

ICB Public Involvement and Engagement Advisory Committee

Date of meeting	25 September 2024
Title of paper	Public and community insights report: June to August 2024
Presented by	David Rogers, Head of Communications and Engagement
Author	David Rogers, Head of Communications and Engagement Communication Engagement Team Members
Agenda item	7b
Confidential	No

Executive summary

The report provides members of the ICB Public Involvement and Engagement Advisory Committee (PIEAC) a summary of insights which have been captured through pro-active public and community engagement activities between June and August 2024.

In this insight report, we share the summary findings from four large scale engagement exercises, focusing on:

- cardiac services
- women's health
- barriers to cancer screening experienced by south-east Asian women regarding cancer care
- community equipment
- Inclusive North, on the needs of BME carers.

The report also presents analysis of two national surveys:

- the national GP survey
- the national cancer survey.

These findings are being considered by the relevant programmes.

Advise, Assure or Alert

Assure the committee:

- The ICB has methods and approaches to capture public and patient insight.

Advise the committee:

- Of insights acquired through engagement.
-

Recommendations

The Public Involvement and Engagement Advisory Committee is asked to:

- Note the contents and summary of insights contained in the report
- Accept the insights presented in the report and recommend any significant findings which require further exploration or analysis

- Endorse the sharing of this report with the ICB Quality committee for consideration of how the findings are relevant to the quality of services provided by, or commissioned by, the ICB

Which Strategic Objective/s does the report contribute to		Tick
1	Improve quality, including safety, clinical outcomes, and patient experience	✓
2	To equalise opportunities and clinical outcomes across the area	✓
3	Make working in Lancashire and South Cumbria an attractive and desirable option for existing and potential employees	✓
4	Meet financial targets and deliver improved productivity	✓
5	Meet national and locally determined performance standards and targets	✓
6	To develop and implement ambitious, deliverable strategies	✓

Implications				
	Yes	No	N/A	Comments
Associated risks				
Are associated risks detailed on the ICB Risk Register?	x			
Financial Implications			x	

Where paper has been discussed (list other committees/forums that have discussed this paper)

Meeting	Date	Outcomes

Conflicts of interest associated with this report
 Not applicable

Impact assessments				
	Yes	No	N/A	Comments
Quality impact assessment completed			x	
Equality impact assessment completed			x	
Data privacy impact assessment completed			x	

Report authorised by:	Neil Greaves, director of communications and engagement
------------------------------	---

Public and community insights report: June to August 2024

1. Introduction

The report provides members of the ICB Public Involvement and Engagement Advisory Committee (PIEAC) a summary of public and community insights captured by the ICB between June and August 2024 or published by partner organisations.

2. Reports, insights and outcomes from engagement activity

2.1 Cardiac service reconfiguration

Following a review of cardiac services and the wider model of care in Lancashire and south Cumbria a list of 'drivers for change' has been established which, on paper, warrant reconfiguration of those services. To support this a series of engagement through focus groups and online questionnaires was conducted in July and August 2024.

We spoke to people about their experience in the Trusts they were treated at asking specifically if they had experienced any of the issues highlighted in the drivers for change. We also asked what good hospital care for cardiac patients should look like and whether changes to the service might create any other issues.

The following is a summary of the key themes, public perspectives and issues raised during the engagement:

- Members of the public said waiting times for appointments are too long.
- Some diagnostics, particularly echocardiogram testing take too long.
- NHS organisations do not communicate well between themselves.
- Provision at the cardiac centre at Blackpool Teaching Hospitals NHS Foundation Trust is excellent but delays in appointments are of concern to patients.
- The severity of cardiac conditions requires patients to have more reassurance in their treatment.
- Patients want either to see the same consultant every time or to be reassured that the person they are seeing has access to all their records and is familiar with them and their situation.
- In-hospital care is usually excellent, but rehabilitation/repatriation is slow and communication with out-of-hospital services needs to be improved.
- Being seen at the centre of excellence is seen as preferable to anywhere else.
- There are a number of services that patients would feel confident in accessing in the community; those being services that are post-operative and do not need specialist facilities or consultant input.

