on co-morbidities and upper age limits. Finally, the patient may face barriers to participation, including travel or knowledge and awareness of research, digital and health literacy. Reducing health inequalities requires action at multiple levels. We need both an upstream approach on factors outside healthcare that contribute to poor health outcomes, and a "proportionate universalism" approach within healthcare. Proportional universalism in this instance means understanding that some patients need more support or additional interventions to access research than others.

In this work we aimed to answer the following questions:

- What is the pattern of participation in cancer research in BNSSG?
- Does inequity exist, and what may be driving this?
- What action can be taken to reduce inequities?

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[7] NHS Constitution, 2013 Available here
[8] Downing A, et al. High hospital research participation and improved colorectal cancer survival outcomes: a population-based study. Gut 2017; 66: 89-96. Available here
[9] Nijar, SK. et al. Participation in clinical trials improves outcomes in women's health: a systematic review and meta-analysis. BJOG 2017. 124; 863-871 Available here
[10] Harding et al. Organisational benefits of a strong research culture in a health service: a systematic review. Australian Health Review. *Australian Health Review* 41(1): 45-53 Available: here
[11] Butt, et al. (National Centre for Social Research). Wellcome Trust Monitor 1. 2010. Available here
[12] Macmillan. Health Inequalities: Time to Talk. 2019. Available here
[13] Engaging for increased research participation. Southampton University. Available here

This approach is a Health Equity Audit, that can then be used as the starting point for a Health Equity Assessment Tool[14] to achieve change with partners.

Methods

Using the research dataset, patients were identified who had participated in cancer research (trials and non-trials based) at UHBW and NBT from 1.4.2019 – 30.3.2020. This period was chosen to exclude the pandemic period. A data sharing agreement and data privacy impact assessment was agreed between North Bristol NHS Trust, University Hospitals Bristol and Weston NHS Foundation Trust and the BNSSG CCG. Individual patient-level data from both Trusts were analysed at North Bristol Trust for age, gender, ethnicity, local authority, cancer type, deprivation status (IMD code of home postcode Lower Layer Super Output Area), route of referral to secondary care (taking latest referral before entry to research), and comorbidities. Patients were checked against the national opt-out process for inclusion.

Comparison cohorts were extracted from the systemwide dataset, with approval and support from the CCG business intelligence and analytical team. Following the opt-out process, data were used from 72 of the 78 GP practices across BNSSG. These comparison cohorts were surrogates for the pool of potentially eligible patients for research participation. Patients may be recruited to research at any point of their cancer journey, so two comparison cohorts were used.

(i) The "incident" cancer cohort - Diagnosed with cancer in a 12 month period: first cancer flag in primary care records, from 1.11.2019 – 1.10.2020, accessed through the BNSSG systemwide dataset. Only living patients reported.

(ii) The "prevalent" living with cancer cohort - based on the patient attribute snapshot of 01/07/2021, records with a flag in the cancer within the last five years fields, accessed through the BNSSG systemwide dataset. Only living patients included.

Due to data sharing restrictions, it was not possible to link the datasets and exclude research participants from the above groups. This does not nullify the results, but means that the analyses were reduced in their power to detect significant differences between the groups. These comparison cohorts also assume that all patients are potentially appropriate for research participation. Some will have reduced performance status, or be ineligible for other reasons, and this is a limitation of the methodology.

Data for the whole BNSSG population were also obtained from MHCLG (publicly available)[15].

Results are reported with suppression of small numbers (less than 5). Statistical tests were chi squared and 2-tailed T-tests unless otherwise reported. 95% confidence intervals (CI) and statistical p values are reported where relevant.

[14]Health Equity Assessment Tool Available here

[15] English Indices of Deprivation 2019. Available here

Results

Profile of Research and Comparison Cohorts

In the period 1.4.2019-31.3.2020 1,052 patients were involved in cancer research at North Bristol Trust (NBT) and University Hospitals Bristol and Western (UHBW). Table 1 below shows a breakdown for research participants and the wider BNSSG cancer cohorts for age, gender and home area.

Table 1. Characteristics of patients involved in research, and the people newly diagnosed or living with cancer in BNSSG.

Patient Group	Patients	Mean Age (95% CI)	Younger Patients (≤18 years) N (%)	Teenagers and young adults (16-24 years) N (%)	Older patients (≥70 years) N (%)	Older patients (≥80 years) N (%)	Gender (% female)	Patients from Out of Area N (%)
BNSSG cancer research participants	**1,052**	**62y (61.0-63.0)***	**36 (3.4%)***	**12 (1.1%)**	**365 (34.7%)***	**74 (7.0%)***	**52.9%****	**189 (18.0%)**
UHBW cancer research participants	656	59y (57.3-60.1), 62y (60.5-62.8) excl. paeds***	36 (5.5%)	12 (1.1%)	198 (30.2%)***	35 (5.3%)	53.8%	143 (21.8%)***
NBT cancer research participants	396	67y (66.5-68.5)***	0	0	167 (42.2%)***	39 (9.8%)	51.3%	46 (11.3%)***
New Cancer diagnosis in BNSSG	**5,193**	**69y (68.1-69.0)**	**46 (0.9%)**	**NA**	**2,827 (54.4%)**	**1,299 (25.0%)**	**55.7%**	**NA**
Living with Cancer in BNSSG	**14,214**	**67y (66.6-67.1)**	**107 (0.8%)**	**NA**	**7,036 (49.5%)**	**2,765 (19.5%)**	**48.1%**	**NA**

*: significant difference to the New Cancer diagnosis in BNSSG and the Living with Cancer in BNSSG patient groups, p<0.0001.
**: significant difference to the Living with Cancer in BNSSG cohort, p=0.0026
***: significant difference between NBT and UHBW, p<0.01

Age

- Proportionally more patients aged 18 or younger were enrolled in research than were newly diagnosed with cancer in BNSSG, difference 2.5% (95% CI 1.5-3.8%), meaning **younger patients appear well-represented in cancer research**
- **Older patients were under-represented in research** compared to the profile of people being diagnosed with, or living with, cancer in BNSSG. See below for details

