



South West London

Joint Forward Plan

Our engagement with people and communities

April to May 2023

Engagement on the first phase of our draft Joint Forward Plan published in March 2023. Focusing on populations and geographies identified through the gap analysis of our [insight from people and communities review](#).

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1. Introduction

In October 2022, we asked our South West London health and care partners to share their existing insight and engagement reports relating to health and care services covering the previous 18 months. Over two phases, we reviewed over 180 reports from partners including many from Healthwatch, but also the voluntary and community sector, our NHS trusts, the six local authorities and our NHS place-based engagement teams. The views and experiences of thousands of residents, from a cross-section of our local communities told us what local people feel about a broad range of health and care services and issues.

We carried out an in-depth analysis to inform both our Joint Forward Plan and the proposed Integrated Care Partnership priorities for the South West London Integrated Care System. You can read the full analysis and report on our website [here](#).

We cut the data and analysis by 'setting of care' so that this insight could influence the ambition within each chapter section such as mental health, acute care and cancer care.

'[Developing our Joint Forward Plan](#)' was the first phase of our plan that we published in March 2023. For each of our settings of care' and 'spotlight' areas we included:

- the context
- our ambitions
- and our summary of what we have heard from local people.

This report highlights the engagement work we have done since we published this first phase of our Joint Forward Plan. The findings outlined in this report have informed the development of our final South West London Joint Forward Plan, which details how NHS South West London, and our partners will work together over the next five years to meet the needs of local people.

2. Methodology

This report details findings from health and care engagement with people and communities who live or use health and care services in the six boroughs, as well as people who work or study locally, covered by the South West London Integrated Care System (ICS): Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth. Engagement activities took place across South West London between April and May 2023.

People could share their views in a variety of ways; including via a survey, by attending focus groups, or by talking with us when we visited groups or organisations, which formed part of our outreach.

We asked people whether their experiences matched the community insights we had already gathered, and whether people agreed or disagreed with the proposed ambitions. People were able to say more about their own views and experiences in open text parts of the survey. During analysis, we explored where views and experiences matched or deviated from the insight we already had. Comments within this report are presented anonymously, and minor editing has been applied, for example to correct spelling mistakes.

This report is structured by care settings and focus areas to reflect the structure of the Joint Forward Plan. These are:

- Health Inequalities
- Preventing ill health and supporting self-care
- Acute care / hospital care
- Cancer
- Children and young people
- Community Care
- Diagnostics
- Maternity
- Mental Health
- Learning disability, autism and ADHD
- Primary Care
- Long Term Conditions
- Urgent Emergency Care (UEC)
- Workforce
- Digital
- Green Agenda

To see whether local people agreed with these insights across these care settings, we carried out engagement activities between April-May 2023. The approach was service specific, so people could talk about their particular experiences with health and care.

Our engagement activities included:

- **Survey** – hearing from people who live, work or study in South West London
- **Focus groups** – led in partnership with trusted community and voluntary sector organisations and advertising to specific population groups
- **One-to-one** conversations with people who need additional support
- **Outreach** at existing events and forums.

Survey

The survey aligned with the chapters in Joint Forward Plan (JFP). A [link](#) to the full JFP was provided if people wished to read the publication in full.

Each section of the survey included the following sub-sections:

- What people and communities tell us – people could say whether or not their own experiences matched the insight previously gathered
- The ambition (or ambitions) for that care setting – people could say whether or not they agreed with the ambition
- Open questions “Is there anything else you would like to say to help develop our plans for preventing ill health?” where people could add views, stories about experiences or other comments about the insights or ambitions. People often used this section to explain why they agreed or disagreed with the insights or ambitions.

We received 599 responses and 1,446 responses to the open questions, providing valuable additional insight into people’s experiences with health and care.

The survey was structured to enable people to complete sections relevant to their experience. The survey could be translated into different languages and completed by people with visual impairments. As with all online engagement; paper copies and other formats were available if requested.

The survey was promoted through various channels and partners including:

- South West London people's panel – a group of over 3,000 local people who are regularly invited to take part in surveys or join a focus group
- Health and care staff from across the partnership, including those who work for NHS trusts, our six local authorities and GP practices across our boroughs
- On NHS South West London social media channels including Twitter, Facebook and Instagram; asking partners to share it through their social media channels
- On the website www.southwestlondon.icb.nhs.uk
- Healthwatch and voluntary and community sector partner channels
- Via posters with QR codes at community events.

A copy of the [survey questions](#) are available as an accompanying document on our website.

Analysing the survey

The survey covered 15 separate care settings or priority areas, each with quantitative questions about the 'community insights' and 'ambitions' included in the draft Joint Forward Plan. Additionally, each of the 15 settings had an open question for people to tell us anything else they thought we should consider. The quantitative questions were analysed to identify the percentage of respondents who agreed or disagreed with the community insight or ambition. The open responses had a very small number of criticisms of the survey itself. The rest of the comments were a mix of shorter comments to agree or disagree with a particular community insight or ambition, examples of the respondent's personal experience of a service, and much longer comments detailing issues with a service or practical solutions which could inform how the ambitions were implemented.

The comments were analysed by care setting or priority area. Every comment was read in detail and themed by allotting it a code. Where a comment covered several different themes, it was given a code for each theme. This allowed all the comments under the theme to be read together to understand similar issues across the responses or to recognize differences in experiences. Three setting areas were selected at the beginning of the analysis and were coded in two separate formats to identify the best approach to coding:

1. Open coding. This started with the comments and developed codes based on the common themes arising.
2. Coding by the original 'community insights' and ambitions that formed the survey questions.

This approach to developing the themes to be coded showed most comments were related to the community insights and ambitions which formed the survey questions. The remaining 12 care settings and priority areas were coded using the insights and ambitions. However, some common themes were identified across the care settings; codes were developed to ensure these were captured. The common themes included: continuity of care, concerns about the loss of face to face treatment, digital exclusion, access to GPs and inequalities. The same analytical approach was taken with the focus groups and comment outreach findings.

When quoting comments as examples of the issues being raised by respondents, some minor changes have been made to a few comments. This includes making the comments easier to read by correcting typing mistakes, explaining acronyms and capitalizing the beginning of sentences. Details that would make the person identifiable have been removed. If a comment as a whole was so specific it would make the person identifiable it has been covered in the text but not quoted. Finally, where comments covered a range of themes, they have been broken down so the quotes only cover the theme in question.

Who we heard from

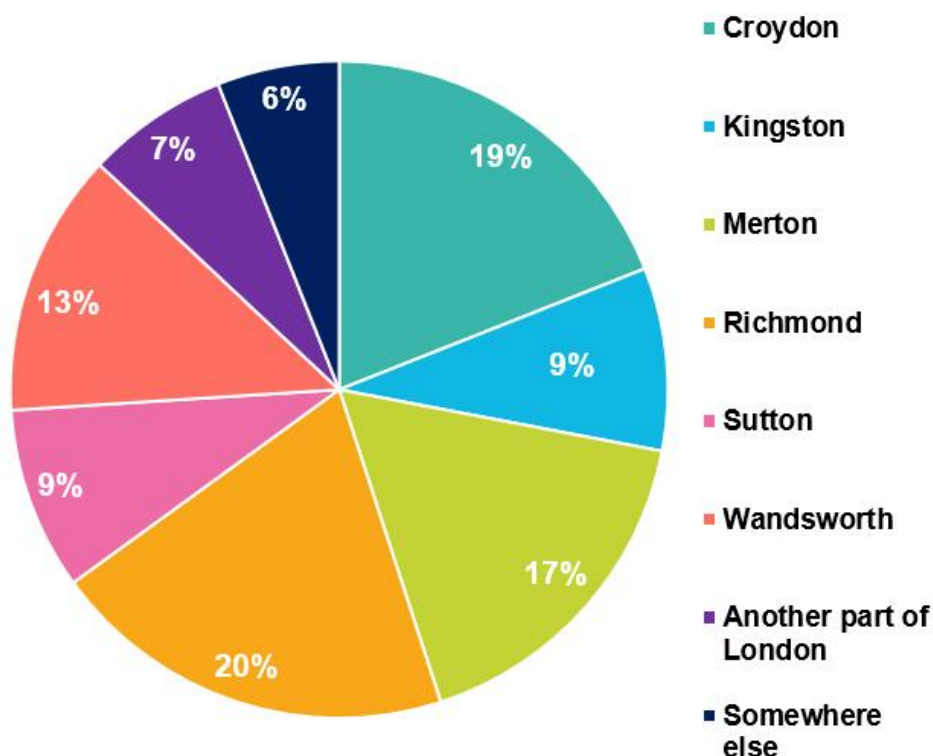
We asked people for information about themselves (demographics) so we could check we were listening to a diverse range of people likely to have different experiences of services and from protected characteristics. Apart from asking about the borough in which people lived, all personal demographic questions were optional and anonymous.

Question 1: Where do you live?

Most people who responded to the survey live in Richmond (20%), Croydon (19%) and Wandsworth (13%).

Percentage of responses by borough

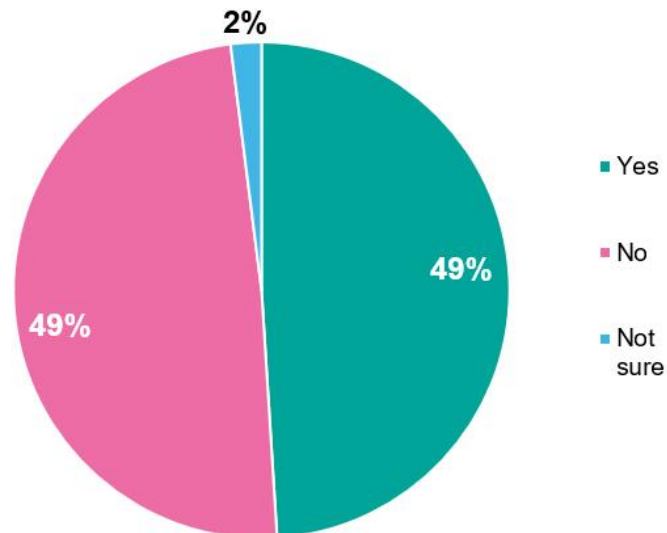
(number of people who responded to this question 589)



Question 2: Do you work in South West London?

There was an equal split between people who work in and don't work in South West London.

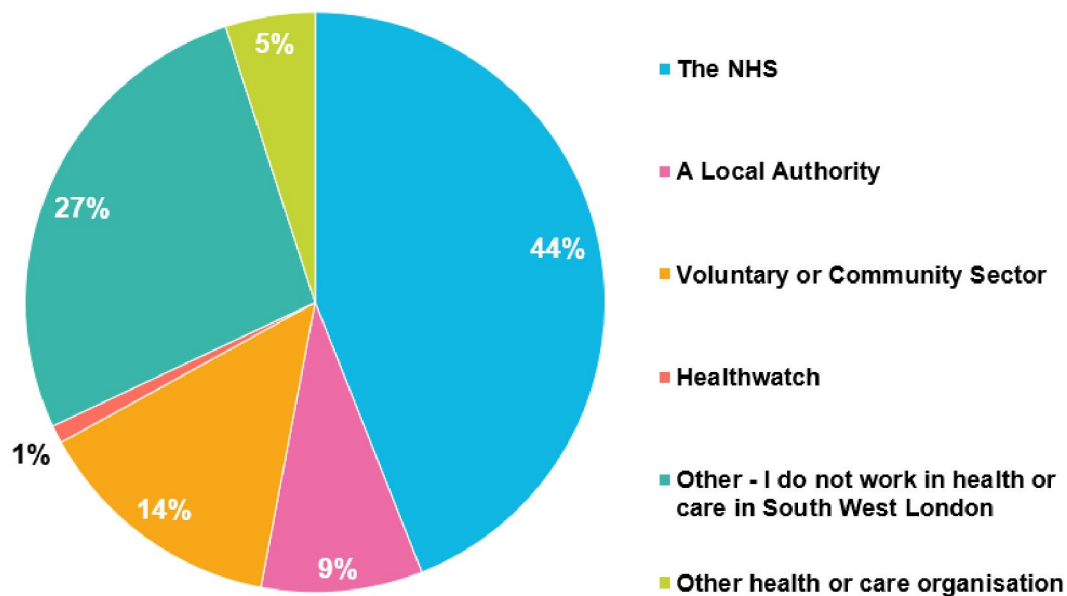
Percentage of respondents who work in South West London
(Number of people who responded to this question 588)



Question 3: If you work in South West London, do you work for any of the following?

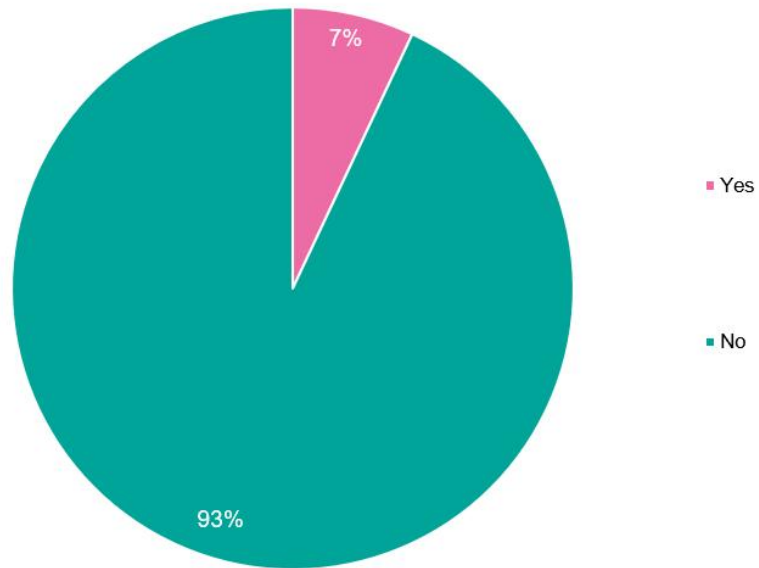
44% of respondents work within the NHS, 27% work outside the SWL health and care setting, and 14% work in the voluntary sector.

Where people work: percentage of respondents by employment/sector
(Number of people who responded to this question 294)



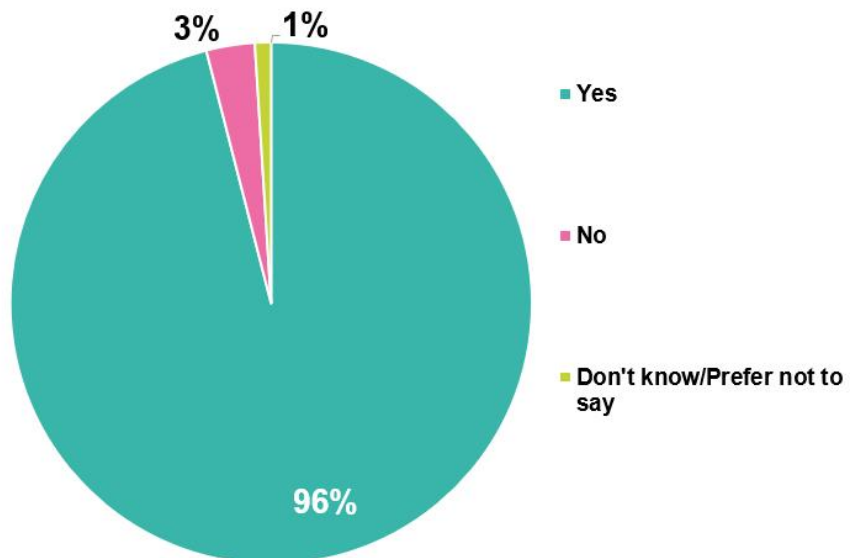
Question 4: Do you study in South West London?

Percentage of respondents who study in South West London
(Number of people who responded to this question 579)



Question 5: Are you registered with a GP?

Percentage of people registered with a GP
(Number of people who responded to this question 597)

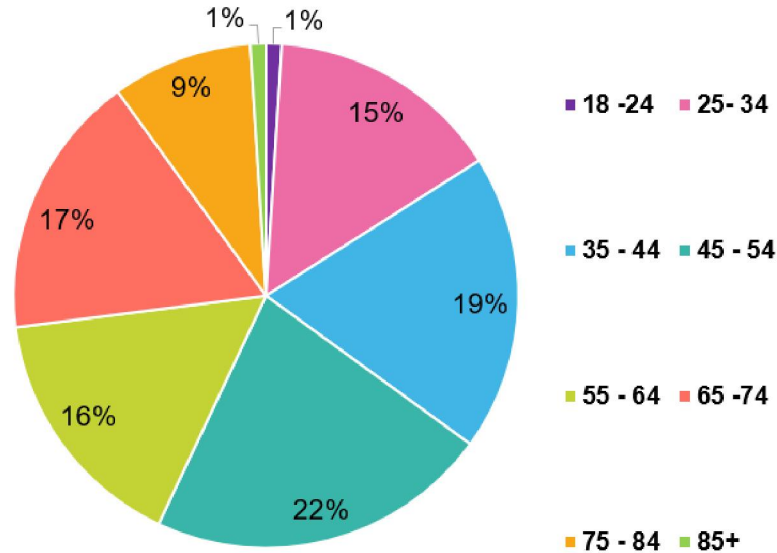


Question 6: What is your age group?

The age group we heard the most from was people aged 44-54 (22%), followed by people aged 35-44 (19%) and people aged 25-34 (17%). People aged 18-24 or aged over 85 made up just 2% of respondents.

Percentage of respondents by age

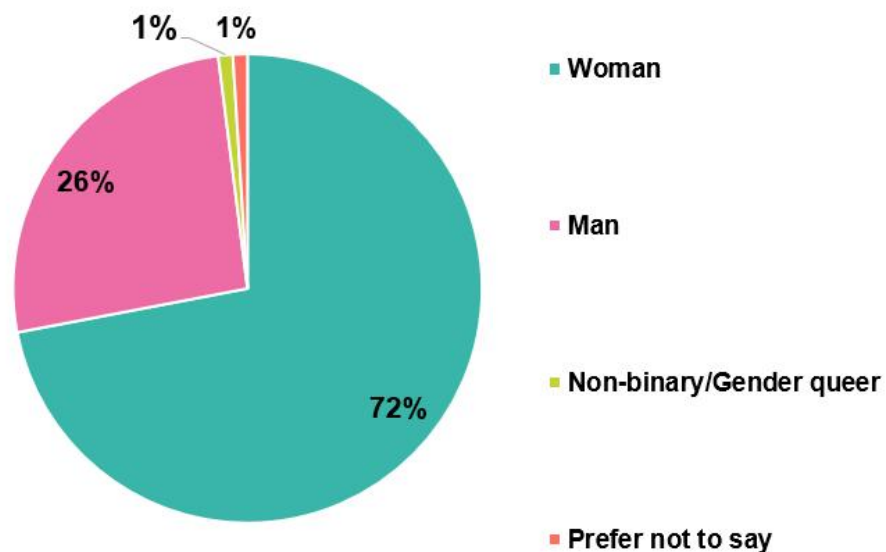
(Number of people who responded to this question 583)



Question 7: Please tell us how you describe your gender

Percentage of responses by gender

(Number of people who responded to this question 587)

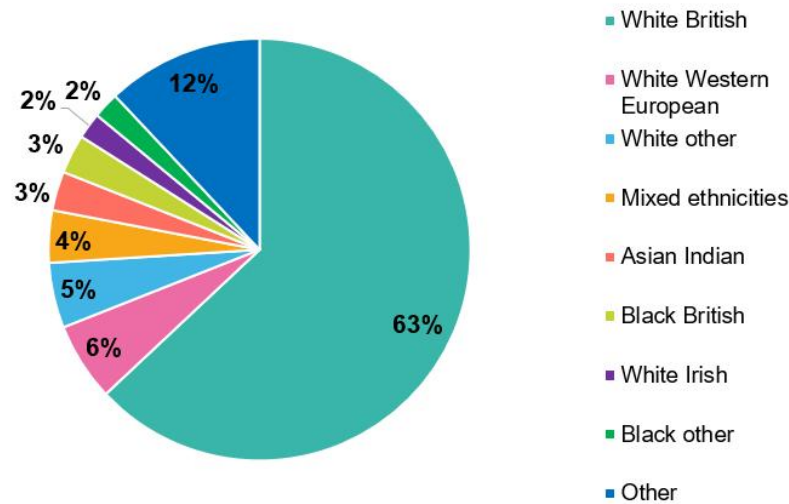


Question 8: How do you describe your ethnicity?

We provided a large number of choices for this question to ensure most people were represented. The main chart below shows ethnicities that received 10 or more responses. The text further down summarises other responses.

63% of all respondents described themselves as White British.

Percentage of responses by ethnicity
(Number of people who responded 577)

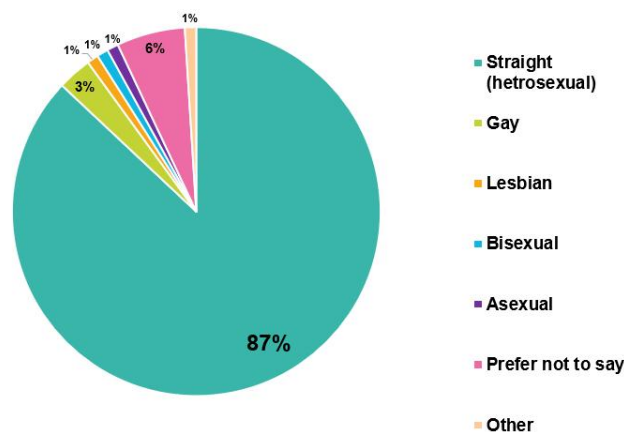


In the “Other” category includes people who identify as Caribbean, White European, Eastern European, Gypsy/Roma/Traveller, Nigerian, Ghanian, Chinese, Sri Lankan, Asian Other, Arabic/Middle Eastern, Jewish, Turkish, Other African, Pakistani, South American, North American, East African, Bangladeshi

Question 9: Please describe your sexuality

We ask this question to ensure we are hearing from a wide group of people and so we can see whether people have different experiences of services that could relate to their characteristics.

Percentage of responses by sexuality
(Number of people who responded to this question 586)

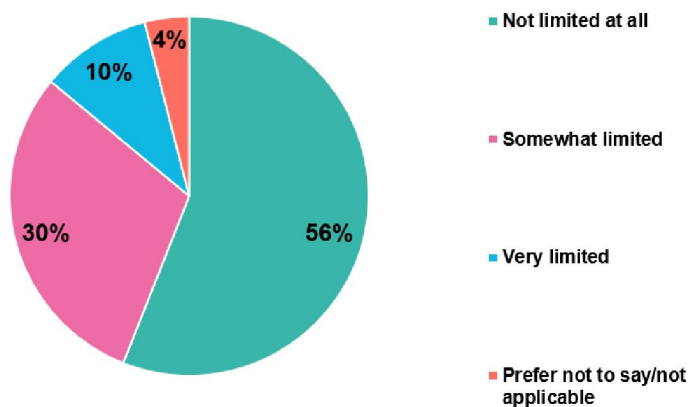


Question 10: Are your day-to-day activities limited because of a health problem or disability that has lasted or is expected to last at least 12 months (including problems related to older age)?

56% of respondents say their daily activities are not limited. However, 40% of respondents do live with a health problem or disability that limits activities.

Percentage of responses from people who identify as having a long term condition or disability that is expected to last at least 12 months

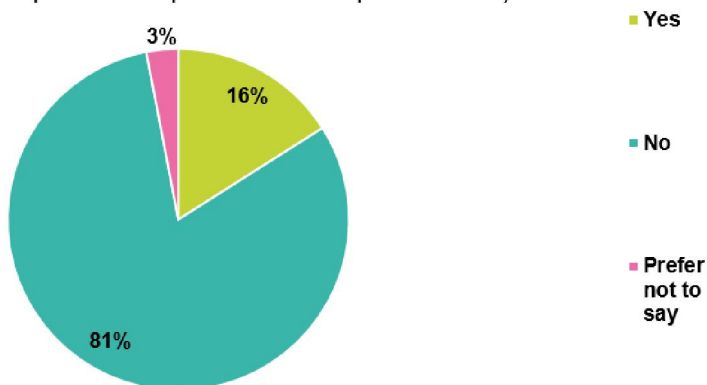
(Number of people who responded to this question 592)



Question 11: Are you an unpaid carer? Unpaid carers are anyone that spends an amount of time supporting a family member, partner or friend who is ill, frail or has a disability.

Percentage of responses from people who identify as unpaid carers

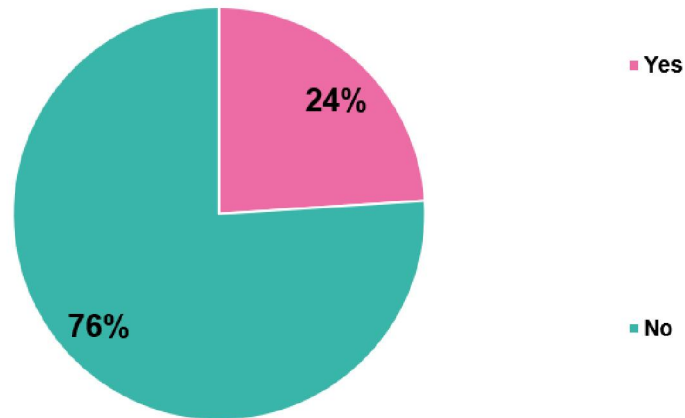
(Number of people who responded to this question 588)



Question 12: Are you a parent or guardian of a child (or children) under 16?