In general, feedback from patients support the case for change and echo some of the issues raised as drivers. Issues around staffing, waiting times for appointments and delays in echocardiogram testing and other diagnostics were highlighted as most pressing.

The findings also show a level of support for a network of services with the condition that communication between all services is improved and robust.

The report on the findings can be found on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

2.2 Barriers to cancer screening – listening to views from black and minority ethnic women in Preston

A number of published studies indicate that South Asian women generally have lower screening rates for cancer than white British women. Evidence suggests they have poorer knowledge of the signs and symptoms of cancer and cancer prevention and experience more barriers to screening.

This engagement project aimed to seek the views of those women connected with Sahara in Preston, a voluntary organisation for women, to understand what the barriers are to attending the national screening programmes for cervical, breast and bowel cancer and what can be done by health services to improve uptake. Sixty-three ladies attended a listening event at the end of June 2024, ranging in age from those in their 20's to those in their 70's.

There were a number of key themes which arose from across all of the discussions. Overall, we heard there is a lack of understanding and education about cancer and signs and symptoms. There are some key barriers to attending for screening, mainly relating to language, culture, fear of pain and the unknown and what to expect which also comes from the lack of information supplied, whether in English or other languages.

The full insight report has been shared with the ICB's women's health team and the ICB's cancer team to consider the points raised and use the insight to influence future service provision.

A report on the findings can be found on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

2.3 Scoping survey to gauge satisfaction with existing women's health services across Lancashire and South Cumbria

There are around 1.8 million residents in Lancashire and South Cumbria – of those, around 917,000 are girls, women and people assigned female at birth (AFAB), aged from birth to over 90 years old.

Lancashire and South Cumbria ICB is working to establish women's hubs focusing on areas of need. In order to make the hubs as meaningful as possible to as many people as possible, we decided to ask women what they wanted to happen with any potential contraceptive and menopause services.

A scoping survey was sent to over 300 organisations and individuals asking for women and people assigned female at birth to share their thoughts on current provision of contraceptive and menopause services.

A survey was designed to ask women and AFAB people about their contraceptive and menopause needs. There were 1549 responses, with a number of themes and recommendations:

- Address unwanted variance in primary care- issues around services provided, accessibility, knowledge and specialism of staff.
- Make sure any future engagement is in non-medicalised language.
- Greater provision of specialist/focused clinics staffed by well-trained, compassionate, and knowledgeable staff.
- Provide services locally at place rather than centrally- consider issues such as transport, deprivation, rurality when planning service delivery.
- Utilise primary care/community spaces as people are already familiar with them- no need to build additional clinical spaces.
- Be mindful of LGBTQ+ service users; avoid gender-stereotypes in communications materials, use inclusive terms.
- Address menopause as holistic condition- does not always require referral to gynaecology or mental health services.
- Improve accessibility- language/ location/ estates e.g. disabled access.

The full report can be accessed on the ICB website here:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

2.4 Community equipment service patient feedback

The provision of community equipment is a vital and relatively complex service, delivered in partnership with local authorities across Lancashire and South Cumbria. An in-depth online survey was developed and circulated in July 2024, inviting patients and carers with lived experience of community equipment services to provide feedback on their experiences. Eighty-one patients and carers responded to the survey and provided over five thousand words of narrative feedback. A handful of these respondents also elected to attend an online focus group session or one-to-one telephone or Teams interviews.

Almost all the respondents had experience of community equipment services, either as patients or as carers:

- Approximately a third of respondents considered most if not all these steps went well. For many others the process was let down at one or more stages. No stage in the process, in any locality, was without a level of concern, some of which were significant.
- Over 10% of respondents had concerns with the assessment process,
- Twenty-six percent felt that the waiting time for equipment was unacceptable,
- Over 12% were unhappy with the delivery process, including communication around this,

- Almost a third of respondents felt the information provided about the use and care of equipment was inadequate or non-existent, while a similar number of respondents were not given information about servicing or maintenance,
- Over a third of respondents were unhappy about the collection process.