- There were 19.7% (95% CI 16.5-22.8%) fewer adults aged 70 years or older enrolled in research than were newly diagnosed with cancer in BNSSG, p<0.0001. **Adults aged 70 or older were 56% less likely to take part in research,** odds ratio 0.44 (95% CI 0.39-0.51)
- There were 18% (95% CI 15.9-19.8%) fewer adults aged 80 years or older enrolled in research than were newly diagnosed with cancer in BNSSG, p<0.0001. **Adults aged 80 years or older were 77% less likely to take part in research**, odds ratio 0.23 (95% CI 0.18-0.29)
- Age and comorbidities: for the **patients enrolled in research aged 70 years or older 68.6% had one or more comorbidities**, compared to 59.3% of the research participants under 70 years old. Difference 9.3%, 95% CI 6.1-12.5%, p<0.0001. **Comorbidities increased with age**, although the population rate of comorbidities in patients with cancer was not available for comparison. It is a positive finding that older patients with comorbidities are being recruited to research, and it may also represent a barrier to participation

Gender

- Results have been described as % female, as all research participants identified their gender as either male or female
- There were 2.8% more females newly diagnosed with cancer in BNSSG than enrolled in research, but this difference was not statistically significant (p>0.05, Odds Ratio 0.89 (95% CI 0.78-1.02)). However, there were 4.8% (95% CI 1.7-7.9%, p=0.0026) more women enrolled in research than were living with cancer in BNSSG. Odds ratio 1.21 (95% CI 1.07-1.37). Interpretation of the significance of this finding is unclear. The research included in this audit represents a 12-month snapshot in time, and differences in gender participation likely reflect the research portfolio for different cancers, as well as other recruitment factors

Differences between the Trusts

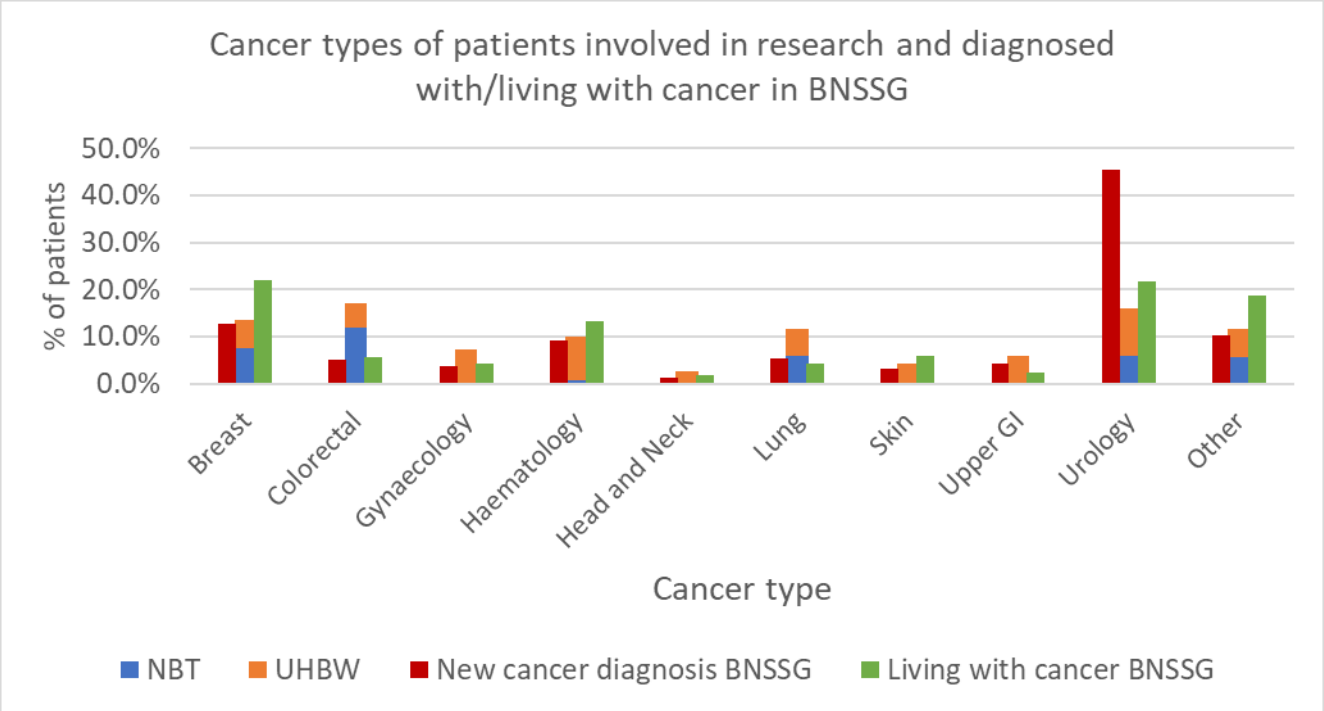
- Out of area patients: **UHBW patients in research were about twice as likely to come from outside BNSSG compared to NBT patients**. Odd ratio 2.09 (95% CI 1.47-2.95).
- Research patients at NBT were on average 8 years older than at UHBW, (statistically significant, p<0.001). No patients aged 18 or younger were enrolled in research at North Bristol Trust. Excluding patients aged 18 years old or younger, NBT patients were on average 5.8 years older (95% CI 4.2-7.4, p<0.0001). This relates to different services provided

Cancer types

Figure 2 shows cancer types for the different groups. “Other” includes brain, sarcoma, paediatric and undetermined cancers. The research cohort is a 12-month period which is a snapshot of time, and will reflect studies that were running in that time. In this period:

- proportionately, more patients with colorectal, lung and gynaecological cancers were participating in research than were newly diagnosed, or living with, those cancers in BNSSG (comparisons statistically significant, $p<0.0001$).
- proportionally, fewer patients with urological cancers were taking part in research, when compared with the wider cohorts of people new diagnosed, or living with, cancer ($p<0.0001$). When compared to the proportion of people living with breast, haematological or other cancers in BNSSG, again, fewer people were participating in research ($p\leq0.002$), however for these cancer types the proportions taking part in research were similar to the proportions newly diagnosed.

Figure 2. Cancer types for patients involved in research, and the people newly diagnosed or living with cancer in BNSSG.



Ethnicity

Due to very small numbers recorded in individual ethnic minority groups in the research groups, ethnicity is reported as White-English/Welsh/Scottish/Northern Irish/British, and as "Any other ethnic background".