Percentage of responses from parents or guardians of a child (or children) under 16

(Number of people who responded to this question 588)



Focus groups, one-to-one discussions, and outreach

We considered key populations groups, geographies, and care settings areas to prioritise where to undertake our focus groups, one-to-one discussions and outreach to make sure it was inclusive, and we heard views from across a diverse range of local people and communities.

We undertook a gap analysis meant that we prioritised the following areas and worked with local partners, particularly the community and voluntary sector who supported us to attend existing forums and advertise open focus groups. The areas of focus included:

- Urgent and Emergency Care
- Primary care with a specific focus on prevention
- Long term conditions
- Children and young people
- Mental health – specifically hearing from Autistic people and people with a learning disability
- People who identify as LGBTQIA+.



Who we heard from

During April and May 2023, we engaged with local groups, with 187 people taking part in our engagement events. These groups were:

- refugees and asylum seekers in Mitcham, two individual focus groups
- parents and carers at Croydon Babyzone
- Sutton Seniors
- LGBTQIA+ group for south west London
- Beautiful Minds in Twickenham for secondary school children
- Searchlight Community Centre in Kingston
- the Roehampton Champions network
- BME Mental Health Forum in Balham
- the Ethnic Minority centre in Merton
- the Young at Heart Croydon BME Forum
- and the St George's Patient Involvement Forum.

We recruited participants through patient experience networks, via community partners, and by advertising on social media channels.

We developed an easy read version of the Joint Forward Plan to help explain our priorities. You can read this easy read version [here](#).

The table below lists engagement events held during April and May 2023:

Borough	Group name, location and approach	Date	Topics covered	Number of people engaged
Merton	Ethnic minority centre, Mitcham Library Focus group with refugees, asylum seekers and people from ethnic minority backgrounds who attend the centre.	25 April 2023	Primary care	17
Sutton	Sutton Seniors Forum, Trinity Church Focus group with people over the age of 65.	28 April 2023	Urgent Emergency Care	20
Merton	Ethnic minority centre, Vestry Hall Focus group with refugees, asylum seekers and people from ethnic minority backgrounds who attend the centre.	3 May 2023	Urgent Emergency Care; Primary Care	19
Wandsworth and Merton	LGBTQIA+ South West London group Focus group with people who identify as LGBTQIA+.	3 May 2023	Primary Care	3
Wandsworth	Roehampton Champions network Focus group with people of all ages living on the Roehampton estate.	9 May 2023	Urgent Emergency Care; Primary Care; Mental Health	17
Croydon	Croydon Babyzone Outreach and one-to-one conversations with parents/carers at a drop in play space for 0-5 year olds.	11 May 2023	Maternity; Primary Care; Urgent Emergency Care	50
Kingston and Richmond	Beautiful Minds event, Twickenham Outreach and one-to-one conversations with secondary school aged 11 to 19 young people.	17 May 2023	Mental Health; Autism; Children and Young People	30
Kingston and Richmond	Kingston Eccop, Searchlight Community Centre, Kingston Focus groups with adults with learning disabilities, profound and multiple disabilities, and autistic people.	23 May 2023	Learning disability; Mental Health; Autism; Primary Care; Digital	19

Croydon	Young at Heart, BME Forum, online Focus group with people over the age of 55.	23 May 2023	Long Term Conditions; Digital	7
South West London	St George's Patient Involvement Forum, Everyday Church Focus group with people who were either currently or previously accessed mental health services and/or had a mental health diagnosis.	25 May 2023	Mental health; Primary Care; Urgent Emergency Care	5

Limitations and mitigations

- Self-selection bias – voluntary participation – people who choose to respond to surveys may have different characteristics or opinions compared to those who do not respond. To mitigate this self-selection bias, we developed a mixed engagement approach with focus groups and 1:1 conversations so that we could reach people who we would not usually hear from through one single approach. To mitigate this, we offered a small incentive for focus groups or 121 discussions and a prize draw for completing the survey. We know from experience that this attracts a wider demographic.
- The survey aimed to be accessible and was divided into sections for ease by the reader, this however made the survey quite long with some people commenting about the length. This may have prevented some people completing it in full.
- Some of the wording of a few statements or ambitions covered more than one aspect. This made it difficult for people to agree or disagree for a part of the statement or ambition. However, people were able to leave their comments and expand on their personal experiences in the open text sections.

The following chapters analyse the qualitative and quantitative responses for each “setting of care”. Each section includes a high-level summary of the findings and a more detailed, in-depth analysis of the ambitions and whether people agree or disagree with what people and communities told us.

3. Hearing from our local people and communities

3.1 Health inequalities

Summary

In total 435 people responded to questions about health inequalities and there were 148 survey comments. Health inequalities was not covered as a main topic in the focus group or community outreach discussions held as part of this work.

Headline findings from survey respondents

- The highest number of comments about health inequalities related to suggestions about additional groups who experience health inequalities, mentioning specific needs.
- 92% of respondents agreed with the ambition for Health Inequalities.
- There were several comments that felt there had been an overemphasis on health inequalities.
- There were some concerns that people who may be digitally excluded contributed to health inequalities.
- Several people explicitly commented that they agree with the ambition for everyone to have equal access to healthcare.
- There were a few suggestions about co-producing any future equality plans with the patients and the wider community.
- In terms of agreement with previous insight, the strongest agreement was with mental ill health often being overlooked in older people (78% agreed).
- Lack of support – i.e., via translation services or digital support - also received high agreement (75%) as did the insight that said some people are more likely to face barriers in accessing services (74%)

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Some people are more likely to face barriers to using NHS services, such as screening or diagnostic appointments, and leading a healthy lifestyle	44	30	14	6	6
B. Lack of support – such as translation services or access to digital services – can mean that some people need help from family members during appointments or to use digital services, which isn't always appropriate	47	28	16	5	3
C. Some Black, Asian and minority ethnic groups say that they are fearful of NHS services which can influence how they feel about their treatment *	22	27	39	7	5
D. Some Black, Asian and minority ethnic groups say that they have felt their views have been dismissed by NHS staff, which may have led to delays in their care *	25	23	38	8	5
E. People say that symptoms of ill health especially mental ill health, can be overlooked in older people	45	36	16	5	1
F: Some NHS staff don't use inclusive or culturally competent language, and sometimes make assumptions about the cause of someone's illness	26	30	30	10	4

Figures represent responses by all demographics. Certain insights show different percentage agreement when filtered by relevant demographic.

By far the greatest number of comments about health inequalities fell into two broad categories: suggestions that health inequalities are not as serious or extensive as the questions imply (19 comments); or detailing inequalities the respondents felt were not being addressed by the NHS (40 comments). A few people commented that health inequalities were felt by everyone. Others

defended the NHS's record on equality, including a few respondents who worked for the NHS as well as service users.

I'm a nurse and I don't think there are inequalities within the NHS.

In my profession, all patients are treated dependent on condition. Black/minority ethnic groups are always treated well and with respect.

I never feel any inequality in NHS service.

Respondents listed a variety of examples of health inequalities experienced by particular groups in society with specific needs. Implicit in a few of the comments was a suggestion that some inequalities were given more profile than others in the survey questions. The range of groups mentioned included: neurodiverse people and people with autism, people with a learning disability, older people, young people, women, transgender people, people with sensory impairments and people on low incomes. Additionally, there were single comments about issues faced by working parents, people with low levels of literacy, people who were overweight, people with dementia and unpaid carers. A few examples of types of comments received will be provided here.

Young people

Because of the caseload of the team, staff if not all of the time has the tendency to overlook sign and symptoms of patients especially for young people.

I think health inequalities shouldn't just be looked at by deprivation and ethnicity, but also by age. For example, child mental health services are far less prevalent and accessible than adult mental health services.

Neurodiverse people

Gender and colour are not the only barriers. Neurodiverse individuals face stigma, and difficulties using online forms, and advocating for themselves in eg medical consultations.

I am an LGBTI person and I am autistic and I feel that both LGBTI people and neurodivergent people need to be considered when addressing health inequalities because both these groups have had and continue to have health disparities with the general population.

Gender

There is a tendency for women - especially older women - to have their symptoms dismissed as hysteria, imagination, not as bad as they say it is. This is especially true if they have had the intelligence and foresight to research their symptoms online before coming to the doctor. We would like to be listened to.

Improvements to the treatment of transgender people in healthcare need to be made.

People with disabilities

Please take into account people with sensory impairment. They are often digitally excluded, on low income and rarely consulted about things that affect their lives. They miss out on screening appointments, don't get information in accessible formats (despite this being a requirement of the NHS) and many have undiagnosed mental health problems

Remember disabled people when they're attending hospital with their seriously ill partners.

Please remember to include those with physical, mental and learning disabilities in the desire to eradicate health inequalities - they too face this issue.

There were a few comments about the impact of **digital exclusion** on groups such as older people and those with learning disabilities, which respondents felt contributed to health inequalities. Across the survey as a whole, the issue of digital exclusion and the loss of face to face services received substantial comment, making it one of the larger issues identified from the survey feedback.

Not everyone has access to online services, some elderly patients, some young adults. This fact is often forgotten and contributes to health inequalities.

Our GP has recently started using 'Klinik'. They insist it isn't but I see this as the very definition of a barrier for vulnerable people. It's all online and while the website says you can call for help, receptionists tell you it's 'just this once then you must go online'. Very scary for the elderly, those with learning difficulties, English as a second language, no reliable Internet access etc.

A small number of comments agreed with the community insights that some Black, Asian and minority ethnic groups being fearful of NHS services or feeling like their views have been dismissed by staff. A small number of respondents mentioned this lack of trust as having an impact on the willingness to be vaccinated.

Fear of authority may be entrenched in some communities which is why not everybody came forward to be vaccinated against Covid. I also know that certain ethnic groups are more likely not to turn up for scheduled NHS appointments; it's hard to know how to fix that.

From my own experience and a member of a minority group, it does feel like my options of treatment and diagnostics are narrowed and limited in comparison to other groups, and I don't say that lightly. As an NHS employee I know and see all options available for patients, and sadly, some of these options are only available (offered) to some people but not the others.

There was a specific question about the community insight that symptoms may be overlooked in older people. A few people commented about how older people tended to be dismissed, with a couple of comments specifically talking about how illnesses and disabilities can be attributed to natural ageing rather than being explored further. Others suggested older people can be treated as though they are 'senile' or have dementia by healthcare staff.

I feel that older people are not given the care that is available to younger people - just written off as old age, rather than trying to allow people to live free of disability.

Elderly people are often not taken seriously and not enough time given to complaints and symptoms.

From personal experience, once an adult hits the over 60 age group, when hospitalised sometimes treated as if they have dementia even when obviously not.

Only four people directly addressed **cultural competence**, with one respondent saying that often people do not mean to get the language wrong, and others suggesting more training is required to understand different cultural backgrounds.

Training for GPs and hospital doctors to tackle unconscious bias and deep rooted prejudices with regards to cultural approaches to personal health. It's not helpful for doctors to make negative comments about these to a patient or prejudice their diagnosis based on these stereotypes/assumptions.

Ambition

In total 82% of the survey respondents 'definitely agreed' with the ambition to eliminate health inequalities faced by people living in South West London and for everyone to have equal access to the same quality of physical and mental healthcare.

We want to see health inequalities faced by people living in South West London eliminated and for everyone to have equal access to the same quality of physical and mental healthcare.



A few comments explicitly supported the ambition to address health inequalities.

Treating everyone equally is the better way to deliver good services.

Others suggested the ambition should be slightly different, with a small number of people stating that health inequalities were caused by social structures or correlated with income. Because of this, they felt it was beyond the ability of individual health organisations to eradicate health inequalities without a system-wide approach.

I think it is important to think about equity rather than equality where some people require more support than others.

So many inequalities are reflections of increased poverty rates faced by different groups. The plan should focus on improving access to services, not expect to eliminate all health inequality as this is impossible without central government/external to health policy.

A few comments suggested approaches to ensuring equality of access, such as increasing opportunities for marginalised groups to work in the health services, more staff training, having people with lived experience to advise on policies or developing them in conjunction with community groups.

A wide range of protected groups should make up the panel that formulate positive policies and review these periodically.

We need to see more experts by lived experiences getting involved, especially Black and Brown Voluntary Groups.

Lots of staff education required, services must be more proactive and reach out to people.

More schemes giving marginalised communities the opportunity to train and study for wider variety of roles in NHS (not just domiciliary care).

Four comments talked about the need for broader engagement with communities to develop solutions and build trust. This included more community outreach, working with the voluntary and community sectors, and more patient involvement.

Must be done in consultation with community, especially those who may or do experience barriers to access, treatment, and support.

Patient involvement to shape services can help reduce inequalities. Practice more shared decision making and give staff bias training.

It goes beyond translation services and appropriate language use. I volunteer with a charity that supports people to register with GPs, they face multi-factor challenges. Working with groups and networks in the community that already have established relationships with those experiencing health inequalities is vital.

3.2 Preventing ill health and supporting self care

Summary

In total, 505 people responded to the survey and 174 people commented about preventing ill health.

Headline findings from survey respondents

- The comments showed there was a lot of agreement about the barriers to maintaining health, particularly the affordability of healthy options. Several comments specifically requested access to cheaper gyms or activities.
- A large range of suggestions were made about the best way to provide information or support for healthier lifestyles.
- There was a lot of agreement with the ambition to move to a more preventative approach.
- There were also concerns that prevention needs to be balanced with urgent treatment needs in a tight financial/staffing environment.
- There were some concerns about the possibility of local healthcare being able to achieve these ambitions given their limited ability to address the social and economic conditions for healthier lifestyles.
- 94% of respondents agreed with the ambition for Preventing Ill Health
- In terms of agreement with previous insight, 94% of people agreed that preventing disease, healthy ageing and improving health are reasons they would consider lifestyle changes
- 93% of respondents agreed that time pressures and costs of things like food and fuel were barriers to healthy living.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People recognise the importance of vaccines in protecting themselves and their families...	36	47	7	7	2
B. People feel they can improve their health by changing habits...	55	34	6	5	1
C. Barriers to maintaining health include time pressures, cost of healthy food and fuel etc	65	28	4	3	1
D. A quarter of people from Black, Asian minority ethnic groups referenced 'cost' as a barrier to healthy diet	26	26	38	6	4

E. Social networks and family can influence a person to adopt healthier lifestyle behaviours...	49	39	9	2	1
F. People said advice and information need to be improved and easily accessible, and in different languages	43	32	20	3	2
G. Preventing disease, healthy ageing, improving health are reasons people would consider lifestyle changes	63	31	4	2	0
H. People prefer group community activities such as diet, exercise and lifestyle changes	32	36	24	7	1
I. Some people want self-help digital apps; however, some people feel they could be digitally excluded	40	36	19	3	1
J. People appreciate the role of the voluntary and community sector in providing support	40	40	17	2	0

There was a high level of agreement with most of the community insights in the survey. However, only a small number of people commented on the role of **vaccinations**, with two wanting more information or better access to vaccines and two not agreeing with the vaccine programme. Far more respondents commented on the **barriers to healthy lifestyles**. These comments were predominantly related to concerns about the affordability of healthy options and wider concerns about the possibility of achieving the social and economic conditions for healthier lifestyles. Some respondents suggested broader social issues of low disposable income, poor housing and pollution needing to be addressed to prevent ill health.

Preventing ill health needs to start with meeting people's basic housing and social needs.

There is much that cannot be individually and solely controlled by adopting a healthier lifestyle, such as all types of pollution and how it affects health. This needs to be addressed as much as personal lifestyle.

Socio-economic issues need to be addressed to be able to reduce the level of stress people are living with. The cost of living is a major stressor which is going to impact people's health, mental, emotional and physical as stress is the root of all disease and illness.

A small number of respondents argued that eating healthily and having active lifestyles did not have to be expensive; a few commented about the need for people to take more personal responsibility. However, the costs of food and exercise were mentioned by more people and seen as a barrier to healthy lifestyles.

These plans are great, but without subsidisation for groceries and basic needs, people in poorer situations will not be able to "prioritise health" during the cost of living crisis.

Cost of food is a major contributory factor to ill health. Healthier options often cost far more than unhealthy mass produced heavily processed options. Not sure how much you can do about that, maybe coordinate a national lobbying campaign for sugar/salt tax, or something more well thought through than that.

Several people argued for more affordable exercise options, sometimes questioning whether

social prescribing or the subsidisation of gym membership would make active lifestyles more accessible.

Affordable gym facilities could be helpful in encouraging more people to take more exercise.

I feel a gym pass at a reduced rate from each council would support people in healthy lifestyles and choices.

GPs should be able to prescribe swimming, gym classes and membership of clubs and societies to aid people struggling with physical and mental health.

A few respondents talked about the need to address inequalities, with some acknowledgement that **health inequalities** needed to understand drivers of difference and to have culturally appropriate engagement, for example through mosques.

Better understanding and discussions around the prevalence of certain conditions/diseases that disproportionately affect some minorities. Not solely due to diet. Raising awareness earlier to address disparities.

While a positive, it would probably be a very time consuming and labour intensive commitment to properly facilitate getting target communities to engage in personalised wellness.

A small number of people suggested other groups who needed to be considered in the promotion of healthy lifestyles, including older people and people with autism. The main target for healthier living identified in the comments was young people, with multiple comments about the need to educate parents and children about diet and lifestyles.

You mention ethnic minorities frequently but only rarely the elderly and the young and middle aged. Targeting the younger age range might mean you get nearer to your goal of healthier lifestyle by 2035.

We have a huge obesity problem in this country that is costing the NHS millions. If we can educate children at school with a healthier diet - that would be a start.

Needs to be in parenting advice and guidance and early years education in schools.

The largest number of comments provided suggestions about how to improve **advice and information** about healthy lifestyles. As well as healthy eating as part of early years education, respondents highlighted the potential of anti-obesity campaigns and advice on healthy eating, such as through cookery classes, at supermarkets, or through leaflets and roadshows.

You need to make it clear that processed food is making people ill. Dishonest food marketing such as 'heart healthy' and 'no added sugar' means that people make poor food choices.

Advice on hand to give guidance in shopping centres on a bad diet and obesity etc

Concentrate on more info leaflets and articles in newspapers. Online is not for everyone.

Two longer comments made specific suggestions about opportunities for providing information and advice on healthy lifestyles: through an information resource 'Bridging the Gap' and using assessment clinics for 'moments of change' advice and screening.

'You have an amazing resource in the boroughs of Richmond and Kingston called "Bridging the Gap" which is a signposting guide locally and nationally. It could potentially be rolled out to the other boroughs like Merton and Sutton if the right funding was available. It is kept up to date and is invaluable and came about because everyone talked about signposting but no one actually did anything to improve it.'

'There is huge potential to use surgical pre-operative assessment clinics. These clinics at Epsom and St Helier alone come in to contact with 9000 patients a year. There is a recognised "teachable moment" with these interactions where patients are in at a place in their lives where they understand the importance of health and where you have the access to a person who has training and experience in health promotion. Screening for high blood pressure, obesity, smoking status, alcohol intake and mental ill health already takes place at surgical pre assessment... the population, and in particular those who will be most receptive and most in need of personalised wellness support, would benefit from recognising the key role of these surgical pre assessment clinics which need investment to optimise their potential.'

A small number of respondents commented positively about the role of **group community activities and peer support** for lifestyle changes.

Long term community/peer support groups are better than lecturing/teaching public health - people know what is healthy, they need space and time to do it.

Must be accessible for all, harness the power of peer support and encourage small support groups.

Although the majority of people agreed that they **appreciated role of the voluntary and community sector** in providing support services for people with a long-term conditions, a couple of people raised issues about the need for appropriately qualified staff.

I disagree with the over-use of volunteers. Often times you need specialist help.

Need to find enough knowledgeable appropriately qualified staff to deliver planned preventative measures.

Finally, several respondents agreed with the need to maintain non-digital routes to support self-help rather than relying on apps.

The digital transformation results in digitally excluded people to miss out: dyslexics, old people, those with poor eye sight. A face to talk to is an important part of healthcare.

It's best people to meet physically than online exercises or online studies. It gives them social gatherings which much more healthier. Many people don't know how to use apps or aren't interested in digital stuff.

Able to speak to somebody in person or online whenever required when in isolation and not have anyone to talk with about my illness or get help from my doctor.

Ambition

We want to support people in South West London to live longer, healthier lives. We want to move away from reactive disease-specific treatment to proactive personalised wellness, so that by 2035 we have improved healthy life expectancy by at least five years. Our ambition can be achieved through prevention of the main risk factors: high blood pressure, obesity, smoking status, alcohol intake and mental ill health



In total 67% of the survey respondents 'definitely agreed' with the ambition to move from a reactive to a proactive approach to preventing ill health and several comments expressly endorsed the move. Additionally, a couple of comments talked about the need for mental health also to move from dealing with people in crisis to preventing crisis.

I completely agree that preventative treatment is better than reactive.

Investment in prevention is needed.

Prevention is important, and providing people with the necessary means to live healthier lifestyles is key. Free blood pressure measurements, advice on diet, more affordable healthy food etc. the environment is an important factor to address, i.e. advertising of junk food, lots of fast food outlets on high street, doesn't help.

Provide preventative mental health care. Currently, people don't get help until they get to a crisis point.

Despite the high level of agreement, some people raised concerns about the implications of a move towards prevention in a tight financial/staffing environment. Two main concerns were mentioned, the first was that it should not take resources from people who were seriously ill and the second was about the impact on GPs. In particular, a small number of respondents wanted to ensure there were options to stop the burden falling on GPs.

Prevention is very important but it's not an alternative to reactive disease-specific treatment. I find it worrying that you plan to move away from this. What about cancer treatment? I suspect that there's an element of cost cutting in this plan...

It's so hard to get an appointment with a GP to treat illness right now that it seems wrong to take up their time with strategies for preventing future illness. This is wrong and there needs to be another way or another route for people to talk about this with a medical professional.

Accessing regular check-ups in the community is so important rather than just the GP office which is too busy.

Finally, a few comments pointed out the scale of the challenge involved in a shift to a preventative approach, with some suggestions that behaviour change would be difficult to achieve, particularly if large businesses do not support the changes.

The NHS is not sustainable by focusing only on reactive care however prevention requires the public to behave differently, and this is a national challenge.

Some ambitions have significant political implications (reducing harmful food won't appeal to food manufacturers), and healthy food will have to be paid for; provision of adequate mental health services will need a lot of extra money. You face a challenge.

3.3 Acute Care

Summary

In total, 450 people responded to the questions and there were 141 comments about hospital care. The focus groups did not discuss hospital care as a main topic.

Headline findings from survey respondents

- A few comments agreed with the insights around people being discharged from hospital without enough information or community care support and planning.
- A small number of people mentioned long waits for hospital care.
- There were several comments questioning how possible it would be to meet the ambition to achieve more with the same resources. However, there were also several comments agreeing with the ambition to drive improvement through sharing data.
- There were many comments about the ambition for a sustainable workforce plan, mostly suggesting the need to employ more staff or pay staff more to improve retention.
- Additionally, the need for more joined up services was suggested by several respondents.
- Around 82% of respondents agreed with the ambitions for Hospital Care. This section had several ambitions, and agreement varied slightly for each one (most received over 80% agreement)
- The ambition receiving the lowest agreement – 77% - was the ambition to reduce costs or achieve more with the same resources.
- 74% of people agreed that they had been treated with dignity and respect while in hospital.
- However, only 36% agreed that they were moderately satisfied with the length of time they had to wait for a hospital agreement.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Across all of our hospital trusts, most of our patients were highly satisfied with the way staff communicate, their professionalism and care	32	40	14	9	6
B. Patients feel that they are treated with dignity and respect	34	40	11	9	6
C. Patients sometimes described feeling lonely while in hospital	28	34	30	5	3

D. Patients sometimes say that pain management could be better – though assessments indicate all four of our hospital trusts provide excellent care in relation to pain management	23	31	36	7	2
E. Patients say that they are moderately satisfied about the length of time they had to wait before being admitted to hospital	10	26	28	21	15
F. People living with diabetes or sight loss have said that waiting times for referrals and appointments are sometimes too long	27	22	49	2	1
G. Patients, their carers and hospital staff are concerned about the process for discharging inpatients from hospital back home or into community care. Some patients don't feel clinically ready to be discharged and some carers say that they aren't given enough information or training to care for someone at home.: Definitely agree	45	25	27	2	1

Community insights

In the survey the majority of people agreed that they were **satisfied with staff** and were treated with **dignity and respect**. However, there were about twenty comments talking about staff and experiences, with many suggesting they would like to see hospital staff have more empathy and better communication skills.

My experiences have all been excellent.