Respondents were asked about what improvements they would like to see. The main improvements suggested were:

- Clearer details about who to return equipment to and waiting times,
- Take away old equipment when delivering new equipment,
- Have a central store where equipment can be returned to,
- Improve communication and information to patients regarding the whole process, dates/times/contacts etc.,
- Provide an information pack about the community equipment service with contact details prior to discharge from hospital,
- Text or phone delivery times before the delivery takes place,
- Follow up to make sure everything is fine with/about the equipment,
- Watch patients use equipment to check it is suitable and safe,
- Empower patients and carers with knowledge about the equipment, how to use it and how to care for it.

The report will be used to inform the development of the draft service specification and several patients will act as the lived experience patient voice during the development process and beyond.

The report is available on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

2.5 Unpaid carers: Understanding the carer experience: challenges and insights from racially minoritised communities on NHS services and hospital discharge

In response to Healthwatch's report on the lived experience of carers in Westmorland and Furness which was shared at the PIEAC in December 2023, PIEAC members discussed the need for a focus to understand the lived experience, insight and views of people from minority ethnic groups. Following this discussion, NHS England invited bids for funding to engage with seldom heard groups and marginalised populations. The engagement team, working with Inclusive North bid for and was successful in obtaining funding to engage with minority ethnic groups to understand their experience of caring in the Lancashire health and care system.

This work has highlighted the insights of the experience of racially minoritised unpaid carers

and their experiences of navigating NHS health care, focusing on:

- GP Services
- Urgent Care
- Outpatient Appointments
- Inpatient Care
- Hospital Discharge Planning

The report of the engagement has now been published and seeks to understand the entire process and difficulties faced by unpaid carers navigating various NHS services, with a particular emphasis on what constitutes a good hospital discharge from their perspective. It identifies common themes, key issues, and provides recommendations for improvement based on the carers' feedback.

These key findings underline the critical areas where improvements are needed to enhance the experiences of unpaid carers from racially minoritised communities in navigating and using NHS services.

GP Services:

- Appointment Accessibility and Delays: Long waiting times for GP appointments and
- difficulties in booking systems were major concerns, with some carers waiting up to six months for an appointment.
- Communication Barriers: Language barriers and poor communication from GPs were significant issues, leading to misunderstandings and inadequate care.
- Staff Attitude and Stereotyping: Carers reported feeling dismissed and stereotyped by GP staff, with frequent use of locum doctors resulting in inconsistent care.

Urgent Care (111 and A&E Services):

- Response Times and Efficiency: Carers experienced long waiting times for ambulances and in A&E departments, causing significant stress during emergencies.
- Communication Issues: The 111 service was criticised for being too scripted, and carers often had to repeat information multiple times to different staff members.
- Staffing Levels and Attitudes: Understaffed departments and unhelpful reception staff were common complaints, with carers feeling that urgent care services lacked efficiency and empathy.

Outpatient Appointments:

- Long Waiting Times: Delays in outpatient appointments and receiving test results were highlighted as major issues, adding to carers' anxiety.
- Appointment Cancellations and Coordination: Frequent cancellations and poor coordination between NHS Trusts disrupted care and caused confusion.
- Professional Attitudes and Communication: Healthcare professionals in outpatient
- settings often appeared rushed, making it difficult for carers to receive comprehensive information about treatment plans.

Inpatient care

- Hospitalisation Experience: Carers reported long waits for room admission, inadequate facilities, and patients being left on trolleys in corridors.

- **Staff Attitudes and Cultural Sensitivity:** Rudeness and a lack of cultural sensitivity from hospital staff were significant concerns, with carers feeling their needs were not respected.
- **Communication and Support:** Carers expressed the need for better communication and regular updates from hospital staff, as well as more support services tailored to their cultural and linguistic needs.

The report and the findings will now be considered by the Lancashire and South Cumbria Carers Group, and an action plan developed in response to the findings. In addition, the findings will be shared with the equality, diversity and inclusion teams across the health and care system to increase awareness and encourage action.