- **For the whole research cohort, there were 2.7% fewer patients (95% CI 1.0-4.1%, p=0.0028) from "Any other ethnic background" compared to those with a new diagnosis of cancer in BNSSG, and 3.5% fewer patients (95% CI 1.9-4.8%, p=0.0001) compared to those living with cancer.** These results are all statistically significant. This means the differences are unlikely to be due to chance, and may reflect under-recording or inequity of access to research for people from ethnic minority backgrounds.

- Ethnicity was poorly recorded, particularly for the North Bristol Trust patients. This makes interpretation of differences difficult, as they may reflect inequity in recruitment to research, or under-recording for some ethnic groups. From the available data, NBT had 4.5% fewer patients in research from "Any other ethnic background" (95% CI 1.7-7.1%, p=0.002) than UHBW.
- Unfortunately, the Trust datasets do not systematically record language spoken for patients, so this could not be analysed alongside ethnicity.

Table 2. Ethnicity for patients involved in research, and the people newly diagnosed or living with cancer in BNSSG.

Patient Group	Patients (n)	White - English / Welsh / Scottish / Northern Irish / British n (%)	Any other ethnic background, n (%)	Ethnicity not recorded, n (%)
BNSSG cancer research participants	**1,052**	**714 (67.9%)**	**58 (5.5%)**	**280 (26.6%)**
UHBW cancer research participants	656	510 (77.7%)	47 (7.3%)	99 (15.0%)
NBT cancer research participants	396	204 (51.5%)	11 (2.8%)	181 (45.7%)
New Cancer diagnosis in BNSSG	5,193	3,838 (73.9%)	429 (8.2%)	919 (17.7%)
Living with Cancer in BNSSG	14,214	11,101 (78.1%)	1,279 (9.0%)	1,819 (12.8%)

Deprivation

In summary, this analysis shows that people from our most deprived communities are under-represented in cancer research. Older adults from deprived communities are also under-represented. Research participants from the most deprived communities were more likely to have a recent emergency presentation, to be from Bristol, and to have comorbidities.

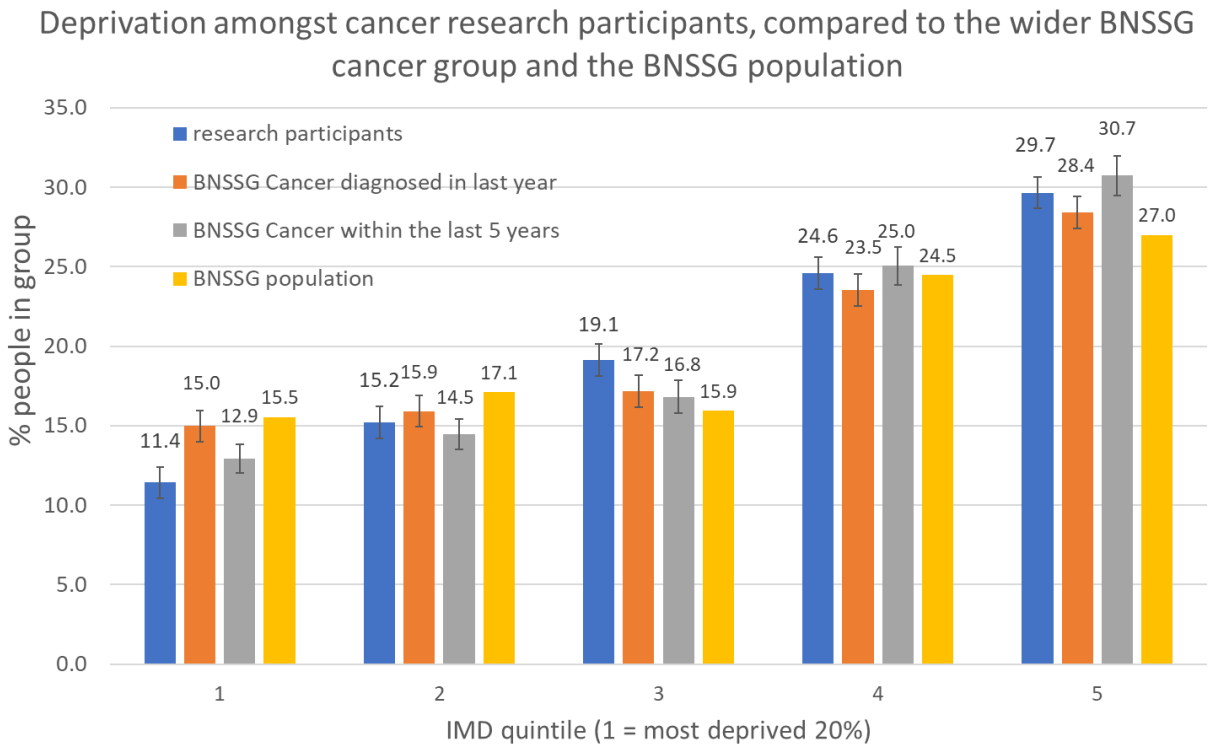
For background, deprivation is measured using a standardised national approach – the index of multiple deprivation. This ranks small areas of England according to multiple domains, so that comparisons can be made. IMD-1 is the most deprived 10% (for deciles) or 20% (for quintiles), and IMD-5 or 10 is the least deprived 20% or 10%, respectively. Unless otherwise stated, most deprived refers to the most deprived 20% and vice versa.

Figure 3 shows a comparison of the research participants with those newly diagnosed with, or living with cancer in BNSSG, and the BNSSG population as a whole.

- **11.4% of research participants come from the deprived communities (95% CI 9.5-13.3%). This is statistically significantly lower than the 15.0% of people diagnosed with cancer in the last year who are from the most deprived communities (95% CI 14.0-15.9%, p=0.0027). It is also lower than 12.9% of people living with/ cancer in BNSSG (12.9% (12.0-13.8%)), but this difference was not statistically significant (p=0.2).**
- **Taking those newly diagnosed with cancer as a surrogate for the pool of people eligible for research, people from the most deprived communities were 27% less likely to take part in research than people from the least deprived communities (odds ratio 0.73, 95% CI 0.88-0.92, p=0.003).**
- **Taking those living with cancer as the pool of people eligible for research, people from the most deprived communities were 8% less likely to take part in research than people from the least deprived communities (odds ratio 0.92, 95% CI 0.73-1.14, p=0.2).**

As described in nationally published literature, and in the BNSSG Healthier Together health inequalities profile 2021, compared to the proportions of people being diagnosed with cancer, there are smaller numbers of people from IMD-1 in the “living with cancer” cohort. This is consistent with the poorer cancer outcomes experienced by the most deprived communities, described above. It is beyond the scope of this health equity audit to explore this further, but must be considered when interpreting the results. It means that comparison of our research cohort to the “living with cancer” cohort may be less likely to detect under-recruitment of deprived populations to research, and also may provide a reason for under-representation in research, as people can be recruited to research some time after diagnosis. Further work is needed to understand the point at which people are recruited to research, and how time since diagnosis affects this.