COMMUNICATION. Talk to us, the patients. It's our health and care but nobody COMMUNICATES anymore.

In our experience the worst thing was the lack of good nursing staff that had empathy with the patient. And they are so overloaded it is very difficult to provide good care as they do not have the time.

Treat the patients with patience and care, sometimes it doesn't happen.

A small number of comments talked about their **experiences in hospital**, with one finding pre-op body shaving, being woken frequently and the food challenging. Although one of the questions about being lonely in hospital, none of the comments mentioned this. A couple did mention being bored in hospital and asked for activities or a television.

Being in hospital is very boring, what happened to TV?

There was a low level of statistical agreement about **moderate satisfaction with waiting times** and one commenter explained that people tended to be accepting of the wait rather than satisfied with it. A small number of other comments talked about their own experiences of waiting for

treatment, sometimes at the cost of a further deterioration of their health. A few people explicitly suggested waiting times had to be improved.

Time to wait from referral is scary and must improve.

Waiting times is a problem. My family member had to take pressure tablets for the first time about a month ago but the appointment with the cardiologist is several months away. Understand that there is no quick fix but finding solutions for the medium to long term is important.

The community insight for acute care that received the most comments from survey respondents was about hospital discharge. The issues mentioned in the comments included long waits for discharge, waiting for medications, poor communication between services and a need to include families and carers more in the planning for aftercare. One comment stated the need to identify carers and engage them in discussions, and to implement the *NHS Carers and Discharge toolkit*. A lack of aftercare was also mentioned, including physiotherapy and support for people without carers.

Excessively long waits for discharge is a big problem. Usually, they are just waiting for their medicines to be delivered to the ward.

Put measures in place for self-management prior to discharging home from hospital. Have more communication between the hospitals and community teams to enable safer discharges home.

Need more help to support people leaving hospital- there aren't enough community rehab services so people get ill and go back into hospital, revolving door.

The care I got as an inpatient was good however no effective plan on my discharge even though everyone involved knew I lived alone with a hearing disability.

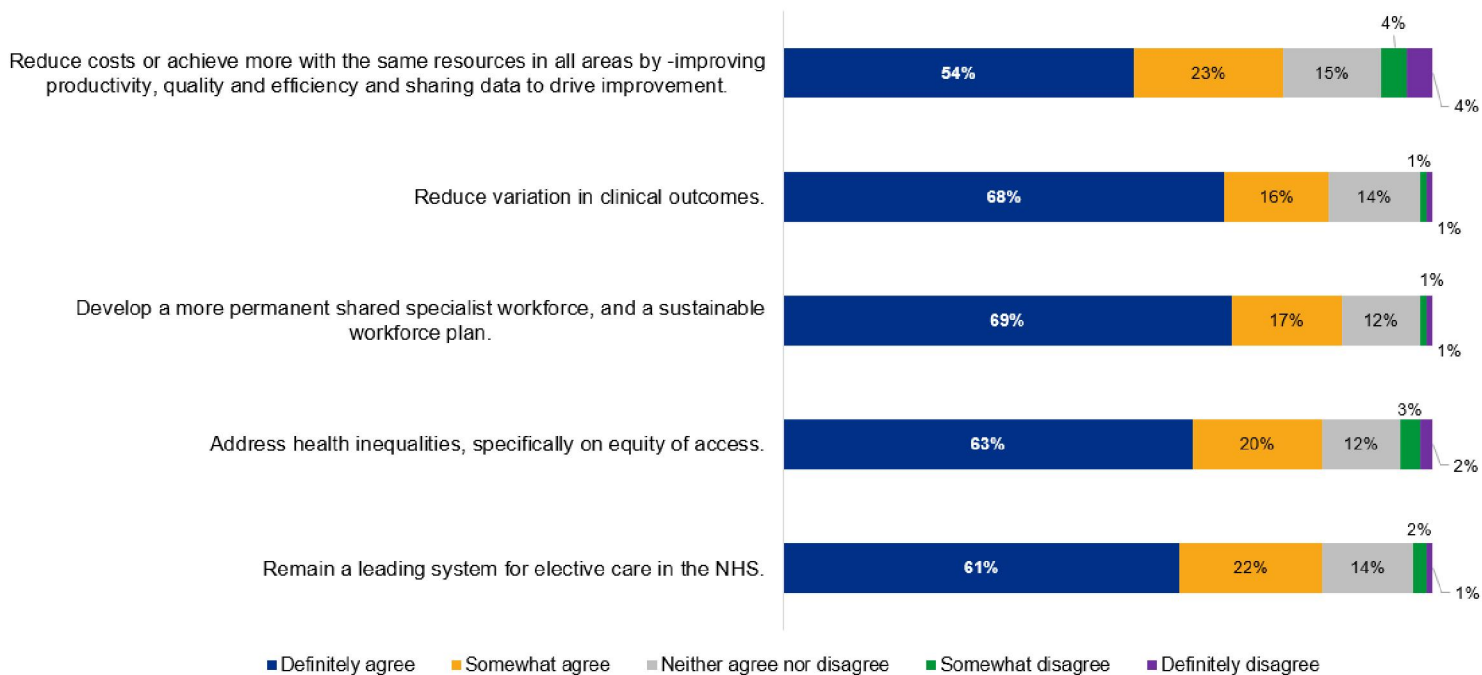
One aspect of hospital care received multiple comments, although it was not mentioned in the questions. That was the issue of better coordination of care and communication across different agencies involved in providing care. Several illustrative comments have been included here as a new finding.

Work better in partnership with mental health, primary care, local authorities to provide coordinated care.

Communication and coordination between different teams is generally abysmal. People are trying to navigate a system they do not know or understand - very frustrating. While individual, teams, departments, people, seem very good - they do not have time to explain and signpost everything. If pushed back to your GP to refer, you are at the mercy of how good your GP is to push and advocate you - can be real gatekeepers.

Currently very un-joined up & if people with dementia don't have significant family resources, they decondition and generally decline extra quickly.

Ambitions



Two specific aspects of the ambitions, to reduce costs and develop a sustainable workforce, received a large number of comments but there were only a few comments about other ambitions. A small number of respondents commented on the variability of the treatment they received across different hospitals in the South West London area.

My hospital care has varied widely. Sometimes I worry that reducing costs and stressing effectiveness emphasises the process rather than the care.

I believe, based on what I hear from others plus my own direct experience at Kingston H, that care quality varies across Kingston, Epsom, St Helier and St Georges' - as to other such as Croydon I simply don't know.

Many people commented about developing a sustainable workforce plan. In general, the comments suggested that with employing and retaining staff, the ambitions could not be achieved. Investing in training and ensuring people had good working conditions were both mentioned, with several people explicitly mentioning the need for better pay to encourage retention,

Without enough well paid staff none of these are possible. Most hospital staff I have encountered have gone beyond the call of duty but everyone has limits.

There needs to be a real emphasis on training staff, checking their wellbeing, making sure they don't do too many hours and get a decent salary. Not just the basic wage.

The only way to improve care in hospitals is investment in staff. Retention of the existing staff so that services can learn and be developed but also not attempting to reduce costs by reducing staffing levels. Staff cannot be spread any thinner and will leave if they don't feel able to deliver good quality care.

The other ambition that received a high number of comments related to **achieving more with the same resources**. A few comments acknowledged there was some waste in service delivery and felt better logistics or fewer managers could help reduce costs. However, many respondents were concerned about whether it was possible to achieve this ambition receiving double the amount of comments. Several people mentioned both staff and estates needed more funding.

Cost efficiencies are the key. The NHS is top heavy with too many managers and not enough trained clinical staff. The NHS pays too much for drugs & equipment when they should be able to negotiate lower prices.

Re ambition E, please read about the Challenger disaster. You can't make things cheaper, better and more productive.

Illusion that by reducing staffing it is possible to increase productivity by data and efficiency. There is a limit.

I don't think reducing costs is a viable strategy - in my experience NHS services are stretched to the limit and providing excellent care in crumbling facilities with diminishing levels of staff - bravo to them but they need more money not less.

While the first half of the above ambition received several concerned comments, the second half – sharing data – had more positive responses. These might suggest the percentage agreeing with the ambition would be lower if it simply mentioned reducing costs. Several comments talked about the need for better communication between departments, with improved sharing of patient records being mentioned several times.

Patients' medical history, records kept by their GPs, should be accessible by hospital staff irrespective of which Trust.

Information sharing across hospitals and with GPs is clunky and slow and often relies on the patient or carer to convey the message, 2 - 3 months is the average time it takes for a hospital letter to go to the GP and ED attendance is not adequately or safely conveyed to GP's. Integration of information with pharmacies is also poor so medication and changes to medication can be complex and time consuming for patients and staff.

Different departments and hospitals need to be able to see and share a patients file and letters.

3.4 Cancer

Summary

In total, 236 people responded to the questions about cancer care and there were 58 survey comments. This topic was not covered by focus groups or community outreach.

Headline findings from survey respondents

- 93% of respondents agreed with the ambition for cancer care
- 93% of people agreed that they want advice from trusted NHS sources about cancer, and to feel empowered to ask questions about treatment
- There were low agreement rates with some of the community insights. However, this could reflect that respondents didn't have personal experience that matched that particular statement. (These statements are marked in the table below)
- Of the 58 comments about cancer care, many covered individual needs, issues with treatment or suggestions for improvements.
- A few respondents praised the treatment they had received.
- A small number of comments mentioned the need for more joined up services and communications.
- The bulk of the comments were about the ambitions. Many related to the waiting time targets for diagnosis and treatment. Some talked about the physical and mental health impacts of delays to their treatment. Others suggested the targets were not ambitious enough. A small number questioned how the ambitions were to be met with current barriers to accessing GP appointments.
- A small number of people suggested there needed to be more focus on prevention or screening.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People report a positive experience of cancer services, and high levels of confidence in the NHS staff looking after them	43	31	20	5	2
B. People get diagnostic tests quickly and are positive about the way they are given their diagnosis **	34	31	21	7	5
C. Some groups don't report the same experience as others – eg	23	21	48	5	3

Itc, deprived communities and Black, Asian, LGBTQI+ *					
D. Need culturally specific support groups for Black men with cancer & to encourage open discussion about cancer *	25	24	43	6	3
E. Some people said being seen by a Black clinician would reduce concerns about racial bias *	15	22	51	9	3
F. More needs to be done to encourage people with a learning disability to take up breast cancer screening	47	26	24	3	0
G. People wanted more emotional support in the community after their cancer diagnosis	49	29	20	2	0
H. Lack of awareness re types of cancer, and we need to reduce taboos and shift perceptions with local people and communities	58	29	11	2	0
I. People want advice from trusted NHS sources about cancer, and to feel empowered to ask questions about treatment	74	19	6	1	0
J. Patients are sometimes unaware of different therapy & supportive care services available to them during cancer treatment	55	30	13	2	0
K. Teenagers and young people with cancer valued access to digital apps support their emotional wellbeing	42	21	37	0	0

* Low agreement could reflect that the majority of respondents did not relate to this experience. This assumption is supported by the high number of people selecting “neither agree or disagree” against these statements.

** Low agreement to the statement “People get diagnostic tests quickly and are positive about the way they are given their diagnosis”, however a significant amount of people selected “neither agree nor disagree”. This could indicate that the statement is not relevant, or it could reflect that the statement covers two things – the speed of getting a test and how positive people felt about the test.

Community insights

More than for any other care setting, many of the survey 'open comment' responses to cancer care did not relate to the community insight questions. With a smaller number of comments than other areas, a lot of the issues raised were personal and individual. Where the same issue has been mentioned a few times, it will be covered in this feedback.

Several of the respondents took the time to comment on the community insight **that people report a positive experience of cancer services, and high levels of confidence in the NHS staff looking after them**. Most of the comments praised the service, with some underlining the equality of positive treatment received.

Outstanding care over many years

It already gives good service

I have had a very positive experience with cancer services.

Mum my had a diagnosis of breast cancer over 5 years ago now, we were with her as her support mechanism throughout this. As a family of ethnic minorities, I can honestly say she was handled and treated with care and the team were amazing, especially Macmillan nurses.

Only two comments singled out a need for more sympathetic care from staff, one within a broader context of positive support, particularly from Macmillan nurses.

More training for cancer staff regarding mental health and be more sympathetic. Each patient is an individual. Give patients options and explain fully.

I had a very positive experience in general but had a rude and uncaring surgeon. They need to have more people skills training! It was really helpful for me to have MacMillan support available in the hospital and to get referred by the specialist nurses - otherwise I wouldn't have known what I was eligible for - especially free support.

While in general respondents were happy with their treatment, a couple of areas were mentioned where the patient would have liked to have more advice about their treatment or opportunities to ask questions. This included a lack of face-to-face appointments and better communication about the treatment being planned.

The use of phone appointments instead of face to face appointments can add to the stress and make it harder for patients to ask more questions about their condition.

While we waited for appointments for unsightly skin cancer, it grew enormous causing my partner much distress. Communication could have been better at the appointments as we were not clear what the procedure would be each time, always hoping it would be removed.

One comment mentioned feeling 'abandoned' between hospital visits for treatment, perhaps suggesting a lack of awareness of supportive care services that are available to them while having cancer treatment. Another respondent talked about the need to understand some people might need be facing other challenges which need support, such as damage from cancer treatment or having incurable cancers.

I was diagnosed with cancer 10 years ago. My care in hospital was exemplary. However, between hospital visits for chemo/radiotherapy treatment, I felt lost and abandoned.

Cancer isn't just about diagnosing new cancers but supporting those living with cancer or experiencing second or third cancers etc. Early diagnosis matters but the cancer patient community is also people who might struggle with multiple cancer diagnosis, the damage of past cancer treatment or who are living with incurable cancers. The previous comment chimes with an

area which received a few comments but was not part of the original community insights **aftercare**. It is being reported here as a new finding. The few comments on aftercare suggested a lack of information about the long-term impacts of cancer treatment and the need for more local post-cancer care.

I am not sure that I was made aware sufficiently of the likely long term possible effects of the treatment that I received. If I did then I had forgotten in the three years after the treatment when the issue suddenly appeared.

After care can be quite sketchy depending on whom you speak with. Not all information is readily accessible.

Post cancer treatment can be very tiring especially as follow up is often at a specialist centre some distance away from home which involves long travel times for a 10 min check up. These follow ups can last for many years. Better pathways need to be developed for local follow up after the initial treatment.

Additionally, one respondent talked about the issues faced in accessing urgent and emergency care towards end of life, particularly the wait for triage at A&E.

A&E admissions were so traumatic coming to the end of my husband's life. A real issue was triage ambulances were not available, triage nurse could not see who was coming through the door and waiting in line was impossible. When we tried to get urgent help we were shouted at, the security guard tried to intervene but unsuccessfully. Once at the front of the queue the care was excellent, and he was rushed through but moments were lost. Triage needs to be reviewed.

Ambition

Our mission is to save more lives in South West London, through earlier diagnosis and reducing inequalities across the cancer pathways. For anyone that might have cancer, we want to make sure that we act quickly so that no one has to wait more than a month to receive a diagnosis, and no more than a further month to start treatment. We know that to do this we need to focus on understanding where variation exists, act on variation in partnership with our communities and place-based teams, continue to improve the cancer diagnostic and care pathways, and embrace new approaches to early diagnosis.



■ Definitely agree ■ Somewhat agree ■ Neither agree nor disagree ■ Somewhat disagree ■ Definitely disagree

There was a high level of agreement with the ambition for cancer care. However, 10% respondents said they only 'somewhat agreed' with it. This might be explained by the number of comments relating to the **one month waiting time targets for diagnosis and treatment**, with a few respondents talking about the physical and mental health impacts of delays to treatment. Others suggested the targets were not ambitious enough.

A month is a very long time for someone with cancer. Cancer needs immediate attention.

A positive diagnosis should be followed up within a few weeks, not a month: there is the mental impact of a positive diagnosis, that must be taken into consideration.

A month is too long to receive a diagnosis or wait for treatment to begin, in that time a person's mental health can be greatly affected and they feel like they have no support from the healthcare professionals. If this cannot be shortened then plans should be put in place to provide peer support or emotional support to those waiting for a diagnosis or to start treatment. Weekly check-ins by GP or Practice Nurse even by phone would be helpful to keep patients reassured and make them feel supported and aware.

A small number of survey comments questioned how the ambition for diagnosis times could be achieved without additional access to **GP appointments**.

Until the access issues to GPs which are the entry point for most cancer diagnosis is improved we will only see a deterioration in cancer survival rates.

Again, make GP appointments available so first diagnosis can be made and so referrals as well. Had to go private as could not be seen by a GP.

The ambition included **embracing new approaches to early diagnosis** and a small number of comments appeared to provide suggestions for potential options, including the use of walk-in centres and GPs to order diagnostic and health checks where there were concerns, to relieve pressure in other parts of the system.

The Haematology dept at St Helier Hospital is brilliant. More depts could be modelled on their system of care, blood tests and appts etc.

Walk in centres providing a range of health checks would be a valuable way of improving early diagnosis. Referring back to the problems of getting GP appointments for anything considered "non urgent" puts many people off getting checks done to put their minds at rest. So potentially easily treated problems, e.g. moles, lumps, rashes, get ignored rather than bothering a GP to get reassurance. I wonder how many patients end up needing life-saving treatment which could have been avoided if it was easier to get such worries checked out and quickly dealt with while they are still minor.

I believe that the GP could potentially do more ordering of diagnostics on the pathway to avoid delays. I also feel some specialties reject referrals unnecessarily causing distress and that more referrals could be made to Rapid Diagnostics if more vague symptoms that don't specifically tick a specialty box. I also think more resources are needed for radiology and particularly pathology services.

A few respondents questioned how this ambition fitted with a more general move to a 'preventative approach' to healthcare in South West London. Some argued for a focus on healthier living or more screening services at an earlier age.

Agree that this is really important but how does that fit in with moving away from specific reactive treatment?

More emphasis on prevention is the key. Diet, exercise, sleep etc.

Screening services for under 50s would be appreciated.

Finally, a couple of respondents suggested the need for more joined up services across the pathway, with an ability to share data digitally.

More joined up working with cancer specialist and GP.

Epsom St Helier and St Georges should have access to each other's digitalised images automatically.

3.5 Children and young people

'Developing our Joint Forward Plan' published in March 2023 did not initially include a standalone chapter on children and young people. This has been added in the final version of NHS South West London's Joint Forward Plan.

For the purpose of this report, we have included insight heard about children and young people's mental health in the Mental Health section on page 58. Additionally, comments about services for people with learning disability and/or neurodiversity mentioned children and young people on page 66.

3.6 Community Care

Summary

In total, 354 people responded to the questions about community care and there were 91 survey comments. Additionally, community care was mentioned in the Merton Ethnic Minority Centre focus group with refugees, asylum seekers and people from ethnic minority backgrounds who attend the centre.

Headline findings from the survey respondents and focus groups

- There were several concerns expressed about the ability and role of the voluntary sector and community groups in providing community care.
- A few comments agreed with the need for more support for unpaid carers.
- A few comments were about the variability of services, especially between boroughs.
- A few people agreed with the need for more joined up services.
- People mentioned the need for more funding to achieve this ambition, particularly around the need to pay care workers better, with a few comments singling out Croydon as a borough which has serious financial challenges
- 93% of respondents agreed with the ambition for community care services
- 94% of people agreed that unpaid carers need more support and more information about what is available for them.
- 91% of respondents agreed that being supported to live independently is very important to them.
- 90% agreed that services in the community need to be more joined up.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Patient satisfaction is very positive - more than 98% of patients say that they are treated with respect and dignity and rate their overall experience as either good or very good *	26	30	28	6	3
B. People want to be able to live independently and be supported to do so	71	20	8	1	0
C. Most people who left hospital to a rehabilitation bed rather than their	25	28	39	7	1

own home, did so because they did not want to be a burden on their family or were worried that they did not have enough space for equipment at home **					
D. Services in the community need to be more joined-up and that communication between services needs to be better – such as between hospital and home	76	14	9	1	0
E. If services were located close where people live and work, we could better support vulnerable communities and people who experience health inequalities	66	22	10	1	1
F. Unpaid carers need more support with their health and well-being, and better information about what is available to them	81	13	6	0	1
G. We should expand support from both large and small voluntary and community organisations, which are highly valued by people with long term conditions	66	20	12	2	1

* Only 56% agreement with “Patient satisfaction is very positive - more than 98% of patients say that they are treated with respect and dignity and rate their overall experience as either good or very good”, however 28% neither agree nor disagree. This could be because respondents do not have a personal experience or could indicate their experience of the service has been variable.

** 53% agreement with “Most people who left hospital to a rehabilitation bed rather than their own home, did so because they did not want to be a burden on their family or were worried that they did not have enough space for equipment at home”. However, 39% neither agree nor disagree. This is likely to reflect the very specific nature of this statement. It will not apply to many respondents.

Community insights

Although very few people commented about **patient satisfaction** with community care staff, a couple of respondents suggested the need for better monitoring of community care, including volunteers.

Need to monitor some community carers as some just do the basics and are uncaring.

Some participants in the Merton Ethnic Minority Centre focus group raised issues about community care arguing there was a lack of continuity of home carers. Other concerns related to the carer not necessarily being the same gender as the person being cared for and poor experiences where carers were not treating the patient with dignity. For example, a carer had washed the feet of someone who had had a stroke before washing their face. Family members had placed a camera in their home to capture bad treatment.

A small number of survey comments related to the community insight that **people want to be able to live independently and be supported to do so**. Respondents explained the importance of continence services, asked for better access to information about the sorts of community care available and suggested a particular needs for community transport support to health appointments.

If it wasn't for community incontinence products, I would be housebound.

I think it would be good to know more about care facilities for older people in the Borough. These should be made available to older people so that they don't have to search themselves. It is difficult when they live alone and have no family.

Help with transport to appointments for all.

A couple of respondents mentioned the need for more **rehabilitation places** and more therapies available in rehabilitation and community services to ensure people become independent more quickly.

There is a need for more residential rehabilitation places.

People go to rehab beds because they need rehab, not just space or time. Rehab services need to be staffed adequately with therapists to offer intensive rehab to enable patients to regain their independence as early as possible. The same applies to community therapy teams, there is a vast inequity in provision at the moment across SWL in neuro teams and this means that people stay longer in hospital and rehab unnecessarily.

One of the community insights which received the most comments from survey respondents was the need for more **joined up services and better communication between services**. A few different issues were mentioned including better access to health records across the system, improved integration between council and NHS services, more coherent and easily accessible community care, and the need for a 'one-stop shop' approach to health appointments.

I feel that everything as we speak is quite disjointed and everyone is fighting with each other for whatever reason and it needs to be brought in together social and medical should be working together to find better solutions instead of being two separate organisations.

In domiciliary care a lot of our clients have been discharged from hospital or are in and out of hospital at different times. Community care and support across the areas we work is patchy - some good, some bad. You need a knowledge of the system to be able to navigate it.

All staff being able to access full health records no matter which organisation they work for is really important.

Better coordination of services so patients and carers can combine health appointments as a one stop shop in the community.

Several people commented about **expanding support from both large and small voluntary and community organisations**. There were particular concerns about the voluntary and community sector capacity to take on further work, questions about the implications of services passing from the public sector and NHS to the voluntary sector and worries about the potential for this to increase inequality of service provision across South West London.

There is currently very little communication between different organisations providing care and support in the community. We need to be careful about reliance on the voluntary and community organisations as this can lead to further inequalities where organisations cover

some postcodes and not others. Also we cannot continue to rely on the goodwill of the voluntary sector to provide community care due to chronic underfunding.

Shouldn't be relying on voluntary and community services to fill gaps in NHS. These services need better funding.

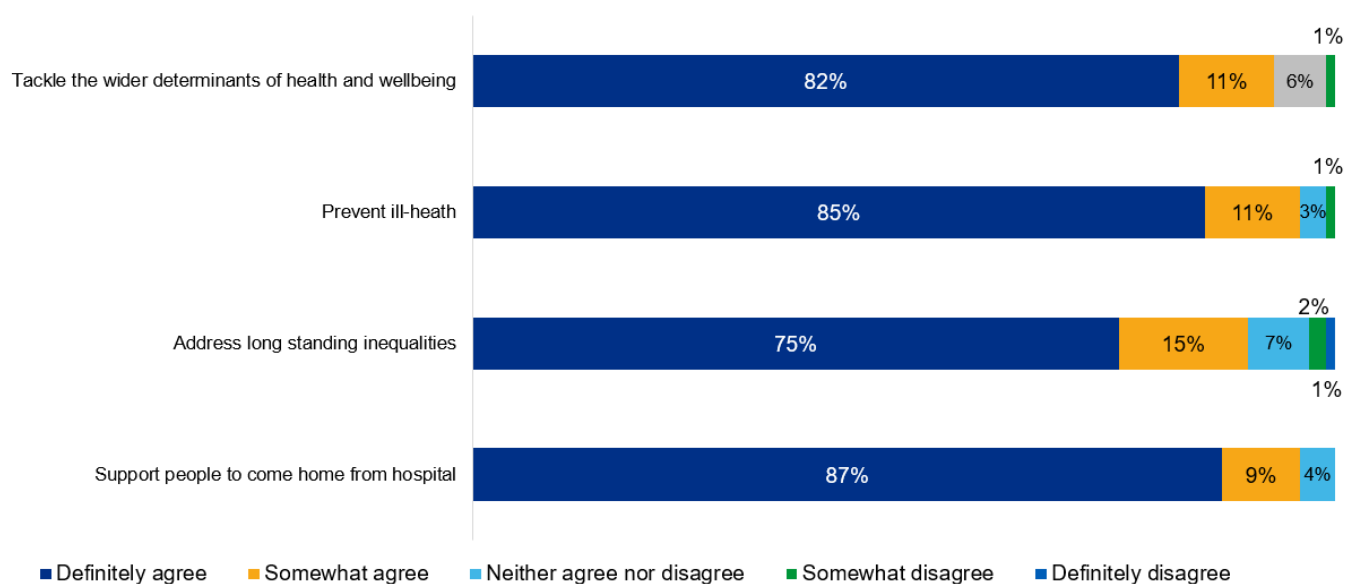
Reliance on voluntary and community groups cannot be a cop out to avoid the need for NHS and councils to provide services themselves. And these groups cannot continue and certainly cannot take on more without proper financial resources, premises, training and professional support. So if this is intended to save money it's a non-starter.