The full report is available on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

Moderate Frailty

This engagement was carried out between February and June 2024. The engagement sought to find out what challenges carers and people with frailty faced on a daily basis, how they access support and what could be done to make this better where they felt improvements were needed.

The engagement encompassed both face-to-face opportunities and a survey, available online or in paper form. Multiple colleagues, partners and community and voluntary sector organisations were contacted. This resulted in 146 people listened to face-to-face at engagement events across Lancashire and South Cumbria and 105 survey responses completed online.

61% of survey respondents gave feedback on their biggest daily challenges and the most significant was being a carer, whether this was due to juggling work and caring for a family, or someone frail looking after someone else who was frailer, or simply the pressure of caring for someone 24/7. Other significant challenges were accessing GP, hospital appointments, support from NHS services, loneliness, isolation and depression. Over 20% of these respondents indicated that most things were a challenge – cooking, cleaning, dressing, mobility, medication, and finding help and support. This information was supported by feedback from face-to-face engagement.

86% of survey respondents gave feedback about their experiences of accessing support. The most significant of these was the struggle to know what support was available and where, and then the struggle to access it. Many felt there was a lack of information or that it was not in a form that they could easily access. This was especially felt by the visually and hearing impaired, by people with dementia, and by those who struggled with technology generally. In some areas care agencies were either not available, did not necessarily meet people's needs and/or were expensive.

Generally, it was felt that people with frailty and their carers needed better information about what support was available and how to access it, and that many services were more accessible, adaptable, and holistic in their approach. Carers were very frustrated, and felt more effort needed to be made in listening to and involving patients and carers. This applied across NHS services and social care, where there was a call for better training, pay and status of care agencies and their staff. Other improvements identified were tailored response teams, dedicated support for people with frailty, earlier interventions for mobility issues and the reinstatement of falls prevention services where these had disappeared.

The full report is available on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

West Lancashire Community Services

In May and June 2024, a questionnaire was developed and distributed which would ask people in West Lancashire about their views and experiences of local community services as part of a review of the delivery of community services in that area.

A total of 66 people completed the questionnaire, 55 of which had accessed community services, either directly or for someone they care for. Some rich insights were received which are detailed in the analysis report.

Key findings

- The majority (85.5%) of respondents who had accessed community services in West Lancashire in the past five years said they were satisfied with the service they had received.
- More than 80% said they would expect to travel five miles or less to a community health services appointment.
- More than three quarters feel involved in decision making around their care. For those that didn't feel involved, 69% wanted to be more involved.
- Most respondents (85.5%) felt information was communicated well and in a format they could understand.
- However, nearly 42% of people didn't know who was in charge of their care.
- Of the 38% of people who received care for more than one condition, nearly 43% didn't feel that care was coordinated.
- Almost three quarters of people were either already using technology or would be happy to use technology to manage their care.
- Meanwhile, less than half of respondents felt they had all the information they need about what services are available to them.

When asked to think about what was positive about the care they received the top three themes were:

- Staff – helpful, friendly, professional
- Clinicians – excellent care and knowledge
- Ease of access – getting seen quickly and easily

When asked to consider what could be done to make the service(s) better, the top three themes were:

- Need better communication and availability of information
- More appointments needed to reduce waiting times
- Better access – in terms of contact

The full report is available on the ICB website:

<https://www.lancashireandsouthcumbria.icb.nhs.uk/get-involved/what-youve-told-us-1>

Virtual Citizens Panel Monthly tracking check in

Between September 2023 and April 2024, the ICB emailed members of the Citizen's Panel via a newsletter, in which we ask them three regular questions: These are:

- How do you feel about your health at the moment?
- How do you feel about the state of NHS services? and
- Thinking of the most recent time you have used an NHS service, how do you feel about your experience?

In our recent polls under half of the respondents were dissatisfied with their own health at the time they responded and over a quarter were dissatisfied with their latest experience of health services. 71.5% of respondents were dissatisfied to some degree with the state of NHS health services, with over a fifth very dissatisfied.

In the period June to August 2024, we reviewed and asked different questions. We focused on mental health and navigating services.