Figure 3. Deprivation for patients involved in research, the people newly diagnosed or living with cancer in BNSSG and the wider population



There are many reasons why people from the most deprived quintile may be under-represented in research. Understanding these reasons is an important part of addressing inequities.

Below is a profile of the research participants from the most deprived communities, compared to the rest of the research participants, and the least deprived participants, alongside the same analysis for the wider BNSSG cancer patient groups.

Table 3. Deprivation and other characteristics for patients involved in research, and the people newly diagnosed or living with cancer in BNSSG.

Patient Group	Number of patients	Age (mean, 95% CI)	Younger patients (≤18 years) (n, %)	Older patients (≥70 years)	Older patients (≥80 years)	Comorbidities (patients with one/more recorded)	Out of area	Recruited following emergency presentation
IMD-1 research participants	**117**	**60.6 (57.7-63.5)***	**<5 (NA) *ns***	**37 (31.6%)***	**8 (6.8%)***	**82 (70.1%)***	**22 (18.8%) *ns***	**10.0%**
IMD 2-5 research patients	844	62.2 (61.1-63.3)	34 (3.7%)	351 (38.3%)	64 (7.0%)	574 (62.4%)	160 (17.4%)	7.2%
IMD 5 research patients	304	64.4 (62.8-66.1)	5 (1.6%)	128 (42.1%)	27 (8.9%)	182 (59.8%)	51 (16.8%)	3.7%
IMD-1 New Cancer diagnosis in BNSSG	777	67.2 (66.0-68.4)*	6 (0.1%)	381 (49.0%)*	191 (24.6%)*	618 (79.5%)*	NA	Not available
IMD-2-5 New Cancer Diagnosis in BNSSG	4,413	68.8	40 (0.9%)	2,444 (55.4%)	1,107 (25.1%)	3,217 (72.9%)	NA	Not available
IMD-5 New cancer diagnosis in BNSSG	1,475	69.8 (69.11-70.5)	10 (0.7%)	854 (57.9%)	367 (24.9%)	1,040 (70.5%)	NA	Not available
IMD-1 Living with Cancer in BNSSG	1,836	65.1 (64.4-65.8)*	16 (0.1%)	793 (43.2%)*	321 (17.5%)*	1,397 (76.1%)*	NA	Not available
IMD-2-5 Living with Cancer in BNSSG	12,370	66.0	91 (0.7%)	6,239 (50.4%)	2,443 (19.7%)	12,370 (67.7%)	NA	Not available
IMD-5 Living with Cancer in BNSSG	4,367	68.2	42 (1.0%)	2,341 (53.6%)	952 (21.8%)	2,858 (65.4%)	NA	Not available

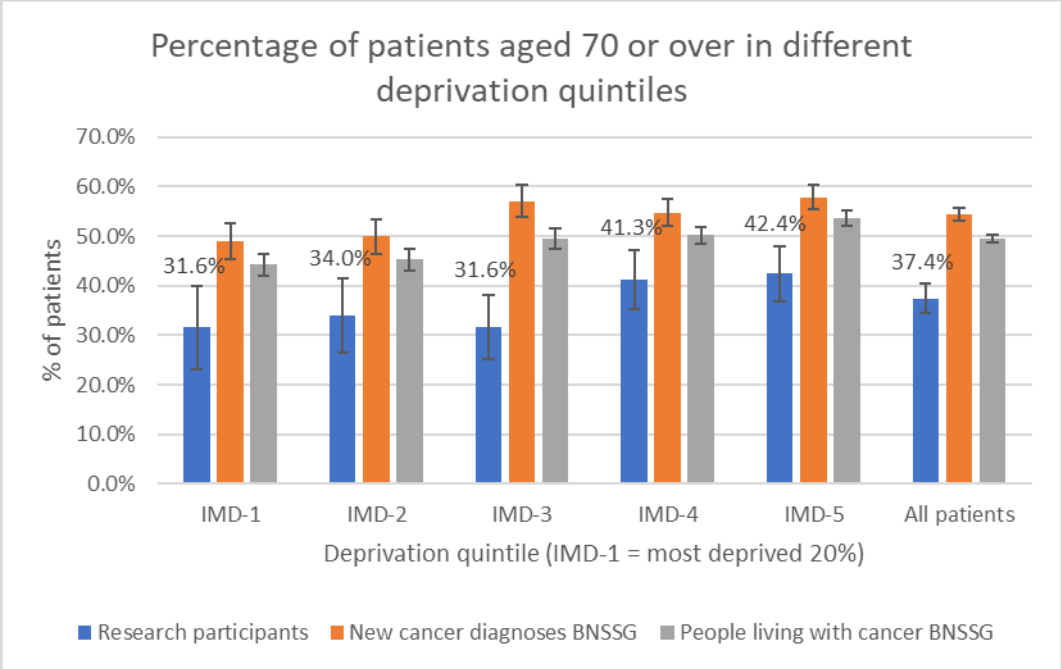
*: $p<0.05$, statistically significant difference comparing IMD-1 cancer research participants to IMD-1 New Cancer and/or Living with cancer cohorts in BNSSG. NA: not applicable, ns: not statistically significant at the 5% level

i. Deprivation and age

The most deprived patients participating in research are statistically significantly younger than those newly diagnosed or living with cancer in BNSSG who are from the most deprived backgrounds. The patients in research from the most deprived backgrounds were also younger than those from the least deprived backgrounds, but this difference was not significant.