A smaller number of comments mentioned concerns about the level of **training and expertise of volunteers** may have had to provide services in the place of the public and health sector employees.

I am concerned that some community / voluntary organisations are well meaning but lack the expertise of NHS staff. Furthermore paid NHS jobs become unpaid voluntary positions.

I think it's crucial to ensure that voluntary and community workers are fully trained

Ambitions



There was definite agreement (87%) from survey respondents for the ambition to **support people to come home from hospital**. Several open comments supported the need for this ambition, including suggesting services require more integration and better communication with families to prevent poor outcomes.

Improve poor hospital discharges.

Discharge planning is a problem. Care doesn't seem to be joined up. More services should be available in the GPs surgeries to save hospital visits.

When a person is discharged with life changing abilities such as inability to walk, or eat, or feed themselves for example, they can fall through the cracks and die. Have seen it happen twice recently.

Communication must be better between hospital and elderly patient's family as to where they are going after being discharged from hospital. We had a bad experience.

A small number of comments noted the ambition around community care to support hospital discharge but suggested the need to address other service shortages in order keep people out of hospital in the first place or to make community care more accessible.

Seems to focus lots of community care as a discharge option or alternative to hospital wards, but really need more outpatient services in community health centres to make services easier to access.

More awareness about the community teams and their positive input and actions so local population understand; More comms around Virtual Wards and how they benefit the local population; More resource provided to community services to prevent admissions which will cost a lot more and block acute care when it is really needed; more support and resource for community hospital and PCN wards.

A few survey respondents commented about **inequalities and variability of services**, especially between boroughs. One respondent noted community care needed to have less reliance on the community sector if inequalities were to be reduced.

Community care is highly variable so to address inequality these services should be provided by the NHS. Relying on the community or the private sector to provide vital services - such as supporting long-term sick or coming home from hospital can be a cause of inequality.

Access should be the same in all Boroughs.

In terms of Place-based inequality, a few comments mentioned Croydon in reference to the need for **funding of the voluntary and community sector to work in partnership with health and social care** to provide integrated community care.

All this acts as if Croydon isn't in the dire financial straits it is. Expanding 3rd sector involvement is only achievable if Croydon commissions them to provide the extra services.

More funding for community care would greatly benefit health and wellbeing of residents in Croydon. Need more face-to-face befriending services, especially for those with dementia and mental health conditions. Befriending/group activities for younger adults (30-60) are lacking. More lunch clubs which are better promoted. Transport is key - dial-a-ride and taxi cards are not reliable or easy for lots of older people to use. Clubs/groups need funding for transportation including drivers.

The lack of **funding for community care** was mentioned by many survey respondents, suggesting a range of services needed more resources, such as rehabilitation services, district nurses and end of life care.

Community care is chronically neglected, rehab needs not meet, acute care seems to suck up resources leaving less for community.

Funding is crucial not just reliance on volunteers.

More resources need to be given to District Nursing Services.

A small number of comments specifically mentioned **End of Life** care needed better funding, more coordination with other services and a faster pathway for the confirmation of death.

End of Life care at home needs more input and resources- More people are now dying at home than in hospital.

Funding for end of life care should be present. Community services cannot work in isolation - please link these to VCSE's and hospice community services as well.

A clear pathway for out of hours confirmation of death. Families should not have to mind the dead body of a loved one for hours before 111 can attend!

In addition to more resources for a range of community care services, a few comments argued for the need for **better pay for carers** to develop the workforce. This included paying carers for their travel time.

The salary of the carers needs to be substantially increased to improve recruitment.

Better support and pay for carers who move around the Borough to their patients + paid travel time.

3.7 Diagnostics

Summary

In total, 368 people responded to the questions about diagnostic services and there were 84 comments. This topic was not covered in the focus groups or other community outreach.

Headline findings from survey respondents

- Several comments agreed with the need to improve communication between services.
- Additionally, more respondents mentioned the need to improve diagnostic feedback to the patient, in terms of time or the way it is communicated.
- A few respondents felt a dedicated diagnostic centre, perhaps in a community location, would improve diagnostics. Others suggested the location had to be accessible and convenient for people who had limited time or ability to travel.
- There was some support for fast diagnostic services in the comments, with a few respondents seeing diagnosis as being an essential element of effective treatment.
- 92% of the respondents definitely agreed with the ambition to improve access to high quality, fast diagnostic services.
- 91% of respondents agree that some patients don't understand the steps between diagnosis and the rest of their care and would like more information.
- 87% of respondents agreed with the need to improve communication between GP practices and diagnostic teams.

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. We need to improve communication between GP practices and diagnostics teams, the patient and hospital staff diagnostics teams – and people would like to choose their preferred mode of communication; for example, texts, emails, or letters	75	12	11	0	1
B. Some patients don't understand the steps between diagnosis and the rest of their care. Patients would like staff to take time to explain tests, answer questions and be sensitive about the impact of the diagnosis.	80	11	6	1	1

C. Familiar processes and consistent, clear communication are key for people if they are to feel they are at the centre of their treatment.: Definitely agree,	74	18	7	0	1
D. People want us to ensure that changes to diagnostics and other stages of their care are made around the needs of the patient	74	17	7	2	1
E. The location of diagnostic services is important but not as important as the speed of being seen and the overall experience	63	18	15	3	1

Community insights

We need to improve communication between GP practices and diagnostics teams, the patient and hospital staff diagnostics teams – and people would like to choose their preferred mode of communication; for example, texts, emails, or letters.

In the survey, 75% respondents strongly agreed that **communications between GPs, diagnostics and hospital teams needs to be improved**, with another 12% somewhat agreeing. Many of the comments emphasised their agreement, with some suggesting it was the main area needing improvement.

Main improvement here is communication between different teams in different hospitals and between them and the GP.

Need better communication between primary care and diagnostic and secondary care services.

Communication between centres providing diagnostic tests and my GP surgery can be poor. Patient should not be expected to be the bridge - which in my experience involves lots of phone calls back and forth and waiting in telephone queues.

As well as improving communications between services, many comments pointed out issues with the communication of test results back to the patient. Some said they had long waits to hear for their results or questioned whether GPs read the results. Without any confirmation of the results having been received, patients mentioned being left with no assurance the diagnostic tests have been conducted and communicated. Solutions to the problem included some form of digital confirmation of the results arriving or sharing a copy with the patient directly.

Communication re test results needs to improve. I'm still awaiting the results of tests I had last November and December!

Patients should be routinely sent the results of diagnostic tests that are carried out on them. In my experience, they are sent directly to GPs who may or may not read them but certainly do not write to inform me of the results or their opinion on them. I suspect they simply don't have time to action them and it would be far more reliable for the patient to have some role or at least knowledge of the process.

The communication of the results does not happen immediately between GPs and patients. There is no reassurance or confirmation that the results have been communicated.

Would be good for patient to receive automated confirmation when results are sent to specialist/GP.

There was strong agreement with the **community insight that some patients don't understand the steps between diagnosis and the rest of their care or would like staff to take time to explain tests and results**. A few comments expanded on this insight, asking for clearer information about diagnostics and their implications or better explanations of the process.

Need to be told why tests are needed, what the tests are and what the results are and what that means. Blood tests are never explained. I would like to be given the results of tests and have them explained.

Medical staff don't explain the process so you have no idea of what happens when. Medical staff can be so familiar with the process that they don't take the time to realise that patients don't know. I have also found that letters and texts from the NHS about tests can be so generic that you don't know what they are talking about which is a problem if you are having multiple tests at different times.

Again there was strong agreement that **consistent, clear communication are key for people if they are to feel they are at the centre of their treatment**. There was only a small number of related comments.

Communication is key around diagnostics and it is often very poor. People are often left unsure of who will receive their results and when. We have heard experiences of people receiving appointments for follow-up consultations without having had the diagnostics that they needed after their initial consultation (and therefore results not available). Similarly there is uncertainty around whether or not diagnostics have been booked.

Several people commented about the **location of diagnostic services** and whether it was not as important as the speed of being seen. A few respondents agreed they would be prepared to travel or suggested more useful locations for diagnostic centres – such as in shopping centres. A couple of other respondents supported a dedicated diagnostic centre which could conduct a range of tests at the same time or speed up the diagnostic process.

Diagnostics need not be in hospitals. Move them to shopping centres.

Would be fab to have non-hospital based/pure diagnostic centres to speed process.

It may be much better to have multiple specialist services under one roof, with a triage system (preferably in-person) at first point of contact so you can be directed towards the relevant specialist service in that same building (or close by) without needing to wait potentially weeks for a GP appointment before being told you need a specialist service.

I don't have a car but if I had something seriously worrying me I would be prepared to travel a fair distance to get seen.

A small number of people did highlight the impact of travel to a diagnostic centre for some patients. For example, some people have fixed working hours which prohibit travel time. Others, such as people with disabilities or on low incomes, may need support to access a centre further away.

For a lot of people like myself with a long term disabling illness and who can't drive and try to survive on an inadequate disability benefit a nearby accessible location is crucial. Otherwise please provide free transport door to door to more distant locations otherwise we can't get there!!

Please consider, people do work. Not everyone will either be able to or in a job that enables time to be taken off at short notice. Time and distance do matter.

Ambition

We want to increase access to high quality, fast diagnostic services for all patients. In doing this, we want to ensure that our patient experience is improved.



There was a very high level of statistical agreement with the ambition to improve access to a fast diagnostic service with 92% agreeing. A few comments highlighted ways in which the ambition should be met, such as having modern equipment, reducing duplication, and implementing clear and consistent methods of accessing diagnostics.

I have found diagnostic testing to be excellent - both at a lower level such as blood testing to the highest level such as various forms of scanning. I am always amazed how quickly my scans have been arranged and carried out.

Access to latest diagnostic methodologies and equipment are lacking currently and too slow to implement these.

Many diagnostic services seem to be repeated for no explained reason - I have an instinct there are improved efficiency opportunities around diagnostic services to go alongside structural change.

It would be useful to have prompt diagnostics, and to advertise what and when things are available. For example I needed blood tests done. In Purley you can do a 'walk in' if you are referred by a consultant, but need to book an appointment if you are referred by a GP. Would be nice if 'rules' like this were made obvious somewhere.

Many people commented on the importance of a **fast diagnostic service**, recognising both the physical and emotional implications of delays to diagnostics.

Waiting for tests or results is very hard emotionally when patients are worried. That has an impact on them.

Scans need to be done as soon as there are signs that there might be a problem. By the time I had a scan my cancer had unfortunately spread. By catching cancer as early as possible you could save money by preventing the need for the patient to have expensive and sometimes damaging Chemotherapy Treatment.

Diagnosis is main to treat a condition so it has to be done effectively and early.

I have recently been through a diagnostic process which involved waiting for a whole year for one of the appointments, making the whole process last one and a half years. I could have

been diagnosed much more quickly and received treatment much sooner if the waiting time wasn't so long.

While there was almost no disagreement with the ambition for improving access to fast diagnostic services, a small number of respondents had concerns about whether the ambition could be achieved without greater investment, particularly in training and retaining staff. Access to GP appointments was also mentioned as a barrier to achieving a faster diagnosis.

You cannot improve access to diagnostics if there are not enough people available to staff the diagnostic units/services. You need to focus on retaining staff and funding more staff and equipment. This won't be achieved by good will alone.

I can only assume that, in the absence of pay rises for NHS staff, and therefore recruitment and retention of NHS staff, more diagnostic services will be farmed out privately.

Again if we can't get GP appointments we aren't going to be able to make use of faster and improved diagnostics.

3.8 Maternity

Summary

In total, 170 people responded to the survey about maternity services and there were 40 survey comments. Additionally, community outreach and one-to-one conversations were held with parents/carers at Croydon Babyzone drop in play space for 0-5 year olds.

This write-up of the findings about maternity services differs slightly from the other care settings. There was a lower number of survey comments, mostly related to the ambitions for maternity care. At the same time, a large amount of detailed insights were derived from the extensive engagement with parents at the Babyzone event. Additionally, separate discussions were held with Black, Asian and ethnic minority parents to enable feedback about the targeted community insights. This has facilitated a great depth of insight but with fewer direct comments to quote.

Headline findings from survey respondents and one-to-one conversations

- Several respondents mentioned the need for more information and post-natal support for new mums, with some suggesting a lack of aftercare had an impact on mental health.
- The role of midwife and health visitors was cited as particularly important by respondents. Although not all people who commented felt that it made a difference if they saw the same midwife, others felt this was important in terms of continuity of care.
- A few people commented negatively on the use of the term 'birthing people'
- There were several comments about the need for additional funding or staffing for particular aspects of maternity care, including health visitors, midwives and lactation consultants.
- On average, 93% of respondents agreed with the ambitions for maternity care
- 91% of people agreed that the safety of mother and baby are important and they want high quality care throughout their maternity journey.
- Only 59% of respondents agree maternity care in South West London is positively rated by women and their families.
- 86% of people agreed with the experiences of Black, Asian and women from ethnic minorities that some women have difficult births and problems when returning home with a new baby, and that early emotional or low-level mental health support could make a positive difference
- 82% of people agreed with the experiences of Black, Asian and women from ethnic minorities that women want clearer information about staying healthy during their maternity journey

Respondents had a high level of agreement with all the ambitions for maternity care. In total, 89% of survey respondents definitely agreed with the ambition for everyone to have access to information **so they can make decisions about their care.**

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Maternity care in South West London is positively rated by women and their families	34	25	27	6	7
B. People said care could be improved if women had the same midwife throughout their maternity journey.	55	29	10	5	1
C. Women want to be empowered to have more choice in their maternity care and for their choice to go beyond which hospital they would give birth in	55	32	12	1	1
D. The safety of the mother and new-born is of paramount importance to people - they want high quality and consistent care throughout their pregnancy, birth, and post-birth	82	9	8	1	1
E. There is a lot of support and enthusiasm for the idea of an app to support women before and after pregnancy journey	36	27	25	6	6

Participants at the Croydon Babyzone had mixed reactions to the community insight that **maternity care in South West London is positively rated by women and their families**. While some people said they had good or very good experiences, others talked about experiences that were not as positive – often due to how the pregnancy and birth had gone. The attitude of midwives made a difference to some people, with calm and sensitive support creating nice memories but ‘cold’ and indifferent treatment leading to one person feeling ‘traumatised’. The choice of hospital appeared to have an impact of the quality of experience for some people. The feedback about aftercare and postnatal support were more consistent, with many parents talking about a lack of contact and services.

When asked **if care could be improved if women had the same midwife throughout their maternity journey** there were, again, mixed responses. Some of the participants at Babyzone suggested the number of midwives involved in their care was of less importance than having good records and caring staff. Others felt having one midwife allowed them to know the person better, for example, one woman talked about how her pre-eclampsia was almost missed due to having different midwives and information about her family’s history of the condition not being

communicated between across the midwifery team. A few survey respondents mentioned the importance of having the same midwife.

Same midwife for the whole pregnancy is standard in other countries.

I saw a different midwife every time, repeating myself over and over, creating unnecessary anxiety and too much different advice which I found hard to sift through.

Some participants at the Babyzone event talked about **having more choice in their maternity care and for their choice to go beyond which hospital they would give birth in**. A few mentioned knowing people who were not aware they could make their own choice of hospital or opt to have home births. Some participants suggested doctors and midwives could occasionally fail to proactively explain the options, with women needing to do their own research or having to find the courage to ask questions. The amount of choice possible was mentioned as being dependent on the hospital offering maternity services.

There was a very high majority of survey respondents strongly agreeing with **safety being delivered by high quality and consistent care throughout their pregnancy, birth, and post-birth**. Participants at the Babyzone event highlighted the lack of post-birth support they had received. Comments included saying that aftercare felt like an after-thought, with infrequent visits from health visitors – sometimes with new parents only receiving a single visit. Parents talked about the lack of breastfeeding and weaning support and infrequent weight checks. A small number of participants suggested the lack of postnatal support meant women could sometimes become ill, with one having developed urinary retention which impacted them both mentally and physically.

A **lack of postnatal information** was a particular concern for the new parents at Babyzone. Issues mentioned included an overreliance on the Red Book, with some women wanting information to be more accessible when they were busy with a new baby, suggesting other formats such as videos or working might be more helpful. One person wanted more ‘real life’ stories’, which would calm their fears that if they spoke up about their difficulties they might have an intervention from social services. Participants mentioned inconsistent advice and wanted the health visitor to explain what sort of support is available for different issues, particularly what are normal thoughts and feelings and when they should seek support for postnatal depression. A few comments from the survey respondents agreed with the need for more postnatal support, particularly around mental health.

Afterwards, when you've given birth it can feel a little lonely and although I had a healthcare worker, it was all quick. Afterwards I relied a lot on my mum. I was so depressed and I wanted a healthcare worker to speak to. I wanted reassurance, I was ill and tired and low, and having someone to speak to properly would have really helped.

More focus on breastfeeding support for all mothers, both at home and at community hubs, often breastfeeding mothers who are struggling with breastfeeding have other mental health concerns and it can be a struggle to get out of the house, so more home visits from HCPs with lactation support qualifications, get more health visitors qualified in giving breastfeeding support and perinatal mental health.

One survey question asked about an **app to support women before and after the pregnancy journey**. The participants at the BabyZone community outreach saw both the potential and had concerns about this possibly furthering limiting in person support. One of the main opportunities from having an app was viewed as having notes in one place and accessible by all the maternity services. Another was being able to track their pregnancy progress accurately. Following on from previous concerns about a lack of information, having a range of trusted information on one app

was mentioned as reducing the need for parents to search the internet about issues. In particular, an app could help plug their perceived gap in postnatal support and information. Finally, the Peanut app was mentioned as being useful because it allowed people to talk to other parents about real life stories. One participant argued any app would have to enable personalised, tailored care rather than limiting the options.

Maternity – experiences of Black, Asian and people from other ethnic groups

Note: as this section related specifically to experiences of Black, Asian and people from other ethnic groups, we have filtered responses accordingly. At the BabyZone event, these community insights were explored with Black and Asian and women from other ethnic groups.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Sometimes they don't feel listened to or understood	51	22	24	2	2
B. Some women mistrust services, based on previous experiences of racism.	47	20	24	4	5
C. Some women described difficult births and problems when returning home with a new baby, and that early emotional or low-level mental health support could make a positive difference	67	19	13	2	0
D. Sometimes notes aren't read, or plans are not followed.	51	13	27	5	4
E. Some people need clearer, simpler information about staying healthy during pregnancy and birth, and want more support with feeding their baby.	67	15	16	2	0

A few participants at the BabyZone event talked about feeling like they **were not listened to or their concerns dismissed**. The experiences mentioned ranged from not being listened to when they needed help with pain, which turned out to be due to an issue with the delivery, to not being taken seriously when they had concerns about bleeding throughout the pregnancy. Additionally, one parent talked about clinicians being normalised to Caucasian skin tones so that jaundice was missed in their baby.

A few of the participants at the BabyZone event talked about being released from hospital to **return home with their new baby** very quickly after giving birth, with one person suggesting this may contribute to emotional difficulties for the new parent. Others mentioned that they had to attend health appointments within days of giving birth, even though they were still in physical pain and would have preferred a home visit.

A few participants had experiences which suggested the need **for better emotional and mental health support**. One talked about having a difficult pregnancy that they thought had resulted in

postnatal depression although they had not had any mental health support. One new parent mentioned the need to improve emotional and mental health support after she had no help with her new baby for two months, other than having some leaflets with out-of-date information. Another talked about telling her health visitor about feeling detached from her baby but just being given a leaflet. The health visitor promised her a return visit and counselling support but never got back in contact.

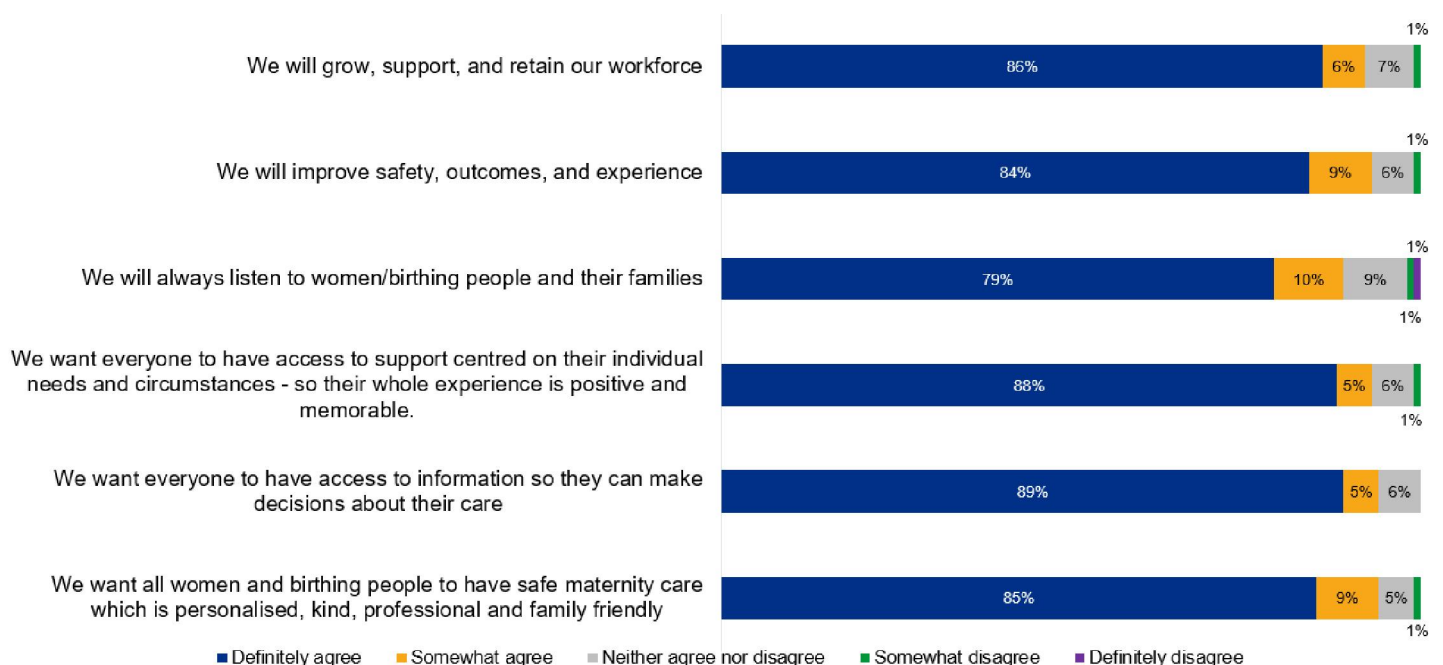
A small number of participants at BabyZone mentioned issues with their **notes not being read** or being misread. For one new parent this meant having to tell their story repeatedly while in labour; for another it resulted in the need for a blood transfusion being missed at an earlier stage.

As with the previous section, **better postnatal support and information**, including around feeding, was an area receiving the bulk of the comments. Parents at the BabyZone event talked about how the focus of NHS support tended to be on the birth, and post-birth they felt they were released home without adequate support. For example, one participant had no help with breastfeeding although she had problems and did not know how to address them. Others talked about how support for second babies was less on the assumption that parents did not need it. This meant that any problems could be missed. In general, there was a strong sense that postnatal support needed to be improved.

“Don’t worry about it, it’s fine” it’s something I heard too much.

Finally, a participant talked about a lack of information about safe pain relief for new mothers who were breastfeeding.

Ambitions



In total, 89% of survey respondents definitely agreed with the ambition for everyone to have access to information **so they can make decisions about their care**. A small number of survey comments endorsed this ambition.

Giving education to the pregnant women is important to get them help.

Give options from whom I will be able to get advice and additional support for the services available to me.