- Eighty individuals responded to our questions in this period.
- 77% of respondents were satisfied with their mental health, and a third of respondents were not satisfied with their mental health.
- More than half of respondents (52%) were confident navigating the NHS and health and care system to get help for their problem.
- A fifth, (20%) were not confident to navigate the health and care system.
- We asked if people came across any barriers to using the NHS and health services, and the majority, said no, although 12% (10 people) said that they had experienced barriers. These were typically to do with poor communication, lack of appointments, and long waiting times.
- There appears to be a marked shift in the satisfaction felt with the state of NHS health services, with 72% of respondents reporting satisfaction with NHS services.
- People were concerned about the following and these are similar to the responses in early 2024:
 - GP availability and access
 - Access to services
 - Dental access
 - Need for new facilities
 - Access to clinical expertise
 - Respect, dignity and being listened to
 - Need for better communication from professionals

- Comparing responses in early 2024 and between June and August 2024, it is evident that waiting times for hospital appointments and support for long term conditions were not referenced in the more recent period as a concern by respondents.

3. Reports, insights and outcomes from national patient surveys

3.1 National GP Patient Survey

The national GP patient survey was published in July. The latest survey consisted of around 2.56 million questionnaires sent out to patients aged 16 or over registered with GP practices in England, from 2 January to 25 March 2024. 699,790 patients completed and returned a questionnaire, resulting in a national response rate of 27.3%.

- 73.9% of patients had a good overall experience of their GP practice.
- 67.3% of patients had a good overall experience of contacting their GP practice.
- Of patients who had contacted or used an NHS service when their GP practice was closed, 55.9% had a good overall experience.
- Of patients who tried to get an NHS dental appointment in the last two years, 69.2% had a good overall experience of NHS dental services.
- 86.8% of patients had a good experience of using pharmacy services.
- 49.7% of patients said they find it (very or fairly) easy to contact someone on the phone at their GP practice (of which 18.9% found it 'very easy' and 30.8% found it 'fairly easy').

The last time patients had an appointment:

- 64.0% had an 'face-to-face' and 28.9% had a phone appointment.
- 89.3% of patients reported having used at least one of the listed pharmacy services in the last 12 months, and of those, 86.8% had a good experience of using these pharmacy services.

Read the report in detail here: [GPPS 2023 National report PUBLIC \(gp-patient.co.uk\)](https://gp-patient.co.uk). A localised report and analysis is available from the primary care team.

3.2 National Cancer Patient Experience Survey

The cancer patient experience survey has been designed to monitor national progress on cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients. The survey was sent to adult (ages 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May, and June 2023. A detailed national report was published in July 2024, along with local findings.

Key Findings:

- 52% response rate
- 63,438 people responded
- 66.6% of people who had contacted their GP practice said the referral for diagnosis was explained in a way they could completely understand

- 80.9% said they had been given the option of having a family member, carer or friend with them when they were first told they had cancer
- 8.89 was the average rating of care on a scale of 0 (very poor) to 10 (very good)
- 87.0% said the administration of their care was very good or good
- 89.9% said the whole care team worked well together
- 63.8% said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had cancer
- 60.1% said the possible long-term side effects, including the impact on their day-to-day activities, were explained in a way they could understand in advance of their treatment.
- 91.2% said they had a main contact person within the team looking after them who would support them through treatment
- 72.2% said that before their treatment started, they were definitely able to discuss their needs or concerns with a member of the team looking after them
- 46.5% said they definitely got the right amount of support from their GP practice during treatment
- 75.8% definitely got the right level of support for their overall health and well being from hospital staff
- 77.4% who had an overnight stay said they had confidence and trust in all of the team looking after them

Visit www.ncpes.co.uk to see detailed results at national and local level. A national report is available setting out the headline findings in more detail. Locally we are considering the findings and we will follow up with the cancer team to establish the response and action following the publication of local findings. We will report these on our website.

Glossary

A glossary of terms to support this paper is available here: <https://www.lancashireandsouthcumbria.icb.nhs.uk/about-us/glossary>