The number of patients aged 18 or younger recruited to research overall is small, and unlikely to explain under-representation of IMD-1. For the least deprived research participants (IMD-5), 42.1% were aged 70 or over, compared to 31.6% in the most deprived quintile. This difference is statistically significant (p=0.045). However, it is important to look at the wider picture of older age in people with cancer in BNSSG.

Figure 4. Percentages of older adults participating in cancer research or being diagnosed with cancer in BNSSG according to deprivation quintile



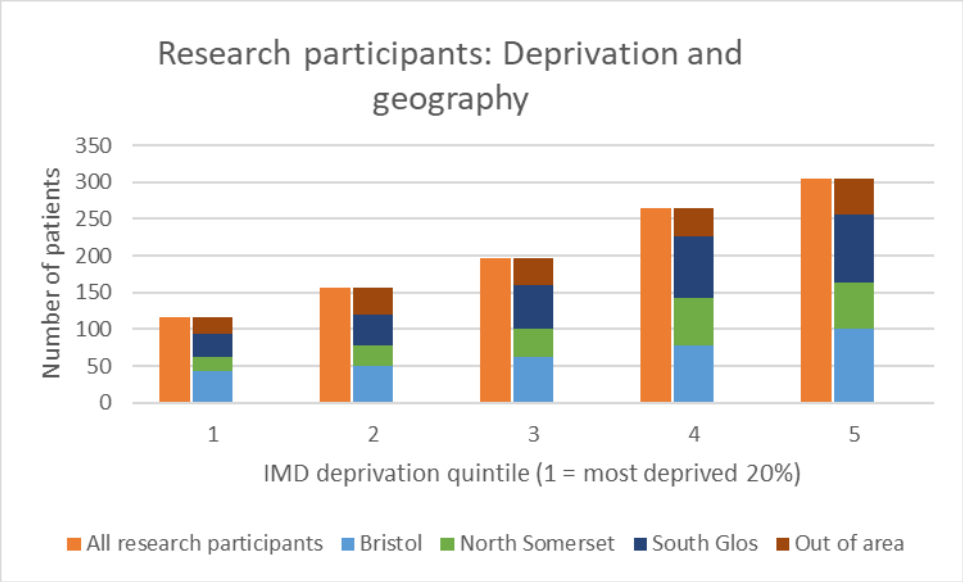
Comparing research participation rates for older adults with those diagnosed with/living with cancer, statistically significantly smaller proportions of these patients are found in research than are being diagnosed, or living with cancer. Importantly, similar differences in participation rates are seen across the IMD quintiles. Data not shown: all comparisons between research and BNSSG cohorts significant to $p<0.05$, with differences in proportions recruited not significant when comparing IMD-1/2/3/4/5. **This shows that older adults are under-represented in cancer research, and particularly from the most deprived communities. It is not however, under-recruitment of older people alone that explains the under-recruitment to research for our IMD-1 cancer population.**

ii. Deprivation and geography

The proportion of patients from out of area was statistically similar for IMD-1 and IMD-2-5 or IMD-5 research participants. There is variation within BNSSG. Compared to the BNSSG average, South Gloucestershire has higher proportions of more affluent populations and Bristol has higher proportions of more deprived populations. North Somerset proportionally has a similar percentage of deprived populations, and more people in IMD 8 and 9 (less deprived deciles), than the BNSSG average.

The graph below shows that proportionally more of the patients from IMD-1 come from Bristol. This is in keeping with the profile of BNSSG, as described.

Figure 5. Deprivation and geography for patients involved in research



iii. Deprivation and route of referral

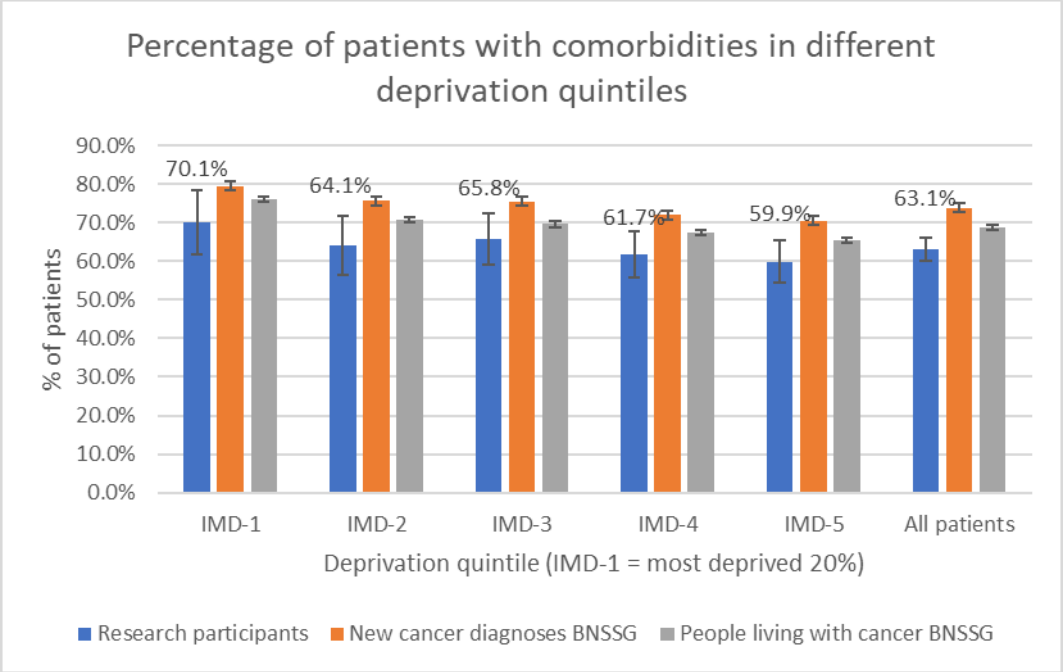
For patients involved in research from the most deprived backgrounds, 10% were recruited following an emergency presentation. This compares to only 3.7% of patients from the least deprived backgrounds experiencing an emergency presentation before recruitment to research. This difference was statistically significant (difference 6.3%, 95% CI 0.7-14.2, p=0.02).

iv. Deprivation and comorbidities

A higher proportion of patients in research from the most deprived backgrounds had comorbidities, compared with patients from the least deprived backgrounds, but this difference was not statistically significant (difference 10.3%, 95% CI -0.9-20.8, p=0.07). In the newly diagnosed BNSSG cancer group significantly more patients in the most deprived

20% had one or more comorbidities compared to the least deprived 20% (difference 9.0%, 95% CI 5.3-12.6, p<0.0001).