What is key is that choice can be offered at latter stage but may have to be altered due to problems that may occur within childbirth and all Mothers, Fathers and family members, who are birthing partners, should be made aware of what precautionary measures, may have to be put in place or taken.

The previous 'community insight' sections have covered concerns from parents about the need for more postnatal support and information. Additionally, some BabyZone participants talked about a lack of awareness of the option to give birth in different hospitals or at home. The confidence of the midwife was mentioned as being important in encouraging parents to think about their options.

It's nice that you have the same midwife/nurse because it makes a big difference. I was very nervous, lots of people telling me different things but my midwife reassured me and informed me of choices. I was glad to be able to choose my own hospital. Afterwards, when you've given birth it can feel a little lonely and although I had a healthcare worker, it was all quick. Afterwards I relied a lot on my mum. I was so depressed and I wanted a healthcare worker to speak to. I wanted reassurance, I was ill and tired and low, and having someone to speak to properly would have really helped. I also had my baby outside of Croydon but within south west London and services didn't join up very well.

A large majority of survey respondents (86%) strongly supported the ambition to **always listen to women/birthing people and their families**. A small number of survey respondents commented on experiences where the parent needed to be listened to and their wishes respected.

Need to listen more to mothers to be. My friend had an awful experience recently at St Georges hospital.

I was made to wait about 20 minutes when arriving at the birthing centre and I was in labour. This was my fourth baby so I knew I was ready to give birth and I had to try to prevent myself from doing so.

The pushback for not having the glucose tolerance test for was intolerable. It was maternal wishes override by nagging.

A small number of survey respondents commented on the ambition to **improve safety, outcomes, and experience**. Issues mentioned included not releasing people from hospital too quickly following the birth and not sending them home when in the earlier stages of delivery.

Stop sending women home until the 12th hour for labour and deliver. My friend has recently had stillbirth because their baby was not delivered sooner. This is the most traumatic thing to undergo after looking forward and planning for a new born child that has been healthy throughout; More continuity of care might make better responsibility for outcomes instead of shift workers getting through their shift across the whole journey!

Several comments related to the ambition to **grow, support, and retain the workforce**.

Respondents mentioned services that need more capacity and a larger workforce, such as health visitors, midwives and lactation consultants. Additionally, a lack of staff at night at one hospital was highlighted as leaving the patient feeling unsafe. In common with some with other care setting findings, a few people questioned how the workforce ambition could be achieved and funded.

Maternity Services are often highlighted as an area that struggles to train and retain staff - particularly Midwives. So, maintaining and delivering these aims may not be so easy.

You need to recruit more midwives and retain those that you have.

The lactation consultant services really need more funding. It was so hard to get an appointment and when I did, they were very rushed.

Need more health visitors as post-natal support is key for both mum and child.

One particularly detailed comment suggested the main solution to staffing levels and costs would be for hospitals to work more closely together to share staff and services.

Finally, some survey respondents commented on the use of the term 'birthing people.'

3.9 Mental Health

In total, 391 people responded to the questions about Mental Health and there were 105 comments about mental health services. In addition to the survey, community outreach was conducted with a range of groups to understand their views on the community insights and ambitions, this included:

- Focus group with Roehampton Champions network
- Outreach and one-to-one conversations with secondary school aged 11 to 19 young people at the Kingston and Richmond Beautiful Minds schools mental health conference
- Focus group with members from the St George's Patient Involvement Forum
- Kingston Eccop focus groups with adults with learning disabilities, profound and multiple disabilities and autistic people.

Headline findings from survey respondents, focus groups and community outreach

- Many of the comments related to a lack of mental health service capacity in general, with a few highlighting CAMHS as being particularly inaccessible.
- Several comments pointed to the need for more support for particular groups, including autistic people, substance abusers, LGBTQIA+, older people with long term conditions.
- A few comments made specific suggestions about training and education to help people maintain mental wellbeing.
- There were some detailed comments about falling between different services or transitioning out of Children and Adolescent Mental Health Services (CAMHS).
- The main comments about the ambitions related to wanting more early support for emotional wellbeing and mental health.
- Two focus groups suggested there should be an ambition for mental health services for children and young people.
- Several comments agreed with the ambition to have services work together seamlessly, with concerns about the current lack of communication between services.
- On average, 82% of people agreed with the ambitions for Mental Health services.
- Highest agreement – 94% - is that no one should feel that taking their own life is their only option.
- Lowest agreement – 77% - is with the ambition that people with mental ill health have the same life expectancy as the general population.
- In terms of agreement with previous insight; 93% agreed that loneliness and isolation, the cost-of living crisis and digital exclusion are major issues that make local people's mental health much worse.
- There was lower agreement with the insight about services being provided in the community: 85% agreed, but only 57% strongly agreed. Detailed insights

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People are concerned about much longer waiting times, and the need for some support while people are waiting for their first appointment, due to a significant increase in demand for mental health services.	76	14	9	1	0
B. Local authorities, schools, primary care, and the voluntary sector need better links into health services to support people and manage demand on the NHS	73	18	8	1	0
C. There is stigma and a lack of awareness among many communities about the challenges faced by people with mental health issues, and some people don't know where they can go for help	71	21	6	2	1
D. Loneliness and isolation, the cost-of living crisis and digital exclusion are major issues that make local people's mental health much worse	75	18	5	2	1
E. Local people are keen on the development of different kinds of services in the community, such as drop-in centres, 24/7 crisis cafés, and community activities	57	28	13	1	1
F. There is a lack of specialist support for people with certain illnesses and lack of understanding about service users from different backgrounds	68	19	11	1	1

There was a high level of agreement with the community insights both from survey respondents and in the focus groups and outreach. However, participants did comment on a range of other issues, such as the particular problems with Children and Adolescent Mental Health Services (CAMHS), crisis services and transitioning from children to adult mental health services. These will be covered in some detail at the end of this section.

A large majority of survey respondents agreed that there were concerns about **waiting times and the need for support** while waiting for their first appointments. This community insight was an area receiving one of the highest number of comments, with respondents finding waiting time for treatment to be too long. Additionally, insight from the Richmond & Kingston schools mental health conference found strong agreement that longer waiting times are the main issue for mental health,

with participants feeling there was little support for children and young people while they are waiting for their appointment.

Referrals into mental health services seem to be delivered to a black hole. I was referred to one-on-one counselling 20 months ago after completing three months of group therapy sessions and have never heard anything back, despite GP chasing. I get fed adverts for NHS crisis lines and the sort all the time - how about stopping people get to a crisis?

The waiting times for appointments are unacceptable, not weeks, sometimes not months but more than a year. This needs to be addressed.

Personally I found contacting services was quick but getting help or response after that was very slow or almost non-existent.

Poor dementia care locally, mental health assessment for dementia are too long a wait.

While participants in the Richmond & Kingston schools mental health conference agreed that better links are needed between the NHS and schools, they made the point that school staff are not professionally trained in mental health support so they cannot substitute for proper NHS support that many pupils need. As a consequence, pupils' mental health can get worse while they are waiting. Several teachers described being 'left in limbo' by the NHS. There was also a suggestion that GPs will not refer children, telling them to get support through school as waiting times for NHS services are so long. Schools and the voluntary and community sector need more funding if they are to plug the gap. A participant suggested youth workers were keen to have more mental health training as they are who young people come to and they already understand issues affecting them

Participants at the Richmond & Kingston schools mental health conference suggested that where mental health support teams, community nurses and other services (Oxygen, Kick London and Headstart) come into schools and work there with groups and individuals it was more effective for children and young people, rather than expecting them to go to where the NHS provides a service, for example a hospital or community centre. The Kingston Eccop focus group with adults with learning disabilities, profound and multiple disabilities and autistic people agreed that there needs to be other community services to go to, as they can see the benefit of attending places like Searchlight, which hosts their group.

Although there was a high percentage of agreement from survey respondents that there is a stigma and lack of awareness about the challenges faced by people with mental health issues in many communities, there was only one comment relating to this directly. The respondent talked about their experiences of mental health stigma in their community.

This is a serious issue with men of ethnicity as mental health is not a topic, they feel suppressed due to culture and religious beliefs as this is stigmatised by the elders within families as they are taught as men in general that expressing emotions is a sign of weakness.

This sentiment was echoed by a participant at the St George's Patient Involvement Forum.

I was worried about being judged, as a Black Woman. I'm meant to be strong.

Many young people in the Richmond & Kingston schools mental health conference felt there was not a stigma around mental health any longer, but agreed they did not know where to go to access support other than school or their GP. The Eccop focus group for people with learning disabilities

felt it was important to talk about mental health more, as even though there is more understanding, some people still feel a stigma.

Again, there were very few comments about **loneliness and digital exclusion making mental health issues worse**, although there was an extremely high percentage of agreement with this issue from the survey respondents.

I have friends who use the service. There is a tendency since Covid for them to feel isolated and not able to access the service in the way they could before covid. Specialist care has greatly reduced or non-existent.

More awareness on what is available locally; more creative ways to provide mental health support without it being obvious that it is tackling the known issues e.g. Loneliness, isolation, low mood; More creative ways to reach those who will not seek support readily.

One participant at the Roehampton focus group, who was a mental health advocate, suggested that digital access will be a problem for some people who cannot navigate or are not used to technology for online sessions. They thought this would impact some disabled people, older people and people with a low level of literacy.

Despite being part of the digital generation, the children and young people at the Richmond & Kingston schools mental health conference talked about their concerns with digital and online mental health service. They would prefer face to face mental health support. The participants suggested a lot of their life happens online, with social media sometimes making mental health issues worse. Additionally, some young people wanted to be free to talk in a safe place that was not their home.

Community services such as drop-in centres, 24/7 crisis cafés, and community activities were not mentioned by many respondents. However, the Kingston Eccop focus group agreed that community centres were important to provide a place for support and friendship. Participants from the focus group with St George's Patient Involvement Forum suggested that Crisis Cafés needed to be available at more useful times – suggesting 10am to 10pm. However, a participant in the Roehampton focus group had attended the Tooting Crisis Café after failing to get through to the mental health crisis line. They found it to be a difficult experience and preferred the help from a community run drop-in centre in Richmond.

Participants were asked about the lack of **specialist support for people with certain conditions** and understanding of different backgrounds. Several survey comments pointed to the need for more support for particular groups, including people with autism, substance abusers, LGBTQIA+, and older people with long term conditions.

These problems are also worse for the elderly living alone with Disabilities and Long Term Health issues, and past funding cuts mean they do not have the support of Wardens now who could help with applying for Grants etc.

Some mental health services (e.g. Talking Therapies) will refuse to see substance abusers who self-refer to the service until they have quit the substance, regardless of how long that may take and/or the potential for further decline of their mental health in the meantime.

Trans health is linked to mental health. Trans people are significantly higher and more likely to take their own life.

All the above to include those with autism.

Members of the Kingston Eccop focus group with adults with learning disabilities, profound and multiple disabilities and autistic people talked about how they felt judged when accessing services.

While they had good support at home, this support was not always available when using services. For them, it was important that staff understand their history and background and find it frustrating when they feel they are not being listened to. Participants from the St George's Patient Involvement Forum suggested that, more broadly, NHS receptionists and other staff need better understanding about perceptions of challenging and difficult behaviour when someone is experiencing a mental health crisis.

Mental health services for children and young people (CAMHS) were mentioned by several survey respondents and participants in the community outreach sessions, but were not covered by a specific question in the survey. The wait for services was particularly mentioned as being too long.

In my experience services for the young are particularly poor and access is difficult.

CAMHS!! omg, what a nightmare, that service affected my mental health while trying to get help for my daughter's mental health. Still waiting a year later for help.

Train up more people so there's not the 18 month wait for CAMHS and other support.

Feedback from outreach at community forums suggested the CAMHS referral system was not working between different agencies, with young people from specific backgrounds being failed by the system. They also raised concerns about low morale among staff working with children and young people, as they felt young people's needs were not being met.

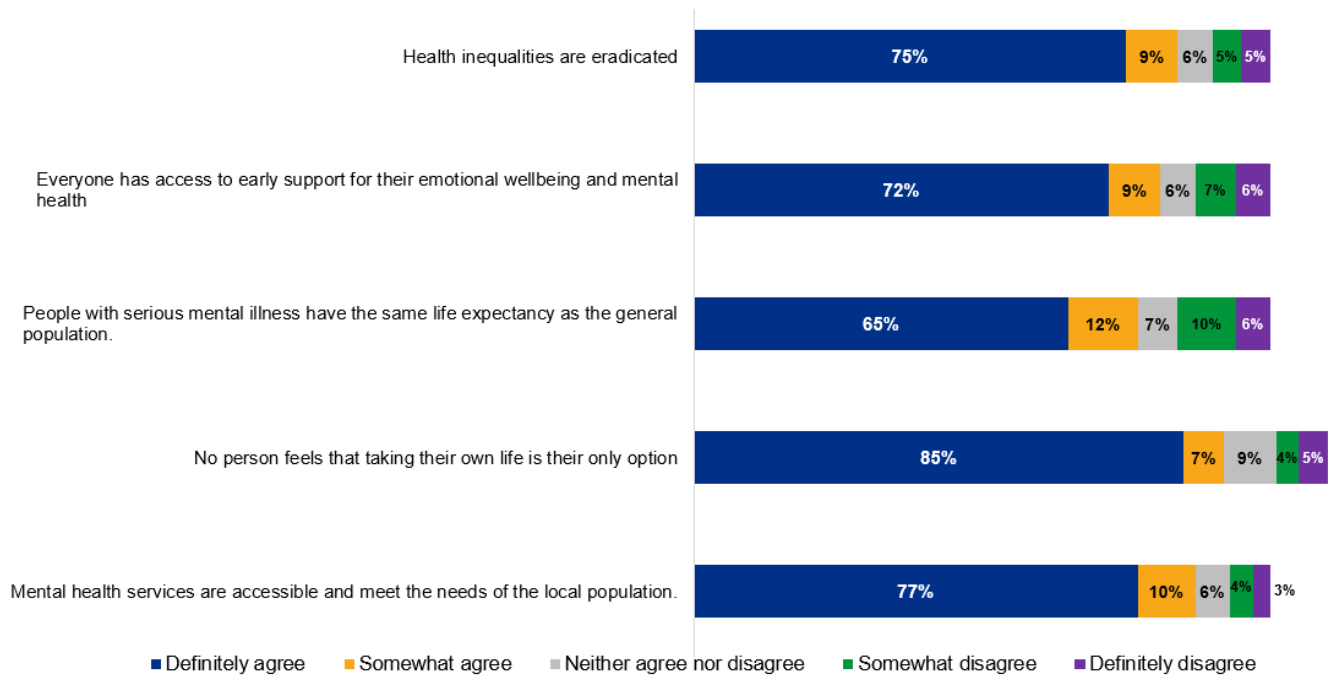
The transition from CAMHS to adult mental health service was mentioned as a specific problem by several survey respondents. Issues included a lack of a joined-up approach to transition, switching to adult waiting lists and the disruption to treatment by having to change therapists.

Waiting months for a CAMHS appointment is totally unacceptable and the transfer from child to adult services is very disorganised.

It would be useful to address the issue of young people 'aging out' of the system. They may have developed a good relationship with a professional and find they have hit the age where they have to go onto adult services and have to pretty much start over. A better transition should be instituted.

I wish CAMHS Services could go up to the age of 25 because some people may be a certain age but they may not be that age mentally due to their understanding with their needs. Our brain stops developing at 25 so I think CAMHS should end at that age.

Ambitions



In general, there was a high percentage of support for the ambitions from survey respondents, although a small number of comments suggested there needed to be more investment and resources for the services if the ambitions were to be achieved.

Put more funding in mental health for all ages.

You need more staff in MH. There are long waiting lists for referrals as the govt isn't funding NHS properly.

Services should be placed in a sensible priority order for funding and not forced to compete for funding so all get appropriately funded to continue and flourish.

Participants at the Richmond & Kingston schools mental health conference similarly suggested the plans were too ambitious given the reality of the situation with MH services currently - unless there was a big injection of funding to make them achievable. Others argued there needed to be a framework for investment based on needs, including those with poorer health outcomes based on population demographic make-up.

Participants from community outreach activities argued that the lack of a specific ambition for mental health services for children and young people needed to be addressed. Participants at the Richmond & Kingston schools mental health conference suggested they would have liked an ambition to provide more support while people wait for help, since there could be a two year wait for CAMHS. They would also like to see emphasis put on improving schools support for exam stress relief.

Moving on to specific ambitions, there was strong support from survey respondents for the ambition for mental health services to be **accessible and meet the needs of the local population**. As well as the comments about long waiting times, a small number of comments specifically talked about the lack of available services and the difficulty of accessing the support that is available.

Needs are so poorly met when patients are forced into the general acute sector because of lack of provision. There should be separate specialist mental health EDs.

Mental health services are woeful. Group sessions are too often the only option and for people with certain conditions or from certain backgrounds need the option of one on one care. This needs to always be an option.

It is almost impossible to get the support needed or even the initial referral. Offering self-referral options to people who are depressed, anxious or neurodiverse is ridiculous, because they do not have the capacity to make that next step as it may have taken a lot to have got themselves to the GP for that initial appointment.

The Roehampton focus group raised issues about accessing crisis services, with one participant mentioning getting an answerphone on the mental health crisis line and another that their partner was left for hours in 'side ward' at St George's Lotus Suite. Another talked about someone being denied access to a clinic when in crisis because she had been discharged a few months earlier. Additionally, a few people at the Roehampton event talked about falling through the gaps in services, either because they had moved borough, were being treated by a different team or had failed to be told about changes to their appointment. This issue was also mentioned by a small number of survey respondents.

I have a bipolar diagnosis which is medicated. However, anxiety and depression are triggered as much by my physical conditions as by personal and environmental factors. There needs to be a more joined up approach when it comes to those with both poor mental health and physical health issues.

I have been pushed from pillar to post. I fall in the gap between the CMHT saying you're not ill enough to the Well-being Service you're too well. Where do you turn to?

While there was agreement with the ambition that **no person feels that taking their own life is their only option** participants at the Kingston and Richmond Beautiful Minds schools mental health conference thought it was unrealistic. They suggested it would be impossible to ensure everyone took up available support. They suggested an ambition to reduce suicide rates by 60% would be more achievable. One survey respondent echoed this sentiment.

Not sure you can stop all suicides, but can see why you would aim to.

There was a high percentage of agreement from the survey respondents for the ambition **for everyone to have access to early support for their emotional wellbeing and mental health**. Several survey respondents commented about not just the need for early support to prevent mental health conditions becoming worse. Some made suggestions about the types of support this could include, such as community activities from GP practices or advice services in schools.

Support/help available as soon as an issue arises and not to be told its e.g. "mild depression" and ending up waiting for counselling for 2 years and by then it is "severe" when it could have been dealt with sooner and therefore also more cost-effectively.

Waiting lists for mental health services are simply unacceptable. It shouldn't be necessary to reach the threshold for being detained under Section 2 before it's possible to access any kind of effective support. Many people could be helped at a much earlier stage if there was more joined up thinking about community based services, which could avoid the need for more specialist support further down the line. Also since Covid many services which used to be face-to-face are still only being provided online which further excludes some sections of the population.

Early intervention is crucial. Would like to see more services based in school to provide support and advice to children and young people, their parents/caters and school staff.

More mental health support needed early in GP surgeries- more community activities needed. So people can recover together.

Participants in the St George's Patient Involvement Forum talked about how difficult it was to get early access to treatment. There was a suggestion that conditions such as anxiety should be taken more seriously to prevent it becoming disabling. One participant neatly summed up their perception of mental health services:

Prevention is meant to be the thing, but crisis is the thing.

The **eradication of health inequalities** did not receive many mentions from the survey respondents, although one suggested *'in terms of outcomes are pronounced in MH and clearly this is an essential area of focus.'* By contrast, this was viewed as an important ambition by people we spoke to in our focus group and outreach.

Participants at the St George's Patient Involvement Forum and community outreach talked about the need to remove the unequal treatment of Black people commenting on the major overrepresentation of Black people in referrals to mental health services and overrepresentation of young Black boys being excluded from school. They suggested there was a lack of strategy to address these issues. Participants from St George's Patient Involvement Forum talked about how assumptions were made about Black people, sometime leading to the wrong diagnosis or medication.

There is bias with Black people. A disproportionate amount of Black people are diagnosed with bi-polar. They see an assertive Black person and label them as having bi-polar.

The final ambition for **services work to seamlessly** was the area receiving most comments from the survey respondents, suggesting there was both a lack of a joined up approach to physical and mental health and poor communication between services.

There is currently a dangerous lack of communication between primary care and secondary mental health services. If urgent action is not taken to develop communication pathways and protocols the shift towards the 'integrated care approach' will lead to more chaos and neglect. My psychiatrist consistently writes letters to my GP with incorrect information regarding medication and when my GP needs to contact the psychiatrist or manual health team for clarification or with questions they must go through SWLSTG rather than direct to the CMHT.

Mental health services are diabolical and disjointed there is a lack of ongoing care and different departments don't seem to work together. Meaning people fall through the cracks.

Participants from the St George's Patient Involvement Forum talked about it being hard to navigate the system, getting bounced between services and a lack of information sharing. One participant had waiting for six months to hear from the Recovery Team following their hospital discharge. Participants argued for a multidisciplinary team approach, with community services joined up and better at signposting. They suggested social prescribers have proven helpful in this approach.

3.10 Learning disability, Autism and ADHD

Summary

In total, 236 people responded to the questions about learning disability and autism services and there 63 comments about services for people with learning disabilities, Autism or neurodiversity. Additionally, community outreach was undertaken to hear the views of people with learning disabilities or neurodiversity: a discussion with Kingston and Richmond's Autism Steering Group and a focus group with Kingston Eccop for adults with learning disabilities, profound and multiple disabilities and autistic people.

Headline findings from survey respondents and community outreach

- Some comments pointed to either a lack of support or long waits for support for different groups of people. This includes adults with Autism, people with Autism who do not have learning disabilities or mental health problems, and parents of children with Autism.
- A few comments suggested a lack of understanding about Autism from a range of professionals. Additionally, throughout other sections of the survey, a small number of respondents have highlighted the health inequalities experienced by autistic people is due to a lack of understanding from healthcare professionals.
- Several respondents mentioned waiting times for diagnosis or had concerns about the process.
- On average, 94% of respondents agree with the ambitions for Learning Disability and Autism services.
- 80% of respondents strongly agree (91% agree overall) that local authorities, schools, primary care, and the voluntary sector need better links into health services to support people and manage demand on the NHS
- Overall, people agree with the experiences of people and communities. There's slightly less agreement (63% strongly agree, 81% overall agree) with the development of different kinds of services in the community, such as drop-in centres, 24/7 crisis cafés, and community activities.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People are concerned about much longer waiting times, and the need for some support while people are waiting for their first appointment, due to a significant increase in demand for mental health services.	75	12	11	0	1
B. Local authorities, schools, primary care, and the voluntary sector need better links into health services to support people and manage demand on the NHS	80	11	6	1	1
C. There is stigma and a lack of awareness among many communities about the challenges faced by people with mental health issues, and some people don't know where they can go for help	74	18	7	0	1
D. Loneliness and isolation, the cost-of living crisis and digital exclusion are major issues that make local people's mental health much worse	74	17	7	2	1
E. Local people are keen on the development of different kinds of services in the community, such as drop-in centres, 24/7 crisis cafés, and community activities	63	18	15	3	1
F. There is a lack of specialist support for people with certain illnesses and lack of understanding about people from different backgrounds	76	15	8	0	1

Community insights

The survey asked about Autism, neurodiversity and learning disabilities. Because of the structure of care settings, these come under the mental health care setting. Several of the comments, both from the survey respondents and community outreach, were concerned with distinguishing the separate conditions from each other and mental health. Additionally, participants at Richmond's Autism Steering Group felt ADHD should be listed as a separate condition in the title of the JFP section.

Respondents pointed out that assumptions should not be made about co-morbidities of people with Autism – many people with Autism do not have any other learning disabilities; however, people with Autism may have other neurodivergent conditions.

Whilst I agree with your points, it's not acceptable that Autism is lumped in with learning disabilities. The prevalence of Autism amongst people without other intellectual disability is significant and completely inadequately addressed

You should include the whole of neurodivergent conditions- Adhd, dyslexia, etc, and recognise that rarely do people only have Autism, or adhd etc.

There seems to be mention of Autism but not other neurodivergencies such as having OCD or having ADHD but these do occur and may even overlap with being autistic so maybe your healthcare plans need to consider other neurodivergencies not just Autism.

A few comments argued for the need to recognise Autism as a condition of neurodiversity rather than mental health.

The ICS has a poor understanding, you are asking about LD and Autism at the top and you have clumped it together and assume it's a Mental Health, not everyone that has LD or Autism has a MH.

Half these questions are related to mental health - Autism is not a mental health condition! It's a disability and should be respected as such.