Figure 6. Percentages of patients with one or more comorbidities participating in cancer research or being diagnosed with cancer in BNSSG according to deprivation quintile



A significantly smaller proportion of patients recruited to research from IMD-1 have one or more comorbidities than are newly diagnosed with cancer from IMD-1 (difference 9.4%, 95% CI 1.1-18.7, p=0.02). The proportion is also smaller when compared to people living with cancer, although this difference is no longer statistically significant (difference 6.0%, 95% CI -1.9-15.1, p=0.1). When doing the same comparison for IMD2-5, similar differences in proportions of patients with comorbidities are seen when comparing the research cohort to the newly diagnosed and living with cancer population cohorts. Difference for newly diagnosed IMD2-5 with comorbidities 10.5%, 95% CI 7.0-14.1, p<0.0001, difference for living with cancer IMD2-5 with comorbidities 5.3%, 95% CI 2.0-8.7, p=0.002. Although this is not concrete evidence, it is suggestive that **all patients with comorbidities are less likely to be recruited to research, from any socioeconomic background, and that this alone does not fully explain under-representation of our most deprived population in cancer research.**

In summary, this analysis does not find one factor alone that is strongly associated with under-representation of our most deprived patients in cancer research. Patients from the most deprived backgrounds were younger on average, and more likely to have presented in an emergency, and to have comorbidities, both when diagnosed with cancer and when recruited to research. Under representation may be due to another factor not included here. It is likely to be multi-factorial. It may include some of the factors looked at here, which our analysis was not powered to detect, or which was difficult to detect with our chosen comparison cohorts.

It is also known that patients from more deprived backgrounds experience poorer outcomes, and lower rates of involvement in research may to some extent reflect poorer long-term survival.

Out of area patients

The only significant difference in patients from out of area compared to BNSSG residents, was the percentage of younger patients. 3.1% more patients (95% CI 0.2-7.6%, p=0.04) were ≤18 years in the out of area group. This likely corresponds to provision of regional specialist services for children. There were no other statistically significant differences in the profile of patients from out of area, including older age and average age, being of an ethnic minority background, having comorbidities, or being from more deprived backgrounds. This is reassuring that it does not seem patients from out of area have differential access to research for these reasons, and **it is evidence that older patients or those from deprived backgrounds are able to travel for research participation**. We do not know from this analysis how many patients from out of area we should expect to see in research at NBT and UHBW, and some variables such as ethnicity are poorly recorded, so we cannot completely conclude that access overall is equitable. There are, however, no red flags raised for inequity from this analysis.

Table 4. Characteristics for patients involved in research comparing those from BNSSG with those from out of area.

Patient profile	**BNSSG patients in research (n=864)**	**Out of area patients in research (n=185)**
Mean age	62.5 years	60.2 years
Patients ≤ 18 years (%)	2.9%*	6.0%*
Patients ≥70 years (%)	38.2%	34.1%
Patients ≥ 80 years (%)	8.3%	7.0%
Patients of ethnic minority background (%)	5.4%	4.8%
Patients with 1/+ comorbidities (%)	63.5%	61.1%
Patients from IMD-1 (most deprived 20%), (%)	11.2%	12.1%
Patients from IMD-5 (least deprived 20%), (%)	29.7%	27.5%

* statistically significant difference between BNSSG and Out of area patients, p<0.05

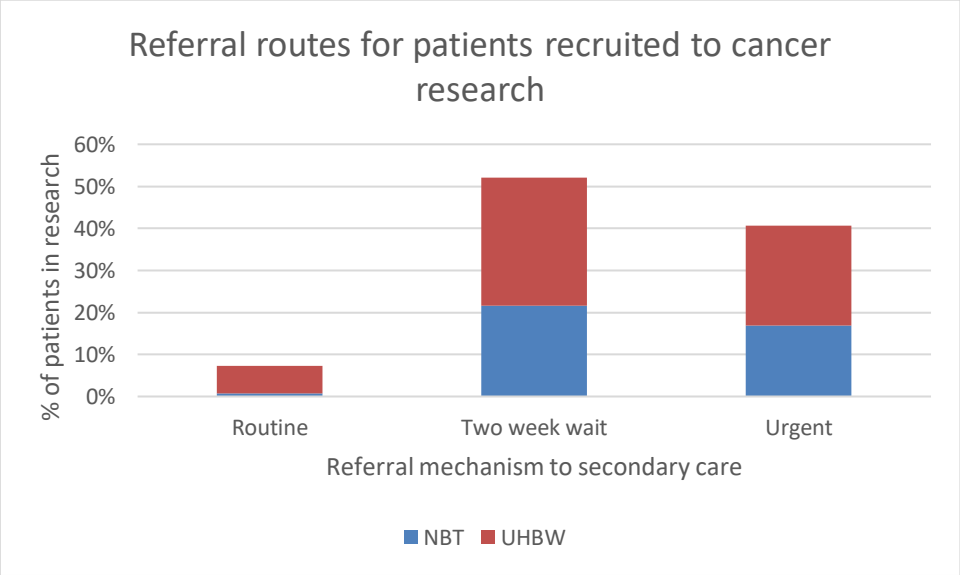
Referral into research

In an analysis of GP practices, the patients involved in research were registered at a total of 43 different practices across BNSSG. There were small numbers of patients with each of

these practices, and due to chance, many practices may not have patients eligible for research in the period of this Health Equity Audit. 38 patients did not have GP practices recorded on the Trust database. GP registration would be likely with a cancer diagnosis, and this may represent a recording issue. Overall, the GP data is reassuring that primary care appear well-engaged with supporting their patients to participate in cancer research locally.

The route of referral is another potentially relevant factor for patient recruitment to research. Patients diagnosed in an emergency may not go through the same pathways and have the same contact with research professionals. Further, one year survival is lower for this group[16], so patients may not survive long enough to take part in research. The latest referral to secondary care before participation in research has been used for this analysis, as in some instances patients were diagnosed years before.

Figure 7. Latest referral route for patients recruited to cancer research.