Turning to the questions relating to community insights in general there were few comments from the survey, possibly as they were felt to cover mental health. The participants in the focus group with Kingston Eccop group for adults with learning disabilities, profound and multiple disabilities and autistic people agreed that **waiting times for support were too long**. This was endorsed in conversations with people at Kingston and Richmond Beautiful Minds schools mental health conference, with one participant suggesting both waiting times and a lack of funding mean there is not enough support for people to receive a learning disability or neurodiversity diagnosis. The Richmond Autism Steering members highlighted the increased demand for ADHD diagnoses and support, particularly for adults. A survey respondent agreed with this point.

Some assessments for example to ADD or ADHD for adults are taking too long. I've been waiting for a diagnosis for almost a year and feel that the delay is now affecting my home and work life.

Members of the Kingston Eccop focus group, largely involving people with a learning disability or their families (as opposed to people with Autism) discussed **digital exclusion**. Most of those at the focus group were not online. Participant agreed that they would like it to be easier to use the internet and wanted support to improve their confidence using it. This would help to make it more accessible, especially for older people. Participants argued people with learning disabilities find it easier to talk to people, particularly when booking appointments. They suggested it would be useful to include phone numbers alongside websites, as it helps them to save numbers in their phone so they can access the service quickly. Where GP appointments can only be made online, there needs to be the ability to explain they have complex needs. Formerly, they relied on developing relationships with receptionists.

Members of Kingston Eccop agreed with having more **community activities and support**, as the group their attend holds activities in different communities, increasing their contact with other people. A survey respondent highlighted the difficulties for people with Autism attending community activities and asked for staff to be more proactive about encouraging attendance. A couple of others suggested a more strategic approach to supporting and accessing Autism friendly activities provided by businesses and community organisations.

Adults with Autism sometimes find it difficult to go to groups. Social isolation is the biggest problem. Support workers need to be more proactive in accompanying them and not wait for them to ask to be taken. Introduction to staff should be the first step to attending anything.

There are a number of 'inclusive performances' and "Autism friendly" activities being offered by bigger organisations/charities. Ensure they are partnering with smaller local and neighbouring organisations to offer free tickets/admissions and even memberships.

People with LD & Autism would benefit from a holistic approach. The loss of local leisure centre is a negative for the whole community but for this group it was an accessible welcoming place that was affordable and inclusive. This is not replicated in the private sector. Places Leisure is also an inclusive employer and again this is not replicated anywhere in the borough.

A small number of survey respondents commented on a lack of specialist support for people with certain illnesses and lack of understanding about service users from different backgrounds. For example, one respondent felt services need to offer more support for adults with Autism.

The focus seems to be on autistic children and adults are neglected.

Raise more awareness for 'uncommon' learning disabilities/diagnosis e.g. social pragmatic communication syndrome and offer the same service/support for these!!!

More generally, a few survey respondents highlighted the need for more **awareness or understanding of people with learning disabilities or neurodiversity**.

Learn continuing healthcare nurse assessors about Autism, learning difficulties and challenging behaviour because they seem to know nothing about them.

Staff should know that people with learning disability or Autism are people have the same feelings and needs as any person.

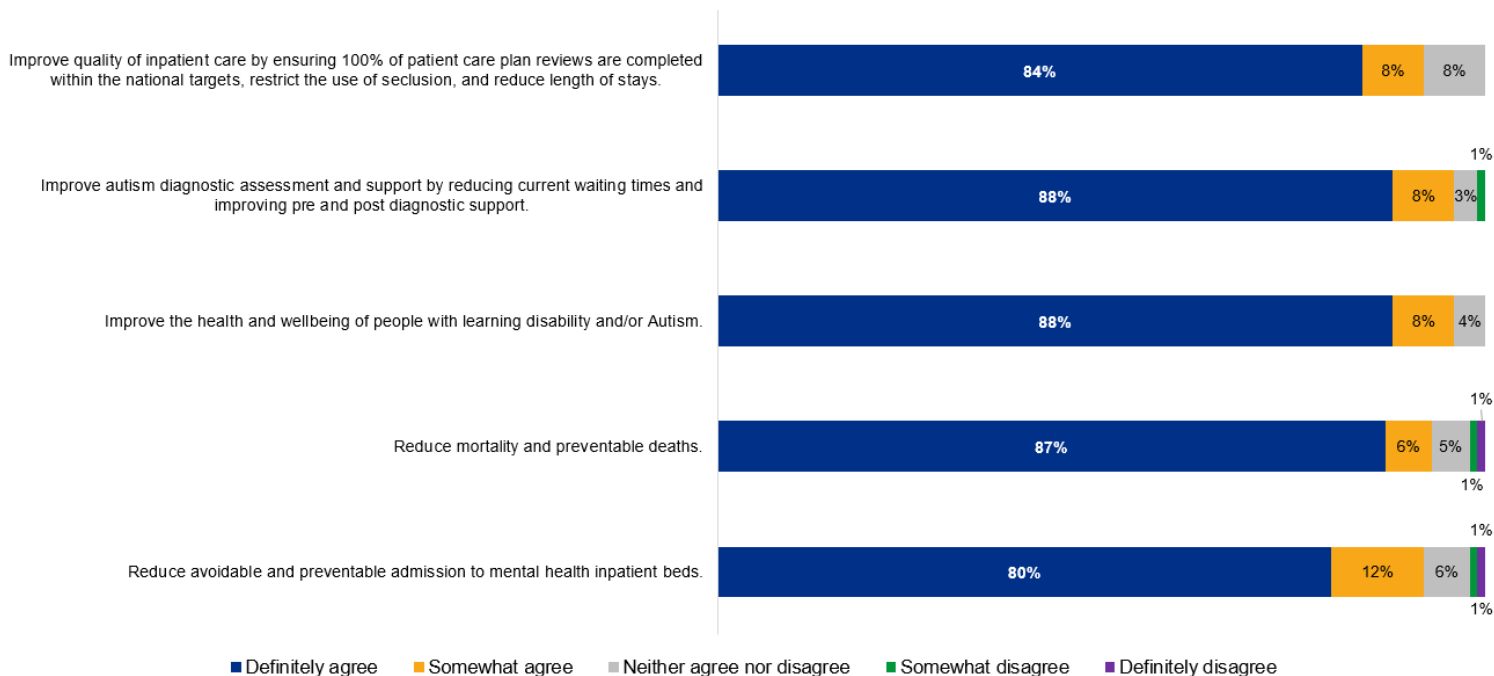
I am autistic person and an LGBTI person and there is a survey data that suggests that neurodivergent people are also more likely to be LGBTI people so when considering your plans you may need to be aware of the intersectionality between neurodivergency and being LGBTI and the implications of that for healthcare.

Participants in the Kingston Eccop focus group talked about the need for awareness training across the NHS system to ensure clear communication with people with learning disabilities. They wanted healthcare professionals to slow down and explain things clearly; understand people's communication and understanding methods differ; be open to questions that might seem odd, or unrelated.

Although it was not asked about directly in the survey, participants in the Kingston Eccop focus group felt there was a need for better data sharing and communication between services. They felt a type of health passport would be useful; so that staff delivering any element of their care would have a more complete picture of the person's needs and recent health history. This could reduce the need for people to tell their story repeatedly and prevent complex situations from being underestimated or not picked up on (examples of such situations were provided). A multidisciplinary approach to sharing data digitally could facilitate the prevention of situations from escalating to a crisis by getting the individual the right support early enough. Participants suggested. This could

be a level down from safeguarding but provide support if the person turns up in another part of the system.

Ambitions



There was a high level of agreement with the ambitions from the survey respondents, although a couple of people suggested there would need to be significant investment if they were to be met. Participants at Kingston Eccop focus group said the ambitions made sense, but they would be surprised if much changed because of the current workforce issues. They argued that staff need to be paid more and the workforce increased if waiting times for services were to decrease.

Few survey respondents commented on the ambition to **reduce avoidable and preventable admission to mental health inpatient beds**, suggesting changes needed to be made to NHS systems if this was to be achieved.

This can only be done if there are proper systems in place to create the ‘avoidable and preventable’ circumstance, at the moment there is not.

ATUs should NOT be allowed to hold people for more than 3 months without an independent advocate’s input/agreement.

As well as having a large majority of survey respondents agree with the ambition to **improve the health and wellbeing of people with learning disability and/or Autism**, there were a few comments making suggestions about how this could be achieved. As well as points about healthcare, a small number of comments talked about support in schools and to help people with learning disability or neurodiversity to work. Starting with work, survey respondents wanted more interaction with potential employers to help develop opportunities.

Employers should be encouraged, incentivised and supported to be inclusive, this will have a positive knock on effect on the health of this group.

It’s hard enough for non-disabled people to find work in the current economic climate. There is nowhere near enough support or information available to help people with LD or Autism to

find appropriate work, but at the same time there are many barriers put in their way if they try to access the benefits system. Many people with disabilities are capable of doing far more than they do, but aren't able to find the opportunities which allow them to do so. There needs to be more cooperation between health services and employment support to give more people the chance of living a life which allows them to feel useful and valued in their local community. Easier access to job coaches and opportunities for finding part-time work rather than being considered a failure for being unable to work full-time. This would also improve mental health for many people, thus saving money on those health services.

In terms of schools, a small number of comments suggested the need for more resources and training of school staff to and support people with learning disability or neurodiversity.

Schools definitely need more funding to employ classroom assistants for every autistic child so that neurodiverse children can remain in mainstream schools.

I do think primary school staff need more training on learning disabilities and Autism and ADHD. Sencos (Special Educational Needs Co-ordinators) need more physical support in school to assess children who need support. They also need to act on parents' concerns instead of just saying their teacher doesn't think there's an issue. Children hide their real behaviour for fear of being told off or judged by others.

The SEN services provided behave as a gatekeeper for funding. This paternalistic approach to managing SEN children's cases in the borough has a negative impact on those children and the timeliness of intervention. It also has a negative and eroding impact on the families/careers of the children, negatively impacting their immediate and long term health.

Two other comments are worth noting in relation to the ambition to improve wellbeing. The first comes from a member of the Eccop focus group who suggested that at times service delivery removes autonomy from people with a learning disability, for example by not allowing an individual to engage in a preferred activity because it was not in a plan. The second relates to a survey response which suggests a range of health and wellbeing activities are not provided for people who only have Autism.

Not enough being done for those with Autism without a learning disability. Health and wellbeing an issue. Dental care, sexual health, annual checks overlooked. Community nurses and social services poor services for many.

The ambition which received by far the most related comments from the survey was the need to **improve Autism diagnostic assessment and support by reducing current waiting times and improving pre and post diagnostic support**. There was a small number of comments about additional needs such as peer support groups for parents and better information about respite care. The majority of comments, however, were about diagnosis. As well as the need for shorter waiting lists, respondents highlighted issues with professional referrals, the diagnostic process and a lack of an interdisciplinary approach to assessments.

It's important that the waiting period for assessment and diagnosis is reduced so that people with the disability can access support and treatment as soon as possible. So many families are struggling with no help especially for the young people with the condition.

The wait list for Autism assessment was so long that we had to go privately, at vast expense, very few people can afford to do this. You need more Educational Psychologists.

As a professional so frustrating to try and refer children for assessment.

Working with autistic people I feel that often the diagnostic process is not done in a way that a full family history is collected to avoid wrong diagnosis.

Need to ensure that Autism diagnostic assessments are multidisciplinary. Need to consider introducing Child Development Centre for Paediatric assessments, previous pilot had positive responses yet no progression made.

The final ambition about **improving inpatient care** did not attract much comment. Participants in the Kingston Eccop focus group wanted to see more care happening in home environments instead of in hospitals. More broadly, in relation to urgent and hospital care, participants thought their experience could be improved by having specially trained nurses for those with learning disabilities and more empathy for patients with learning disabilities. The group argued for crisis services for people with learning disability so they did not have to attend A&E. Participants asked for activities to help improve the mental health of those with learning disabilities in hospital.

3.11 Primary Care

Summary

In total, 487 people responded to the questions about Primary Care and there were 147 comments. Two focus groups discussed primary care as the main topic:

- Wandsworth and Merton LGBTQIA+ group
- Merton Ethnic Minority Centre.

Additionally, the topic was covered by focus groups and community outreach with:

- Sutton Seniors
- Roehampton Champions focus group with people of all ages living on the Roehampton estate
- Croydon BME Forum Young at Heart group for people over 55
- Kingston Eccop group for adults with learning disabilities, profound and multiple disabilities and autistic people and Roehampton Champions Network.

Headline findings from survey respondents, focus groups and community outreach

- The highest number of survey comments related to concerns about not being able to access an NHS dentist and the cost of private dentistry.
- Survey respondents and focus group members agreed with the need for more GP appointments, including face to face appointment, but also commented about the difficulty of using some GP booking systems.
- There were many positive comments about GPs and pharmacists.
- There were a few comments agreeing with the range of insights about pharmacists. Additionally, a small number of respondents said they had concerns about whether pharmacists, as businesses, were as neutral as GPs.
- A lot of comments suggested an agreement with the ambition to enable people to access primary care in the way that suits them best, with many people talking about the problem of digital exclusion and the need to have face to face appointments.
- 96% of respondents agree that patients with different needs (such as dementia or Autism) need different types of appointment.
- 95% agree there needs to be better coordination throughout their treatment – eg communication between GPs and diagnostic services.
- 95% agree they would like an increase in GP appointments to be available, and more face to face appointments rather than by video or phone.
- 90% agree they cannot find or register with an NHS dentist.
- 96% agree that private spaces are important if talking with a pharmacist.

Detailed findings

Insights from People and Communities

GPs

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. GPs are highly valued by local people, but lack of access to GP appointments means that some residents avoided contacting their GP, or go to A&E instead.	72	19	4	3	1
B. Many people would like to see an increase in appointments, with some people preferring face to face appointments to video or telephone appointments	79	16	3	2	0
C. Different patients may need different appointment types – for example, people living with dementia, asylum seekers, refugees, carers, homeless, vulnerable, mentally and physically disabled and other groups such as autistic people	75	21	4	0	1
D. Most people want to be seen at their own practice but many are willing to travel to another GP practice if they could get an appointment sooner	43	30	15	10	1
E. The way that some conditions are treated varies between GP practices	55	22	22	0	1
F. Some people say that GP support after someone has left hospital is not always adequate	40	20	35	2	1
G. Some Black women feel that GPs do not listen to their symptoms, leading to multiple visits and delays before referral *	19	14	62	2	3
H. Interpreting and translation services are important – it can be	37	29	29	2	3

embarrassing for a family member to translate for a patient *					
I. Carers would like better access to the GP of the person they care for	52	29	19	0	0
J. Patients would like better coordination throughout their treatment, incl communication between GP and diagnostics services	80	15	4	1	0

- When statement G is filtered to show only responses from women who identified as Black, Asian or another non-white ethnicity, 52% agreed. Likewise, 73% of non-white respondents agree that translation services are important.

Where there is low agreement with some experiences, this could reflect that the survey respondent doesn't have a relatable experience. This could be why there are higher figures in the "neither agree nor disagree" box.

There was a lot of praise for GPs and pharmacists in the comments. Across both the survey and the focus groups, the issues raised were predominantly about accessing GPs rather than problems with their service.

In general my GP Practice is incredible and they go the 'Extra mile', and so does my Pharmacy which delivers my medication.

I have found services provided very good.

Accessing appointments was a big theme in both the survey comments and the focus groups, with some people feeling that there were not enough GPs and that supply was not keeping pace with demand. A small number of comments suggested people had had to use other services to get treatment or to go without.

It is so difficult to get a GP appointment that myself and my family have had to use the walk in centre in Teddington several times. This service is excellent and should be used as an example for other health care providers.

It is virtually impossible to get appointments now. I find I ignore medical issues as I cannot see a doctor.

My GP practice has not been providing access to appointment for months if not years but is still getting paid for every registered patient. People are now paying for private GP appointments just to get some primary care but the NHS GPs are blocking access to follow on care.

The process of **booking an appointment** was commented on negatively by many respondents, with people talking about the difficulties of several different appointment booking methods. A few comments talked about how the booking systems, particularly digital ones, meant some people were less likely to be able to access appointments.

GP service dreadful. Appts on line have a wait of about a month. Only way to get a quick appt is to queue up outside for about an hour. Hard for older and ill people. Telephone service is a lottery. Really awful.

Just sort out GP appointments system; I should not have to wait for an hour on the telephone but now it is the app system or something similar dreamt up by a 6th former.

It can be difficult for many, especially the digitally excluded to actually get a GP appointment over the phone. Even if they do get through, people are told to get in touch digitally.

One of the biggest topics raised across the focus groups was also the complexity of accessing GP appointments. Members of the Ethnic Minority Centre group talked about their experiences of long waits in telephone queues to get an appointment or their difficulties with online appointments. The Kingston Eccop focus group for adults with learning disabilities and LGBTQIA+/asylum seeker focus group discussions found strong variation in accessibility depending on the GP practice.

Some people in the Sutton Seniors, Ethnic Minority Centre and Roehampton focus groups said they were excluded from accessing services due to not being able to use appointment booking systems or QR codes, which was widening variation in treatment.

“I don’t understand online appointment – that’s how I am supposed to get an appointment now since covid! I can’t use online so I just have to go without”

Online booking systems were also raised by the Kingston Eccop focus group about learning disabilities, with one participant explaining that the online booking for GP appointments made it difficult to tell the surgery about complex needs due to this not being part of the options menu. Instead, they are obliged to send an email, with the response sometimes taking several days. They said they were reliant on building a relationship with receptionists familiar with their care needs but were unable to do this online. They mentioned building a relationship with a pharmacist instead.

Members of the Roehampton focus group agreed with the insight from people and communities that a lack of GP appointments, and a complex booking system, were leading to an increase in the use of A&E. They suggested patients want to call their GP and if they cannot make contact they will go to A&E or call 111. They also suggested that receptionists were suggesting people use urgent and emergency care options when there are no available appointments.

There were a few comments in both the survey and focus groups expressly about receptionists. Although one commenter acknowledges the booking systems have put receptionists under more pressure, a small number of other people suggested there were issues with their approach.

Pressure is then put upon reception staff when people either cannot or are too anxious to complete forms get in touch. Receptionists are no longer allowed to just make an appointment and are having to fill in the online forms themselves for submission.

Receptionists are not trained to deal with vulnerable people.

Better patient care needs to be provided by reception staff.

A few people in the Ethnic minority Centre and Sutton Senior focus groups said they had received rude treatment, including from **receptionists**, but thought if they complained they would be ‘struck off’. Members of the Kingston Eccop focus group said they had been treated with a lack of respect at their GPs and found the initial contact difficult. Additionally, The Ethnic Minority Centre focus group also had concerns about their privacy due to being asked for personal information by the receptionist in a public space.

A few survey respondents mentioned being happy with video and telephone appointments, but others talked about the need for more **face to face appointments**. Members of the Young at Heart group raised the question of the lack of face to face appointments, discussing their preference for these rather than telephone appointments.

Improvement needed on face to face appointments

Don't exclude those who cannot manage digital access. Telephone appointments are not always the safest for patients

GP face to face appointments are so important especially for holistic assessment

A small number of survey comments talked about the format of appointments, finding them too quick to discuss conditions adequately. The EMC focus group were not aware that they could ask for a longer appointment with their GP if they had multiple concerns.

Having 10 minute appointment slots are a waste of time. They're counter-productive if you give several concerns. No-one wants to feel rushed or as if they're not being listened to.

In general, the LGBTQIA+/asylum seeker focus group had good experiences of primary care and of translators being provided for GP appointments. However, a participant in the Ethnic Minority Centre focus group noted that she supported people in the community with English as a second language and there was a difference in response when patients cannot speak English.

Members of the Roehampton focus group felt continuity of care was important and aided by seeing the same GP ('family doctor'). A few comments mentioned coordination across services, particularly around diagnostics and information sharing.

I don't want to book an appt for a GP, book a separate appt for a blood test, book a separate appt to follow-up, take a separate trip to the pharmacy...this is a waste of my time and NHS resources!

Finally, a small number of comments in the survey and Ethnic Minority Centre focus group mentioned the additional services in GP surgeries (known as ARSS), including suggesting these should be expanded to relieve pressure on GPs and their role clarified.

ARRS roles in GP practices and new services in community pharmacy can improve access for patients and reduce pressure on GPs.

I think we need to be able to see a wider variety of staff in the GP surgery like Occupational Therapists and podiatrists, GPs can't do everything.

Dentists

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Local people highly value dentists but some people aren't able to find or register with an NHS dentist.	67	23	7	1	2
B. People have difficulty getting routine or emergency appointments	61	21	15	2	1
C. Dentists need to provide better information about their services – for instance, websites could be improved and updated	52	20	24	3	1

The largest number of survey comments about primary care related to a lack of **NHS dentists and the prohibitive costs of using private dentistry** – about 30 comments overall. Many of the respondents talked about how they had to use a private dentist to get any treatment, with a few questioning the impact on those who could not afford it. Some comments suggested there needed to be more NHS dental capacity in the area, although one recognised the lack of funding available.

There are almost no vacancies for NHS dentist patients. This needs to be addressed because private care is prohibitively expensive. The lack of accessible dental care is causing such a widespread decline in people's oral health.

NHS dentists are rare and cannot provide a good service due to financial constraints. I haven't used an NHS dentist for 20 years.

Need to consider the charges for dental services, especially for the elderly. Many pensioners may not feel comfortable going to the dentist because of the high cost, and many suffer in silence with dental problems as a result.

As well as mentioning private dentists, a few of the survey comments talked about other services that they felt were no longer being provided by the NHS – with one person pointing out that the survey did not even ask about services such as optometry. A couple of comments suggested this was part of the perceived privatisation of some NHS services.

I have to go private for the optician and optometrists.

There has for some time been an 'under the radar' move or coercion to replace certain services with private care, rather than NHS: e.g. podiatry being unavailable on the NHS, except for vulnerable, or 'in need' patients.

In my area, many people are ending up going private, especially to dentists, which presumably is what the Govt wants.

Although there were many survey comments about the problems of accessing dentists and delays to ordinary dental appointments, only two people specifically commented on the difficulty of getting emergency appointments. However, the Ethnic Minority Centre focus group talked about the difficulty of accessing **emergency dental appointments** to get treatment, with one member waiting a month for an appointment for a broken tooth and another revealing they had had to do their own temporary filling whilst waiting. The group mentioned attending A&E for emergency dental treatment only to be told this was not accessible anymore. The group discussed whether dental appointments could be accessed through 111 in emergency cases.

Need to get appointments in an emergency situation rather than waiting for longer periods.

One area where a new issue was raised, was responsive dentistry for neurodiverse people. One parent in the Kingston Eccop focus group described a lack of understanding of neurodiversity by their son's dentist. He had asked not to have students attend his examination but they were included regardless of his wishes. The appointment had to be abandoned due to his anxiety. It took three months for the rescheduled appointment, during which time he had to be coached through his fears about attending. There was a detailed comment in the survey about the need to go private to ensure consistency of treatment for people with autism.

NHS Dentists are very hard to find, and consistency of care is non-existent as staff turnover seems to be high. I have registered my autistic son with a private dentist as it's the only way to provide him with a familiar dentist in a familiar environment so that his anxiety doesn't prevent him from attending appointments.

Pharmacists

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. Pharmacists are very important for information and advice but sometimes give inconsistent advice on medication and dosage	29	25	31	12	3
B. People can be put off visiting a pharmacy due to busy queues, poor previous experience and not being able to talk in private.	38	31	15	11	4
C. People are more likely to visit a pharmacy if they are confident about the pharmacist's qualifications, services offered and opening times	65	21	10	2	2
D. Privacy and confidential spaces are important as some discussions can be sensitive	78	18	3	0	1

There were several positive comments about pharmacists in the survey responses.

My local independent pharmacy is marvellous, always go for advice before going to see a doctor.

Pharmacists stood up when GPs stood down over the last 3 years. I now go to a pharmacist for primary healthcare needs. They have much better people skills than GPs, see you without an appointment and seem more knowledgeable than GPs.

Only a few people commented on poor previous experiences, problems with waiting for services whilst pharmacists provide consultations or vaccinations, or privacy issues.

Pharmacists are too often unavailable for medication advice as often giving immunisation. Very frustrating waiting for medication to be signed off as Pharmacist is doing a consultation. More than one Pharmacist needed in each Pharmacy.

I do not like discussing things with my pharmacist, they have built a small room, but you can hear the conversations inside if you are waiting outside, and this seems inappropriate.

Two other issues were raised about pharmacists in the survey comments. The first was a suggestion that pharmacists, as a business, may not always be as impartial in their advice as GPs. This was raised by only a few people but has been included as a new finding.

The pharmacist is not impartial as the GP is. Sometimes they have sold us things which weren't particularly effective. Not blaming them as they are running a business. I have a very helpful pharmacist and sometimes you just want to be listened to.

Lots of people are put off using their local pharmacy because pharmacists can see them as customers and constantly try to upsell products to them. A lot of people I know have had to

get prescriptions rerouted to other pharmacies rather than our local because of harassment from the pharmacist to buy more and more every time we go to collect medication.

The other issue was about the expansion of pharmacy services. There was some support for expansion, with a few people wanting pharmacists to be able to prescribe more medicines or offer other services. However, other commenters raised concerns about how this would be funded and whether remaining pharmacies would have the capacity to cope with a larger role.