The urgent category includes Emergency Department attendances and emergency admissions. Emergency-related referrals represented 7% of research participants. As stated, this doesn't reflect diagnostic pathways, and it is difficult to know what percentage would be expected to have experienced an emergency referral before recruitment to research. However, for context, 23% of new cancers are diagnosed following an emergency presentation[12].

Summary of results

The following are key findings for this health equity assessment:

- Older adults (aged 70 old or older, or aged 80 old or older) are significantly under-represented in cancer research, and are more likely to have co-morbidities

- Compared to the age profile of people newly diagnosed with cancer in BNSSG:

[16] Routes to diagnosis. NCIN data briefings. Available here

    - Adults aged 70 or older were 56% less likely to take part in research
    - Adults aged 80 or older were 77% less likely to take part in research

- People with cancer from the 20% most deprived communities are statistically significantly under-represented in research in BNSSG when compared to the group newly diagnosed with cancer. They are also under-represented when compared to the group living with cancer, although this difference was not statistically significant.

- Compared to the deprivation profile of people newly diagnosed with cancer in BNSSG, the most deprived 20% of patients are 27% less likely to participate in research compared to the least deprived 20%

- People with cancer from the 20% most deprived communities are more likely to be younger, have one or more comorbidities, and have recently experienced an emergency admission than those from the least deprived backgrounds. Finally, they are more likely to be from Bristol, consistent with the BNSSG socioeconomic profile. Under-representation is likely multifactorial, including poorer long term cancer survival for the most deprived communities

- People from an ethnic minority background appear under-represented in cancer research, but recording of ethnicity was poor, particularly for NBT, so that meaningful assessment of ethnicity was not possible

- Patients from outside BNSSG (18%) appear similar in profile to those recruited to research from within BNSSG. We do not know how many patients we would expect to see from out of area. This is, however, reassuring that people from extremes of age and deprived communities are able to travel for research participation

- There are some differences in the profile of people taking part in research between the two Trusts. Differences include patients at UHBW being on average 8 years younger, and twice as likely to come from outside of BNSSG. In addition, the cancer types affecting patients recruited to research differ. Some of these (younger patients and cancer types) likely relates to available services

- Data recording needs to improve for some factors crucial to assessing equity and cancer pathways. This includes:
    -ethnicity, particularly at North Bristol Trust
    -stage of cancer
    -Inclusion health factors in Trust datasets: homeless people, Gypsy, Roma and Traveller community members, vulnerable migrants, people who leave prison and sex workers
    -participation in research within the systemwide dataset

Limitations

This Health Equity Audit has been carried out with data that was available in the Trust and CCG datasets, and there are limitations on recording of some of the variables. In addition, data sharing restrictions limited some of the analyses that could be performed. The comparison cohorts are not perfect representations of the pool of people eligible for research. The 5 practices that opted out of the audit were based in South Bristol, so fewer patients are from this area proportionally. Both cohorts contain people who are likely not fit for active treatment or research participation. They also have a survival bias, as they only contain living patients. In BNSSG 12-month survival for cancer is 74%[17]. There's evidence that people from more deprived backgrounds have (a) higher cancer rates for most cancers, and (b) poorer survival rates[18]. This means that people from more deprived backgrounds will be under-represented in the comparison cohorts, so that the degree of under-representation is likely greater than has been described here. However, it's also true that involvement in research can happen years after diagnosis, so that disparities both reflect and drive inequalities. As discussed, this analysis may have been underpowered to detect some differences in participation rates, partly due to duplication of patients in the research cohort and comparison groups.

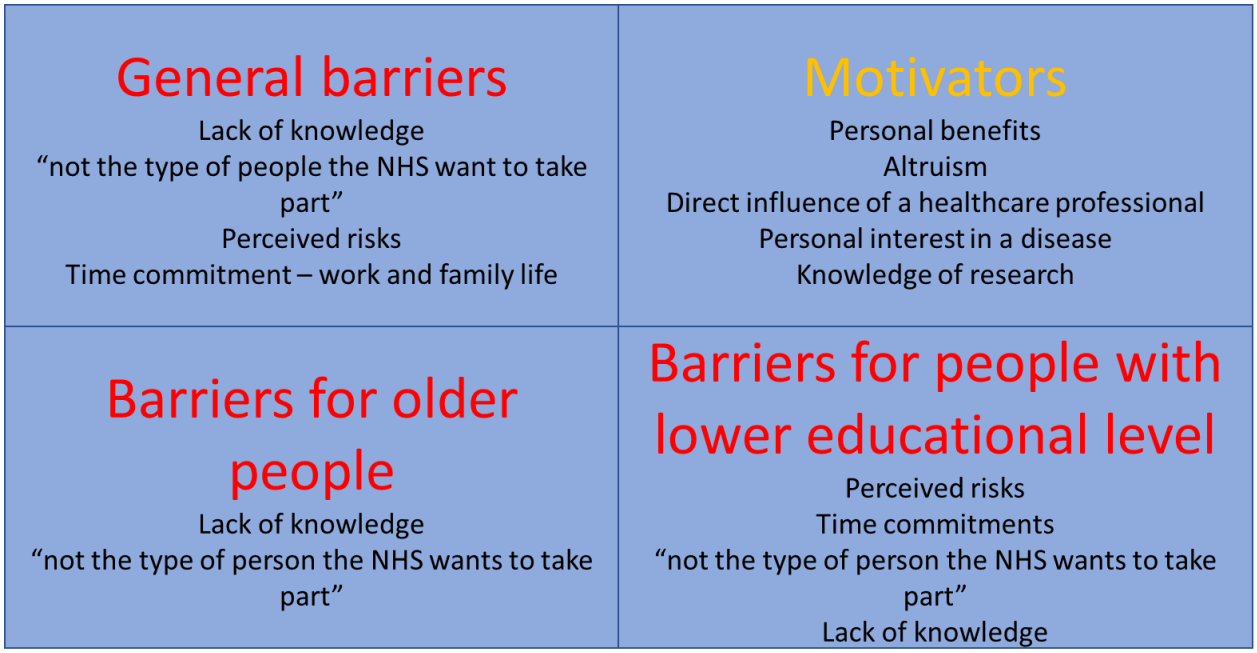
Evidence for interventions to improve equitable access to research

There is little published literature on evidence-based approaches to improving access to research. The figure below summarises evidence from members of the public on motivators and barriers they perceive/describe to research participation[19], and those that were more dominant in the older people and people from lower educational level backgrounds. The latter is broadly associated with socioeconomic status. Research was seen as less important, and participation less likely for those of poor health, lower educational level and the unemployed.