Would like to see pharmacist about post-operative dressings needing changing

Allow pharmacies to offer more and write prescriptions too esp for those of us with long term conditions asthma, hayfever etc

If Pharmacists are to become prescribers of antibiotics etc they need to be resourced to do so as you would expect to resource a GP/Doctor; Clinical duties and more responsibility cannot keep expanding without remuneration and adequate registration protection if duties are more risk orientated.

Ambitions

We want people in South West London to access primary care in the way that suits them best so that they can get the information, care, and support they need quickly. We want fully digital and connected primary care which eradicates clinical variation, improves health outcomes, and looks proactively at the needs of patients so that we improve the continuity of care for those who need it and keep people healthier for longer.



There was agreement with the ambitions for primary care from survey respondents (74% definitely agree and a further 17% somewhat agree). The main comments relating to the ambition seemed to be in agreement with allowing people to access care in the way that suits them best.

It doesn't have to be fully digital, just fully accessible in whatever way people choose/are able to access it. Some people much prefer being able to talk to someone directly or don't have digital skills etc.

My GP practice is fabulous and the envy of friends. The ease of getting different types of appointments (face-to-face, phone, video, GPs, nurses, etc) should be an example for everyone to follow.

A couple of people commented about not understanding what 'fully digital' primary care meant, and it is clear that some interpreted this as meaning all access would be online in future. In this context, people raised concerns about digital exclusion for certain groups.

Going "fully digital" as you describe it means that a proportion of residents. Mainly older people, will be denied access to care.

A few other comments supported the potential of digital and connected primary care to improve communication across services, particularly so that patients' notes could be accessed across the NHS.

Fully connected and digitalisation system is necessary for the whole of health sector. If a patient gets admitted to a hospital in another part of the country their medical

history/information (from GP, their usual treatment hospital) should be accessible to that hospital.

IT integration is key to improving communication between services and reducing inefficiencies.

GPs need to be much more open to sharing patient clinical information across other health and social care providers. The rightful owner of the information is the patient, not the GP.

Finally, a small number of comments supported the need for improved continuity of care, especially for those with long-term conditions.

Continuity of care is critical for those of us living with long term conditions &/or after serious illness like cancer. I want to see a GP but the GP who knows me.

3.12 Long term conditions

Summary

In total, 328 people responded to the survey questions about long-term conditions and there were 74 comments. Long term conditions were discussed in a focus group with the BME Forum Young at Heart group for people over the age of 55.

Headline findings from survey respondents and focus group

- Overwhelmingly, the survey feedback talked about the need for more support for long term conditions. In particular, the respondents mentioned there was not enough help with transport to appointments, pain management, the need for support with the mental health impacts of dealing with a long-term condition, financial support and monitoring of their condition.
- A few people commented on the lack of joined up services and information sharing.
- Face to face appointments were important for some isolated people with LTC and digital exclusion was a concern.
- Several comments supported the ambition for preventing or detecting long term conditions early, although a small number mentioned that not all long-term conditions were preventable.
- A few comments agreed that people with long term conditions should be provided with pathways which prevent A&E attendance.
- 99% of respondents agree with the ambition for long-term conditions.
- 97% agree that staying physically and mental well is important to people, helping them to maintain independence.
- 73% agree online webinars and digital help could reduce the amount of travelling and number of appointments – but only 36% strongly agree.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People prefer group community activities and learning at affordable prices, peer support, mentors, and coaches to promote prevention, such as diet, exercise and lifestyle changes. People have asked for condition specific activities, such	47	24	22	6	1

as diabetes-specific supervised exercise classes.					
B. People with long term conditions want better and clearer information about the support available and activities need to be improved and easily accessible, and information should be produced in different languages	69	21	8	1	0
C. Online webinars with clinicians, digital self-help apps and peer support could reduce the amount of travelling and the number of appointments for people.	36	37	18	7	2
D. Some people feel they could be could be digitally excluded or need a technology package to match their needs if digital resources replaced more traditional ways of getting support.	62	26	11	1	0
E. Some people feel alone and unsupported in managing their long-term condition.	63	26	10	2	1
F. Staying physically and mental well is important to people, helping them to maintain independence	83	14	3	0	0
G. People on low incomes have more barriers to keeping-well, for example in buying healthier food, self-help equipment like blood pressure cuffs, and taking part in affordable activities	72	21	4	2	1

The survey revealed that only 36% of respondents strongly agreed with the community insight that **online webinars with clinicians, digital self-help apps and peer support could reduce the amount of travelling and the number of appointments for people**. A further 37% somewhat supported it. A few comments pointed to possible explanations of the response. A small number of people agreed that it was difficult to get the support to travel to appointments, which might be aided by online support. Others, however, highlighted that not everyone was able to access digital services.

Not everyone has computers or able to use them and not everyone has a smart phone.

Having a long term medical condition is often very isolating and if all the support provided is a review appointment every 6 months or every year, it's vital that there should now be an option to attend in person

Members of the Young at Heart focus group talked about how isolating some long-term conditions can be, with face to face contact with health professions creating a social support system. They

gave the example of a friend with a kidney condition who felt lonely and isolated at home, so valued the social aspects of attending hospital for dialysis. Participants found the Young at Heart group to be a good support mechanism for people with a long-term condition. They highlighted the benefits of peer support and having someone to talk to, suggesting mentors could help people with long-term conditions with their mental health and wellbeing.

One survey question asked about the community insight: **some people feel alone and unsupported in managing their long-term condition**. While there was almost no disagreement with the statement, only 63% of respondents strongly agreed with it. The largest number of the survey comments, however, related to people detailing their support needs for a range of conditions. In particular, the respondents mentioned there was not enough help with pain management, the need for support with the mental health impacts of dealing with a long-term condition, financial support, monitoring of their condition and support to access transport to appointments. Given the number of responses submitted about the need for support, several examples will be included here.

I have a [painful and disabling long-term condition] and I've thought about suicide because of the lack of support, help and adequate treatment including regular appointments, community support and the isolation, loneliness, hopelessness and depression that are consequences of this brutal disease.

Some people who are house bound and live alone or have no family to support feel left and alone and feel a burden on everyone so don't want to cause trouble.

My COPD support has been conspicuous by its absence.

People with long term health conditions need help we need mental health support, community support, medical support, none of it is there and we are forgotten.

Not enough is being done to support people with long term health challenges; particularly with if they can't work and need support and with mental health support. Working with charities would give some insights and help. Also counselling.

Support for chronic pain linked to mental health needs to improve and physio access.

Some help for young people with long term conditions with PAIN. Currently nothing for my teenage daughter.

Anyone with long term health conditions needs financial support to prevent more stress.

More support from surgeries, I am pre diabetic and I am left to my own devices as to whether it is monitored or not.

In addition to the above support requirements, the Young at Heart focus group members discussed the role of transport as an enabler of independence. Most members of the group used public transport. Where people had mobility issues, support to get out was essential to prevent loneliness and isolation. The participants in the group discussed the example of a person who had lost their disability independence allowance, resulting in them losing their independence.

As with the responses to the open comments for the 'preventing ill health' section, there was a range of comments on the role of **low disposable incomes** in creating barriers to healthier lifestyles. A small number felt the issue was one of educating people to cook better and be more active, rather than of low income per se. Others repeated the need for free or subsidised exercise classes and gyms mentioned by many in the 'preventing ill health' comments.

Pressures on low income families and those in working poverty are increasing barriers and triggers.

More accessibility to free exercise facilities for people on low income and the aged.

100% the NHS need to connect and form partnerships with local gyms offer after doctor's assessment as reduced rate gym passes based on circumstances or long term health conditions at a reduced rate, as the current economic is making health a serious crisis issues due to people's financial demands rising because of cost of living.

A number of other issues were commented on by a small number of respondents which had not been covered by the survey questions. The first broadly related to treating the patient as a partner in their care by listening to them about their needs and allowing them to access medications through the pharmacist rather than requiring their GP to prescribe them.

Listen to the people who manage their own chronic conditions.

Better community-based access to medication and support etc. not GP as gatekeepers - we know our own condition better than them. Let pharmacies prescribe.

The second was about the role of co-morbidities in people with long-term conditions. A small number of people argued for a more holistic approach to dealing with co-morbidities and their interactions, including concerns about medication clashes.

A lot of the current resources available to support long term conditions tend not to take notice that those with multiple conditions may need an entirely different type of support, or, as in my case, the resources on offer are not suitable due to their treatments for different said conditions contradict each other.

People with long term conditions and taking different medications worry about the clashes in side effects of the medications.

Finally, a few respondents mentioned the variation in knowledge about and support for particular conditions. The comments suggested these conditions, such as ME, needed more research, specialist healthcare practitioners and consistent awareness of treatment guidelines across clinicians.

Lesser known and seldom researched long-term conditions need more lobbying and funding for research to better understand these and how best to treat or manage the symptoms and know what changes patients can expect in the future from other patients being surveyed.

Certain conditions like ME and fibromyalgia need more understanding and more specialists.

I have ME the severity of which is frequently underestimated. The SW London ICS should make sure that all clinicians have training on the updated NICE guidelines (2021)

Ambitions

We want to prevent or detect long-term conditions early. If people do develop a long-term condition we want to reduce the risk of the condition worsening, and we want them to have the fewest avoidable hospitalisations and A&E attendances in the UK.



There was a high level of statistical agreement with the ambition for long-term conditions but only a few comments related to the ambition. **Prevention and early detection** was a theme for a small number of respondents with suggestions about the best approaches to achieving the ambition. Participants in the Young at Heart focus group argued that education about preventing long-term conditions needed to start in schools, with school meals also requiring improvement to be healthier. Other comments proposed integrating routine advice about healthy living into all appointments and increasing screening programmes. Where a long-term condition cannot be prevented, the focus could be on reducing risk.

There is a lot of overlap between long-term conditions and prevention, since lifestyle choices are causal factors in many LTCs and these are often common across multiple LTCs. The current system is overly disease-specific and reactive. Integrating advice and support for lifestyle changes into existing medical appointments (Making Every Contact Count) is essential, in order to tackle the root cause of LTCs and improve outcomes.

Prevention is better than cure; earlier screening would prevent large costs further down the line and hospital admissions; Payout to screen sooner so people can annually track their progress or decline with visual management aids such as run charts of Cholesterol levels; BPs; Weight etc Annual MOTs from less than 40 years.

Some long term conditions can't be prevented, I have primary epilepsy. Helping people reduce risk where able is more practical - but supporting people with self management doesn't mean no medical care or support. We are still living with long term conditions.

The Young at Heart focus group discussed how best to utilise community networks to understand the requirements of **high risk or deprived populations for preventing and managing long-term conditions**. The participants suggesting communicating by advertising at busy locations such as public transport stops and cinemas. Messaging should particularly focus on the addressing the issues of mental health and loneliness in long-term conditions. These messages could also be displayed on screens in NHS waiting rooms.

A small number of comments related to reducing **A&E attendances** for people with long-term conditions. Respondents highlighted the need for better pathways which allowed people to access support early in the community.

People with chronic conditions shouldn't be attending A&E. There should be a known pathway for them rather than just heading to the local emergency department.

A&E for long term conditions feels risky & firefighting. Better community access via GP, specialist nurses in community would be best way to avoid repeat A&E.

As with several of the other care settings covered by the survey, several respondents mentioned the need for better coordination between services, continuity of care and shared information if people with long-term conditions are to be adequately monitored and supported. The role of a consistent GP who understood the person and their history of the condition was mentioned. The Young at Heart focus group discussed referrals between primary care and other services, with one participant talking about how they had had podiatry support cancelled after waiting for months because their GP had failed to note a change in criteria for people with diabetes with good blood flow.

These services need to be joined up and well co-ordinated, and waiting times for certain services reduced.

Every time I see any kind of medical person I have to explain my long term condition, it's treatment, it's implications and the side effects all over again. I can take five minutes having to go through it all. Medical records should be shared across hospitals and GPs, along with results.

Continuity of care from GP Practices help; seeing a different GP every visit means no one tracks and follows a patients experience and journey and trials and tribulations of a long-term condition.

Finally, a small number of comments noted that the support for people with long-term conditions had to include the needs of their unpaid carers as well.

Ensure when talking about people with long term conditions, you explicitly also talk about unpaid carers.

More support for carers.

3.13 Urgent and emergency care (UEC)

Summary

In total, 374 people answered the survey questions about urgent and emergency care (UEC) and there were 74 comments. Two focus groups discussed UEC as a primary topic:

- Sutton Seniors Forum for people over 65
- Merton Ethnic Minority Centre group with refugees, asylum seekers and people from ethnic minority backgrounds who attend the centre.

Additionally, the topic was covered by:

- Kingston Eccop focus groups with adults with learning disabilities, profound and multiple disabilities and autistic people
- Roehampton Champions focus group with people living on Roehampton estate.

Headline findings from survey respondents and focus groups

- The largest number of survey comments agreed that people sometimes used A&E because people could not get appointments at GPs or because there was a lack of walk-in and urgent care centres.
- Several survey respondents commented about the good care they had received from A&E and ambulance staff. Merton Ethnic Minority Centre focus group participants agreed they had experienced good treatment from UEC clinicians, but some members of the Kingston Eccop focus group had poor experiences at A&E, with staff not understanding how people with a learning disability feel or present, especially when in crisis.
- A few people commented on the high number of people using UEC for mental health issues, and the need for better signposting to more appropriate treatment centres for mental health crises.
- People in the Roehampton focus group agreed that there was a link between the accessibility of GP appointments and A&E footfall, both in terms of wait and problems for digitally excluded people who cannot use the appointment system. They also suggested GP receptionists were telling patients to go to A&E if they could not get an appointment.
- A few people agreed with the need to help people to leave hospital safely after treatment, especially at night.
- Members of the Sutton Seniors focus group felt the ambition to help people leave hospital safely would only work if services joined up effectively to ensure support, equipment and [information about] medication were in place.
- The Sutton Seniors group suggested that getting ambulances to people more quickly was not a complete ambition unless ambulance transfers and time to treatment at A&E were also reduced.
- On average, 94% of respondents agreed with the ambitions for urgent and emergency care.
- Strongest agreement (97% overall, 89% strongly agree) was with the ambition to get ambulances to people more quickly. when they need them.
- Lowest agreement (91% overall, 72% strongly agree) was with the ambition to provide more and better care in people's homes.
- 90% of people agreed that they want better communication between NHS services, and data sharing between pharmacies, GPs and GP hubs, could improve the urgent and emergency care experience.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People have praised the care and kindness of urgent and emergency care staff, particularly London ambulance staff.	64	19	11	3	2
B. Satisfaction with urgent and emergency care services varies for women, younger people, those from Black, Asian, and other ethnic minority backgrounds, and those with disabilities *	24	19	44	6	6
C. People feel less confident about urgent and emergency care services, due to: waiting times, perceived lack of staffing and some staff not having enough time to listen to patient symptoms	51	30	14	3	2
D. Some people want mental health crisis cafes to be expanded, especially during weekends, which could help reduce the number of people going to A&E	50	26	22	1	1
E. Some people go to A&E or don't seek help at all, because of waiting times to see their GP.	66	23	9	1	1
F. Some people go to A&E because they feel their injury is too serious to be seen outside of hospital	52	25	18	5	0
G. Some people take their children to A&E because they want their child to be seen in a hospital, rather than a GP surgery or other service in the community **	31	25	34	6	3
H. Better communication between NHS services, and data sharing between pharmacies, GPs and GP hubs, could improve the urgent and emergency care experience	70	20	9	0	1

* when filtered by responses from people who identify as Black, Asian or another ethnic community, 49% agree with this statement (32% strongly agree), compared to 43% of all respondents.

** When filtered by responses from people who said they were parents/guardians to a child under 18, 50% agreed with this statement, compared to 56% of overall responses.

There were several survey comments praising the treatment respondents had received from urgent and emergency staff, including ambulance staff.

My personal experience of ambulance service and emergency services has been excellent.

When I had a seizure, the ambulance response and 'on board' treatment were first class.

People in the Ethnic Minority Centre (EMC) focus group said, overall, they had good experiences of UEC, had good interpreter support when needed and found clinicians to be kind and supportive. Although most people agreed they received good care in A&E, there were some degrees of **variation in satisfaction with UEC** across the focus groups. Some people in the Sutton Seniors focus group felt they were talked to as though they were 'senile' and were not taken seriously. A participant in the Merton EMC focus group thought doctors should be better trained to understand cultural needs. Some people in the Kingston Eccop focus groups with adults with learning disabilities, profound and multiple disabilities and autistic people had poor experiences of A&E, with staff not understanding how people feel and present with in crisis and responding inappropriately to behaviour they perceived as challenging or difficult. There were very few comments about variance with satisfaction from the survey. One disagreed with the insight; another suggested more needed to be done to accommodate people with autism.

My experience is they do an excellent job regardless of gender or race.

I've been in A&E 3 times and there was very, very little help for me as an autistic person, the lights, noise, people. First time they wanted to keep me in and I had to leave from sensory overload, so actually this could have been serious.

A few survey respondents commented on the high number of people using **UEC for mental health** issues, and the need for better signposting to more appropriate treatment centres for mental health crises.

Thousands of people unable to access mental health services result in many 999 calls being for people who are desperately frightened and a danger to themselves. They need the right help but it often seems that calling an ambulance is their only option.

At A&E recently. High number of people suffering with mental health problems

People in the Merton Ethnic Minority Centre focus group said they thought that information and signposting for emergency care for mental health needed to be better as it was unclear what people should do in a crisis.

Several of the survey comments agreed that people sometimes used **A&E because of waiting times to see their GP**. Additionally, in both the survey comments and the focus group discussions, people suggested GPs and receptionists were directing people to A&E.

Poor access to GPs = crowded A&E

GPs are sending people to A&E when they don't have appointments. The waiting times in A&E are far too long and not always appropriate for the medical issues/illness

People in the Roehampton focus group agreed that there was a link between the accessibility of GP appointments and A&E footfall. They also suggested GP receptionists were telling patients to go to A&E if they could not get an appointment. Members of the Roehampton focus group talked about how those who are digitally excluded from making GP appointments are forced to go to emergency care instead. They questioned why they had to call 111 to go the GP hub.

One survey commenter talked about their knowledge of local A&E use to explain they had found **people with children are often directed to A&E by urgent care and NHS 111**. They suggested GPs will often see children the same day, avoiding A&E visits and that GP Hubs and Out of Hours services are a good way of avoiding A&E visits but are always not available when needed.

Another comment made some suggestions about how pressures on A&E could be reduced for the treatment of children.

GP practices should have specialist doctors in every surgery or at least on call for the borough or the Trust area. This way, especially for children, people can access a specialist without having to go to A&E. An on-call, 24/7 paediatric service could significantly reduce referrals to A&E. More Walk-in clinics that are open 24/7 that can deal with paedics too. Pharmacists should also be able to see people who cannot get a GP appointment but are acutely unwell and can be treated with antibiotics.

Some people in the Sutton Seniors focus group suggested there was a need to improve the communication between ambulance services and hospitals, and the continuity of care when in A&E. A couple of comments agreed with the need for **better communication across NHS services and data sharing between primary and urgent care.**

Above all proper integration of information, sharing between practices and hospital departments and sometimes even between individual hospital departments. Eg: right-hand, not knowing what the left-hand is doing.

In addition to the community insights stated in the survey, there were some other insights about urgent and emergency care from survey respondents and focus group participants. A few comments talked about pressures on A&E being due to a lack of walk-in centres.

Needs to be Walk-In Centres for minor injuries in front of all A& E departments to reserve A&E for the most serious conditions with Triage GP only person to sanction who gets inside the actual A&E Dept

Smaller walk-in centres would ease the burden on A&E at hospitals

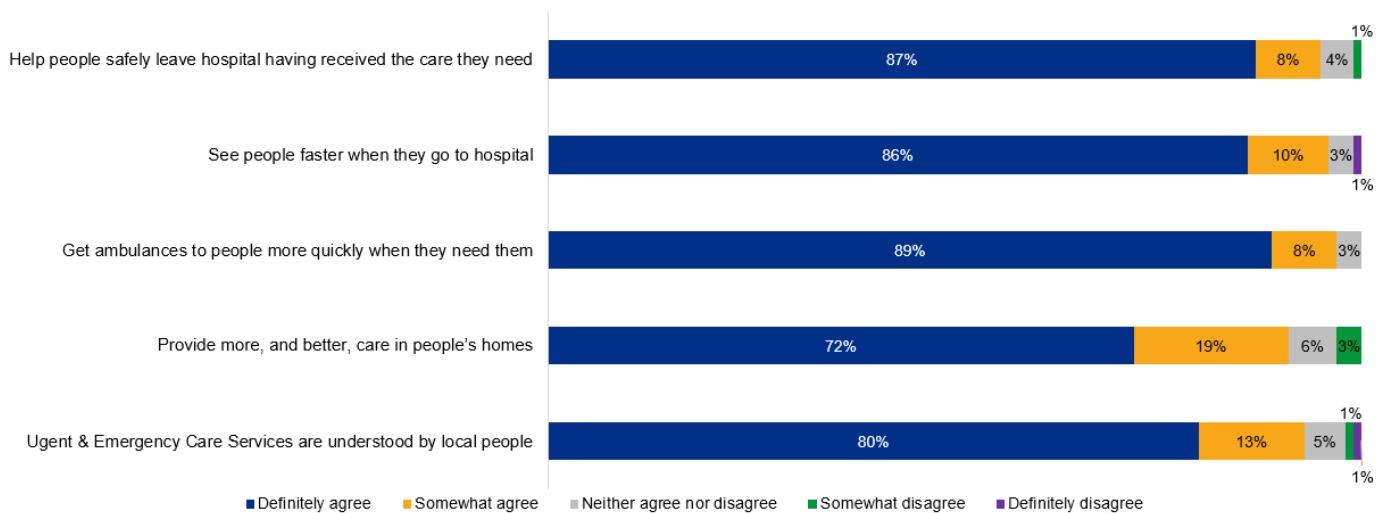
Some people in the Sutton Seniors focus group suggested that transport to Urgent & Emergency Care Centres can be an issue for older people, particularly those who no longer drive. For example, some bus routes do not take patients to Epsom & St Helier Hospital. They would like to see parking improved at hospitals for those attending relatives in A&E.

A few survey comments talked about how to improve the experience in UEC centres when waiting for treatment:

When someone is very poorly their experience in the ED setting is what can improve the outcome; make sure food and drink available as people who are very ill may not have eaten or drunk; Noise can be an issue - Turn off loud TVs as never on the right channel and causes more distress than distraction

More care for patients waiting for long times, to be offered food/drinks and update how long the wait times are. Better reception to call families.

Ambitions



Members of the Merton Ethnic Minority Centre focus group questioned how the ambitions would be achieved with tight budgets and suggested there was a lot of waste, including medicines. Although the comments generally agreed with the ambitions, a couple felt they were not ambitious enough and a few questioned how this could be achieved without additional funding or increasing staff.

‘You need more resources and staff to improve A&E. Waiting times can be v long and the staff are often working in poor conditions.’

A few comments agreed with the ambition to ensure local people both understand when to use different UEC options and which options were available. This included awareness of urgent care centres and the services available for people having a mental health crisis.

More capacity/staff and patient awareness of the urgent care centres would relieve the burden.

Better signposting to local communities about what services are available at each acute site to help reduce the delay to specialist review and treatment. Epsom Hospital has very little acute services on site. Epsom ED should be made in to an urgent treatment centre. Having it as an ED is confusing to patients who then need to be transferred to St Helier's or St George's before they can be seen by a specialist in many areas particularly out of hours.

People with MH should go to Spring field UCC than Local hospital A&E

People in the Sutton Seniors, Merton Ethnic Minority Centre and Roehampton focus groups mentioned long waiting times for urgent and emergency care. A Roehampton participant talked about their ten minute wait for 999 to answer in an emergency and long GP/111 messages about covid before the call was answered. Sutton Seniors suggested a need for better communication about waiting times for triage from 111. The Sutton Seniors group criticised the ambition to get **ambulances to people more quickly**, suggesting that getting ambulances to people more quickly was not a complete ambition unless ambulance transfers and time to treatment at A&E were also reduced. Only a couple of survey comments related to this ambition, despite the high level of statistical agreement with it.

Emergency care in the UK is unacceptable and the reason why I am leaving the country soon. My husband had to wait for 6 hours for an ambulance when he had a bad lung

infection with high fever and couldn't breathe or move anymore and was then made to wait the entire night in the hospital seated on a metal chair.

There was a high level of statistical agreement with the ambition to see **people faster when they go to hospital**. One participant in the Roehampton focus group talked about how she had left Kingston A&E to go to Chelsea and Westminster instead as she was feeling too ill to sit upright in a chair in the waiting room. A couple of survey respondents made suggestions about how this ambition could be implemented.

Triage need to see people as soon as they arrive and send them to a local pharmacy where applicable. Two queues, quick fixes to move people quickly out where cuts can be dressed quickly for example.