There are restrictions on eligibility for some research, and this is particularly relevant for comorbidities and age. Those with more comorbidities are likely to have a lower performance status, meaning potential tolerability of new treatments, or ability to travel is lower. Some of the work to improve access to research for deprived communities needs to therefore be upstream, so that people are diagnosed at an earlier stage and not through emergency routes. It may also be inevitable that older people are more likely to have comorbidities and less likely to be eligible. However, there is national evidence that healthcare and research experiences differ for these groups, and equitable access requires a proactive approach to analyse local barriers and develop local solutions.

[17] CADEAS Cancer Alliance Statistics. Available here
[18] Cancer in the UK 2020: socio-economic deprivation. Available here
[19] Engaging for increased research participation. Southampton University. Available here

Figure 8. Barriers and motivators for public involvement in NHS research



This research also identified **barriers for healthcare professionals involving their patients in research which included workload, time, lack of research information, concern for their patients and the doctor-patient relationship.** From the national cancer patient experience survey, people from the most deprived backgrounds are: more likely to report a need for more emotional support and practical support inside and outside the home[20].

One study that has looked at recruiting more people from deprived backgrounds to research used "lay advisors" who were trained in the research objectives and methods, then worked with communities, community gatekeepers and local stakeholders (e.g. local authorities), to increase awareness of the research, and offer participation opportunities that worked for those communities[21]. This might not be feasible for individual studies, but could also help identify and address more general barriers to research participation.

Not all patients will want to take part in research, and there may be differences in those who have research discussed with them, and those who are then recruited. It is however a patient's right to participate if possible. The national cancer patient experience survey shows that in answer to the question "Someone discussed with the patient whether they would like to take part in cancer research", in 2019, there is variation across the Trusts, but also scope for improvement in all three Trusts[10]:

[20] National Cancer Patient Experience Survey 2018. Available here

[21] Recruitment and retention of participants from socioeconomically deprived communities: lessons from the Awareness and Beliefs About Cancer (ABACus3) Randomised Controlled Trial. 2020. BMC Medical Research Methodology. Available here

Table 5. Scores for the Acute Trusts in BNSSG on "Someone discussed with the patient whether they would like to take part in cancer research"

	Organisational score	National score	Expected range
NBT	33%	30%	21%-40%
WGH	27%	30%	19%-41%
UHB	42%	30%	21%-39%

Involvement of patients and carers in research is a national priority, and recommended for every stage of the research process[22]. This is important when considering how to address and prevent inequity of access.

Action plan/recommendations

This health equity audit is a starting point and a call to action. It provides a platform to collaborate further using the Health Equity Assessment Toolkit[23] to develop an action plan.

The following recommended actions are needed to further understand these inequities and review our research recruitment pathways, as well as improve our ability to do further Health Equity work.

1. **To improve and target healthcare systems' data recording and sharing to ensure assessment of equity in our services is facilitated. Specifically, the recording of ethnicity and cancer stage must be prioritised**

This equity profile has been completed using data from the two hospital Trusts and the CCG (the system-wide dataset). Data recording within the Trusts, and data sharing restrictions within the healthcare system have made this process challenging to complete.

The variables listed below need to be more completely recorded and easily accessible within the Trusts, so that equitable access can be reassessed for cancer research, and looked at for other areas of research or clinical practice in the future.

a. First language spoken by patients
b. Ethnicity
c. For cancer: tumour stage, route of diagnosis and date of diagnosis and other milestones in the cancer pathway
d. Within the systemwide dataset: participation in research

[22] Royal College of Physicians. Work with us not For us: improving patient access to research. Available here
[23] Health Equity Assessment Toolkit. Available here

Working to develop a data sharing agreement between the Trusts (for instance under the provider collaborative for the direct improvement of care), would streamline the process and facilitate joint working to improve the healthcare available to the BNSSG population. Similarly, joint working with the CCG intelligence team to review processes for data sharing with the Trusts for similar purposes of improving patient care could make this kind of work more routine, make further use of the systemwide dataset, and reduce the burden on the CCG analytic team.

2. **To embed the involvement of patients and carers in the whole research process to improve access and explore their views in increasing equity or barriers to research.**

This is true with respect to which studies are being run locally, and also for identifying and reducing barriers to participation proactively and retrospectively. We should strive for diversity in patient involvement, particularly from under-represented groups.

3. **To enable and facilitate effective clinical conversations with all around cancer research**.

Compassionate clinical leadership from Clinical Research Networks, research infrastructure and senior leaders can support clinical engagement with research. This cannot be replaced by a broad public awareness approach. Clinicians need to know what research is available for patients, the processes of recruitment, and have the skills and confidence to discuss it with patients. This is most relevant to the secondary care health care practitioners, but continued communication with primary care is also needed.

4. **To provide information about research and clinical trials are provided alongside all other information given to patients accessing healthcare, in accessible, relevant forms**

Information should specifically challenge the misconception that people are “not the type of person the NHS wants to take part”, alongside the other barriers and motivators identified above. Patients need to know that clinical research is part of the NHS. Information should be in plain English, with options for information in other languages or in non-written formats. This might include patient information leaflets, online service information, consultant profiles

5. **To review the research delivery methods, particularly with respect to practical and emotional support for patients, with the knowledge that older patients and those from more deprived backgrounds are currently under-represented locally**

Strategies to deliver this should be developed with local clinical and research teams, and patients using the Health Equity Assessment Tool. Ideas might include:

- a requirement for in the governance of new studies to explicitly consider equity of access, including how to meet the information and support needs of different patient groups
- digital solutions that reduce time commitments for patients
- access to research as part of the NHS Long Term Plan personalised care for cancer work
- communicating with commercial partners on how equity might be included in research design and funding
- targeting specific groups eg older adults from deprived areas, to develop referral networks and pathways

6. To explore novel out-ward looking approaches to address inequities

Health inequalities require multi-pronged joint commitment and working. This should include new solutions, including for instance the INSPIRATA Artificial Intelligence pilot trial navigator where patients potentially eligible for studies are flagged up by the system.