Have quicker pathways for chronic conditions. For example a person with type 1 diabetes should have a quicker and easier pathway through to care they need rather than sitting in A&E for eight plus hours getting sicker. Having a quick route through to something like SDEC would probably reduce hospital inpatient by 50-75%. Patients wait until sicker before seeking help. Earlier and easier intervention routes would potentially dramatically reduce inpatient time.

Members of the Sutton Seniors focus group felt the **ambition to help people leave hospital safely** would only work if services joined up effectively to ensure support, equipment and [information about] medication were in place. A few people in the Sutton Seniors focus group talked about their poor experiences of discharge from A&E/Hospital, including being transferred home in the early hours of the night or without enough information about the medication they had been given. The group suggested hospitals should ensure patients return home during daylight hours with a care package or family support at home. A small number of comments from survey respondents echoed this theme.

Ensure that vulnerable people are not discharged from A and E without help. People should not be left to go home in nighties and slippers or late at night

Exemplary care in A&E but I wasn't happy with the speed of discharge. My husband had almost died, and was out the next day, having broken several bones and still throwing up. I had to get him home over potholes and upstairs - alone... but the care was perfect from Ambulance staff.

3.14 Workforce

Summary

In total, 383 people responded to the questions about the workforce strategy and there were 84 comments. Focus groups and community outreach did not cover workforce issues.

Headline findings from survey respondents

- Several people commented to agree with the need for compassionate staff, with a few saying their experiences of NHS staff were positive.
- A few respondents agreed with the insight that people with a long-term conditions should be recognised as ‘partners’ in their treatment.
- Several comments appeared to agree with the ambition to have great managers.
- Although many comments supported the need for SWL to have workforce supply to overweigh demand, several explicitly asked where the clinical staff would come from or how pay could be increased to retain the NHS workforce.
- A few people commented positively about staff from local communities.
- On average, 96% of respondents agreed with the ambitions.
- 98% of respondents agree they want compassionate treatment from staff who care.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. People would like compassionate treatment from staff who care.	90	8	2	0	0
B. Staff shortages and pressurized environments can often mean some staff don't have the time to listen to, or consider, patients specific needs e.g., ethnicity, people with dementia, people with mental health issues, neurodivergent people, trans people.	67	21	8	3	2
C. People from Black, Asian and minority ethnic communities say there is mistrust and fear about using NHS services due to experiences of racism from NHS/public services. *	24	18	48	5	5
D. Patients with long-term conditions would like to be	58	30	11	1	0

recognised as experts in their condition as many have lived with illness for years. Patients are keen to be 'partners' with clinicians around their care plans and decision-making					
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* when filtered by responses from people who identify as Black, Asian or another ethnic community, 58% agree with this statement, compared to 42% of all respondents.

Insights from People and Communities

Although the survey found a massive majority agreed with the community insight that people would like **compassionate treatment from staff who care**, there were very few comments directly relating to this insight. A small number recounted poor attitudes, but others praised the workforce or suggested training to aid greater understanding.

Most staff I have encountered have been professional and praiseworthy.

Those who work in NHS must be compassionate. Some form of training should be in a care home.

A couple of respondents commented about **staff shortages and pressurised environments meaning some staff do not have the time to listen**. The comments were a mixture of agreement with the original community insight and suggestions that this applied to all patients, not specific groups.

It's not just particular people who suffer from over pressurised staff who don't take the time (or have the time) to listen properly. I think it's everyone.

Need more training in understanding differences in symptoms and its presentation in women and in people of colour. Some doctors still use the same symptom list as is described for white/ Caucasian men to diagnose for women and people of colour. GP and hospital doctors are not willing to listen to patients (people of colour) concerns about their symptoms and suspected disorders.

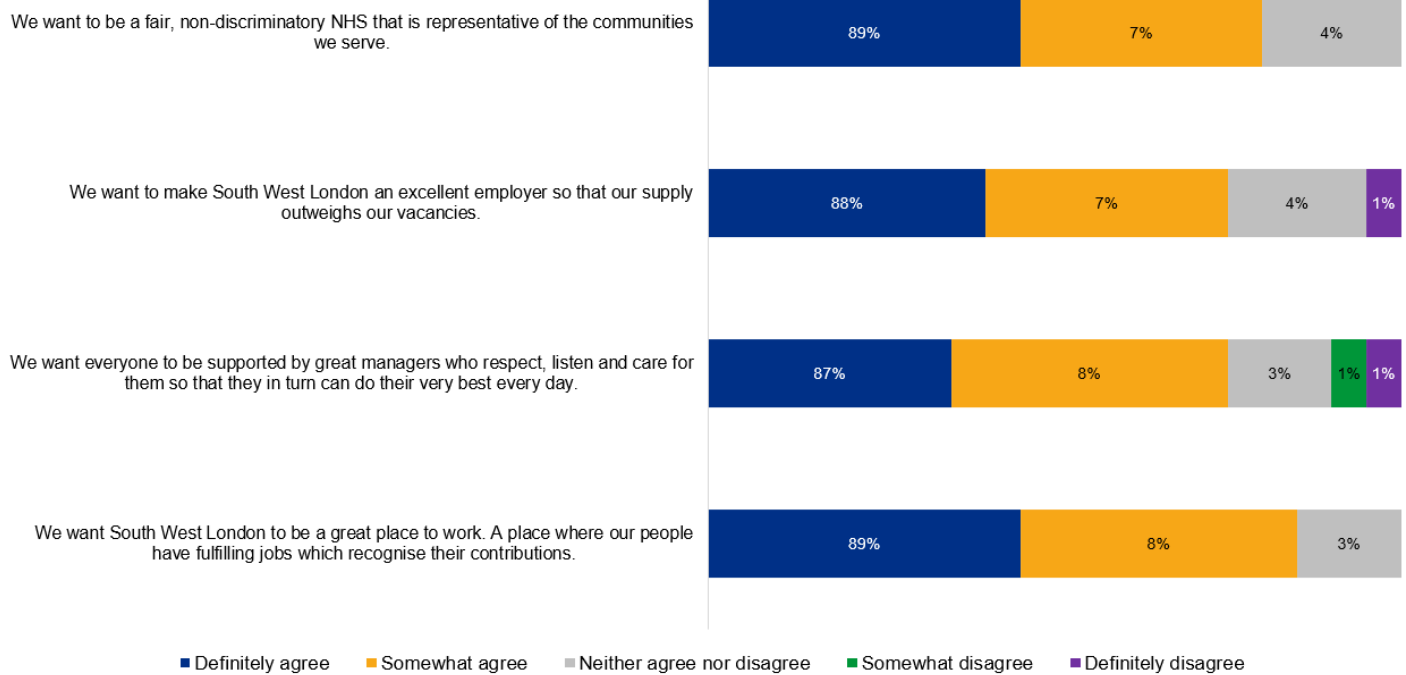
A small number of comments were made about the community insight that **patients with long-term conditions** would like to be recognised as experts and partners in their care, the majority wholeheartedly agreeing with the statement. However, others highlighted it was also important to recognise that not all people with long-term conditions will be as confident about their care or know what they need.

I particularly agree with the point that the patient with a chronic condition should be treated like an expert and a 'partner' in care plans & decision making rather than the 'one size fits all' approach of the NHS at present!

We would generally agree with people with lived experience being experts in their conditions. This is right. The caveat to this is that it does not apply universally and there are people who will wish to listen to and be guided by clinicians.

Most important point is to listen to those patients who have chronic or multiple chronic illnesses and for the system to have the ability to work outside the current rigid guidelines where clinicians are given the flexibility to work with patients on a case by case basis where they feel there is benefit.

Ambitions



There were high levels of agreement with the ambitions, as seen in the above chart. There were many in-depth comments about issues around managers, retaining the workforce and the need to appreciate staff. Additionally, there were a few comments concerned with the ability of South West London NHS to achieve these ambitions, particularly without improved finances and being able to pay staff salaries which enable them to meet high costs of living locally. These concerns about NHS pay levels ran throughout the responses to the workforce questions.

Huge ambition but worth striving for. Difficult ambition on the current tight budget.

The low pay in the NHS is an issue to filling vacancies.

It's often very difficult for the health and care workforce in SW London to afford accommodation in the same area - long commutes add to tiring and stressful days. Perhaps more money could be spent on workforce accommodation?

Several comments appeared to be addressing the ambition to make South West London a great place to work. The respondents outlined some challenges to achieving this ambition, such as low morale, overwork and low pay levels.

There is significant work to do here as currently morale is low across primary and secondary care and there is little support for staff and poor pay parity.

The NHS workforce are wonderful. My family have had so much support and kindness from NHS staff in many different departments, but they are asked to do the impossible with ever decreasing resources. The only way to recruit and retain high quality staff is by providing them with a good employment package and working environment.

NHS staff seem massively overworked. Recruit and train more people? Update systems? Have a review of manager and front-line staff numbers and aim to put more out front.

The largest number of responses mentioned the role of managers who support their staff. Respondents talked about managers who were not aware of the conditions and levels of work on the frontline, a target driven approach to management, and managers with a need for improved people skills. Implicit in a few of the comments was the sense of lack of resources meaning staff

felt it was hard to deliver the job. Moreover, a few comments talked about low morale and the need for more support.

There continues to be a lack of support to staff from managers... and being over-worked and underpaid... nothing has changed much in the last decade, and seems to be getting worse, the concerns are not being listened to, this is affecting morale and mental health.

It would be nice for management to compliment their staff, show some appreciation. We often feel we are doing a bad job because of the pressures and we really want to care for the people we look after and that motivates us, but managers don't always appreciate the hard work we put in. It would be nice for the things you get right to be noticed as much as the things that don't go so well.

Morale is at an all time low, I no longer want to work in the NHS. It can often be an exploitative working relationship. Having staff counselling and being told how appreciative management are for us working so hard, with lack of staff and having to more work to keep things going is not good enough. This is part of the reason why people are leaving. We already know that we work hard, are team players and will go above and beyond to support our colleagues. Everything needs to be managed better from recruitment, who sits on recruitment panels to having strong leadership. Without strong leadership nothing changes.

The **retention of staff so that supply outweighs vacancies** again attracted several comments agreeing with the need but questioning how this can be achieved without improving pay and reducing the workload. A few suggestions were made about changing working patterns or addressing housing issues to help retain staff.

We need to do everything we can to keep and motivate our GPs, nurses and health workers. It speaks volumes that some leave to work abroad.

You can't do this while saving money by cutting staff in cost reduction programmes. NHS staff want to provide excellent care and will do the best they can with the resources available to them. When they can't do this, they leave or burnout and you lose excellent people and all the training invested in them

Being more flexible with patterns and shifts could really help that the load of healthcare workers. Trusts should look at implementing 4 day week rotas for 5 day working week staff or 7 day rotas for 8/9 day working staff, to relieve some of the pressure of their workplaces and also to have time to recharge and look after themselves and their families. Food vouchers and retail discounts should be provided to lowest paid staff as well allowances for laundry and personal healthcare provisions.

Finally, there were a small number of comments about diversity not being an issue in the NHS, but more agreement with the ambition to have **a non-discriminatory NHS that is representative of the communities** it serves. A couple of comments made suggestions about the costs of living in the local area and the impact of commuting in from other areas. Ideas to address the issues included key worker housing initiatives and not having to pay for parking.

The hyperlocal recruitment that has worked in other areas of the country might connect with people that do not see/respond to NHS adverts. Any SWL level collaboration/partnership with other entities on housing, like key worker housing on new developments etc, would help the biggest barrier to staff staying in area - the cost of housing.

It is important for health care workers to be able to live near the areas where they work, and to be able to travel to and from work without difficulty. They should not pay parking fees at their place of work.

3.15 Digital

Summary

In total, 341 people responded to the survey on digital and data services and there were 97 comments. Digital services were discussed in a range of focus groups and community outreach events including:

- Croydon Young at Heart BME Forum focus group with people over the age of 55.
- Merton Ethnic Minority Centre focus group with refugees, asylum seekers and people from ethnic minority backgrounds who attend the centre.
- Kingston Eccop focus groups with adults with learning disabilities, profound and multiple disabilities and autistic people.
- Roehampton Champions network focus group with people of all ages living on the Roehampton estate.
- Sutton Seniors focus group with people over the age of 65.

Headline findings from survey respondents, focus groups and community outreach

- There was strong agreement with the digital ambition from survey respondents (79% definitely agreed and 14% somewhat agreed).
- Some comments highlighted the need to provide training and support for people who needed help to use digital solutions.
- Several comments supported the need to use better digital integration to improve information sharing and continuity of care.
- By far the most comments were concerned with ensuring that the use of digital technology did not replace human interaction or limit face to face appointments.
- The comments suggested people would welcome the ambition to keep a range of way to communicate and receive care from the ICS, particularly face to face appointments and care.
- A few comments showed strong support for digitalising healthcare or using big data to drive improvements in outcomes.
- A few comments suggested concerns about poor IT security or data management leading to a loss of patient data or confidentiality.
- 93% of respondents agreed that they worry about digital exclusion
- Lowest agreement is that digital apps, websites, online community meetings and appointments have helped to deliver health and care services – 37% strongly agree and 40% somewhat agree.

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. NHS and council websites are trusted sources for information.	46	35	11	5	2
B. Smartphones are the most popular way to get online.	45	32	12	8	3
C. Digital apps, websites, online community meetings and appointments have helped to deliver health and care services.	37	40	15	5	3
D. Some people were worried about digital exclusion. For example, older people, people living with dementia, people with a learning disability, people with autism, and people for whom English is not their first language	75	18	6	0	1
E. Some younger people were more confident to access digital healthcare	65	23	10	1	1
F. Social factors affect digital use. Some people need community spaces for support, training to gain skills, and/or financial support for IT equipment or data packages.	66	25	8	1	1
G. Improved IT would provide better continuity of care and co-ordination between services	62	26	10	1	0

Community insights

The survey showed more people ‘somewhat agreed’ than ‘strongly agreed’ that **digital apps, websites, online community meetings and appointments have helped to deliver health and care services**. The comments about digital services were a mix of people highlighting good experiences with NHS apps and online services and more ambivalent experiences due to poor functionality and difficulties in navigating digital services. Good experiences from digital services included appointment booking and reminders, ordering repeat prescriptions and good communication with people with long-term conditions.

I think some aspects of on-line facilities are good - such as routine appointments and so on, much better than having to go to the GP, for instance just to get a repeat prescription.

Two of my hospitals now offer a Patient Portal, a way to message, access results and access new appointment information. This has been essential in helping me to not miss appointments, especially during the recent postal strikes.

Appointment management and digital communications are a great way to engage with people with chronic conditions.

By contrast, members of the Croydon Young at Heart BME Forum focus group with people over the age of 55 suggested there were too many apps, making it difficult to understand the NHS systems. They argued there needed to be a move to a single NHS for communication, appointments and prescriptions. Additionally, there had to be education and support to access digital services for those who may otherwise be excluded. Some survey respondents agreed with the need for a more joined up approach to digital access to healthcare and greater usability of available apps.

As a digital native, I still find digital services variable, confusing and contradictory which is frustrating. Much more work needs to go into this, to make information accessible. I have needed to look at some other practice websites for local relatives and am stunned at how unwelcoming some can be, and how unhelpful their appointment access is, by requiring downloading of an app & accessing at a precise time to have any hope of an appointment.

Regarding use of certain apps for smart phones, (assuming that the entire population has them, which of course is completely untrue), apps such as 'My GP' or NHS app or 'Patient Access' has become confusing and duplicating.

Health apps need to have good usability so that people will actually use them and continue using them. For example, getUBetter was terrible so I gave up and felt I'd wasted NHS money by signing up for it.

How can I get my data from the community (e.g. pharmacy) or my smart phone back to the GP system. I keep having to go to the GP to do everything. Isn't there technology to do this? How can I get my blood tests done in a pharmacy or walk-in centre when it is convenient for me and the information goes to my phone and back to my GP.

Digital exclusion was a key theme across the community outreach and in the survey comments, with concerns that some groups do not have access to smart phones or other forms of IT to use apps, find information and make appointments.

I am 88 - half my friends do not use or understand smart phones.

I have an old second hand phone that is limited in what it can do and not reliable. I cannot afford a laptop or PC which makes me even more isolated and lonely.

Some people in the Sutton Seniors, Merton Ethnic Minority Centre and Roehampton focus groups said they were excluded from accessing services due to not being able to use appointment booking systems or QR codes, which was widening variation in treatment.

"I don't understand online appointments – that's how I am supposed to get an appointment now since covid! I can't use online so I just have to go without"

Online booking systems were also raised by the Kingston Eccop focus group for people with learning disabilities, with one participant explaining that the online booking for GP appointments made it difficult to tell the surgery about complex needs due to this not being part of the options menu. The Croydon Young at Heart focus group thought a move to apps and online services was increasing the digital divide for older people and those experiencing homelessness. Similar concerns about older people or people with disabilities were highlighted in several survey comments.

It is necessary to recognise that in neighbourhoods with ageing populations the majority of patients will not actively use smart phones or the internet and are therefore digitally excluded and require service provision that is appropriate for their access needs.

As acknowledged, some older people may struggle with booking appointments online due to digital vulnerability.

People with sight loss are more digitally excluded than many other groups. They need additional support to use accessibility tools and to get online.

I would have liked to see more on your approach to communicating with and meeting the needs of patients who are digitally excluded, or not comfortable/confident with the use of digital technologies. It seems likely that this group will increasingly overlap with groups who have complex physical and mental health needs, and to an extent with those who live in deprived material/social circumstances, so it would have been helpful to see more in terms of a positive strategy for these multiply-disadvantaged groups.

A few comments agreed with the insight that some **people need community spaces for support, training to gain skills, and/or financial support for IT equipment or data packages.** Suggestions about how to overcome access issues or skills gaps included pop-in centres to help people with apps, access to online services in waiting rooms and trainers to teach people IT skills while they were recovering in hospital.

Even for people with experience of smart phones and apps find it difficult to transfer the details onto the app. THERE SHOULD DEFINITELY BE POP-IN CENTRES TO HELP ACCESS HELP ON THIS PROBLEM.

How about access to the NHS website in every waiting room.

Instead of being scared to use digital because you think not everyone can use digital, make your digital the best there is, intuitive and clear (because it's neither at the moment) and then run training sessions to show people how to use them. You have people trapped in hospital for days with no TV or books to occupy their minds, you could use that time to get an IT trainer to show them how to use the apps - although to do that you'd have to actually offer free wifi in your buildings, like every other public building in the country does.

A few respondents mentioned how an improved IT would provide better continuity of care and co-ordination between services. In particular, the comments suggested the need to integrate different IT systems to enable information sharing between services and across locations.

Join up all NHS IT programs so all professionals involved in a patient's care can see all notes from different boroughs etc.

It would help if there was one IT system throughout the NHS. As it is Kingston hospital and West Middlesex hospital do not communicate I needed to have another blood test in west Mid even though I had had the same in Kingston within in two days, waste of money.

Participants in the Kingston Eccop and Merton Ethnic Minority Centre focus groups also suggested the ability to share patient data across the NHS would help improve patient experience. For example, allowing access to a patient's patient record when a person had to use urgent care services in a different place to where they lived. For members of the Eccop focus group for people with learning disabilities, they would like to see a fully multidisciplinary approach to digital data sharing. That would enable them to tell their story once and for all services involved in their care to understand their needs if they turn up in another part of the system.

Ambition

Digital technology is now a significant part of our everyday lives. We want to use that technology to change the way we deliver services, providing faster, safer, more convenient care and supporting patients to self-care. Through our use of technology, we want to make the jobs of our clinicians and staff easier and improve productivity and patient outcomes. Recognising that not everyone can or wants to engage with the NHS digitally, we will continue to offer a range of ways in which people can receive care and support, and interact with us.



There was strong agreement with the digital ambition from survey respondents (79% definitely agreed and 14% somewhat agreed). A few of the open comments identified opportunities for ways to utilise digital technology. This included using data to improve population health management, perhaps with the increased capabilities offered by artificial intelligence. Other opportunities covered clinical capacity and information for patients to increase self-care. One respondent highlighted the need for high quality training for staff to enable their use of digital technologies.

Improved and innovative digital solutions can transform healthcare across delivery of clinical services, capacity management and information support for self care and decision-making. Build on some of the extraordinary examples already out there in healthcare and learn from other sectors too.

Digital technology, data, and population health management are essential parts of modern healthcare. By utilizing digital technology and big data analysis, we can better monitor and manage population health, and provide personalized medical services.

Closed, verified data sets are ideal for AI. This should be a no1 national priority for the NHS.

Provide an excellent training platform for staff and regular updates.

Both in the community outreach and survey comments across a range of care settings, the issue of wanting to maintain options about how to book appointments and access healthcare was a concern for many. The largest number of comments from the digital open question related to wanting to keep face-to-face healthcare, suggesting strong support for the ambition to **continue to offer a range of ways in which people can receive care and support, and interact with the NHS.**

Too much digital and too little face-to-face will de-humanise the NHS. Technology is important for administration, but using it as a replacement for medical care can be very dangerous.

Increased use of digital and AI technology has the potential improve the way health services are delivered, but it will be important to retain a significant element of human and face to face interaction with patients.

There is nothing like person to person interaction. The digital world is a cold unfeeling uncaring place.

Participants in the Eccop focus group said people with learning disabilities find it easier to have a person to talk to, particularly when booking appointments. Where GP appointments can only be made online, there needs to be the ability to explain they have complex needs. Formerly, they relied on developing relationships with receptionists. They suggested it would be useful to include phone numbers alongside websites, as it helps them to save numbers in their phone so they can access the service quickly.

Although most respondents recognised the potential of digital and data services to improve management and patient experience, a small number of comments expressed concerns about **data security**.

My chief concern about the digitisation of healthcare, is the security of the data, and the cost. The government have shown they are incompetent in securing our private data. All their IT projects are inefficient and too expensive and aren't successful.

You have an extremely long record of utter incompetence with IT and patient confidentiality, I would not trust you with my data.

Participants in the Sutton Seniors focus group highlighted the need to reassure the public about the appropriate use of personal data by the NHS. Some believed the NHS was selling their data, after receiving unsolicited phone calls from wheelchair/stair lift companies after visiting services. This impacted their trust in data sharing between services.

3.16 Green agenda

Summary

In total 289 people answered the survey questions and there were 74 comments about the green agenda. The green agenda was not discussed in focus groups.

It is important to note that the Joint Forward Plan includes a detailed green plan. For the purposes of this survey, the extensive ambitions were reduced to a single emission target. This has impacted the responses to the ambition significantly.

Headline findings from the survey respondents

- The main comments about the community insights related to whether increasing walking and cycling was possible for older people and those with a disability.
- Several people who commented felt the targets to reduce emissions did not go far enough, fast enough.
- About the same number of people felt this should not be the priority for an overwhelmed NHS, with a few thinking it was not important.
- A few commenters wanted to know what the green plan was in more detail.
- 85% of respondents agree with the ambition for the Green Plan
- 98% of respondents agree that open spaces and parks improve mental and physical wellbeing
- 97% agree that litter and antisocial behaviour reduces enjoyment of green spaces

Detailed findings

The table below summarises insight gathered from previous engagement activities with people and communities. Survey respondents were invited to indicate how much their own experiences matched the experiences of other people living in South West London.

What people said	% strongly agree	% somewhat agree	% neither agree nor disagree	% somewhat disagree	% strongly disagree
A. What people value most about where they live, is green space and parks.	52	35	9	4	1
B. Open spaces and parks improve mental and physical wellbeing and create spaces for communities to thrive.	84	14	2	0	0
C. Litter and antisocial behaviour reduce the enjoyment of parks and green spaces.	83	14	2	1	0
D. Reducing traffic is seen as being the main way to improve air	46	34	10	6	4

quality, which has an impact on healthy living					
E. More emphasis on walking and cycling as positive for health. 'Active travel' could tackle obesity, increase exercise, reduce air pollution, and has mental health benefits	61	26	8	3	2

Community insights

Despite the very high levels of agreement with the community insights about **open spaces, and parks**, there was only a very small number of related comments, primarily asking about definitions or suggesting ways to access spaces.

Train fares need to be much lower to enable easy access for people from the towns and cities to the countryside with all of its health benefits (clean air, exercise etc...)

There were a few comments about the **reduction of traffic to improve air quality**, ranging from criticism of the ULEZ policy to the need to improve public transport to enable the necessary reduction. Additionally, some of the comments were concerned about the impacts of traffic reduction on those with mobility issues.

Whilst we'd agree with the general principle of reducing traffic, road traffic is a key tool for independence and access for those with limited mobility, cognitive, sensory and mental health impairments, those acutely unwell as well as for emergency response, carers, social care and community provision. Exemptions for these groups should be considered but are not always effectively applied.

All this is very long-term. We need frequent bus services now going into hospitals. Some will need cars but staff could carshare if on the same work pattern. None of us can continue to drive everywhere or fly often so public transport will need to be better than now.

The effects the ULEZ is having on people's mental health will far outweigh the so called /misled 'positive health' effects from reducing traffic (emissions) and improving air quality. People are stressed about not being able to afford a new compliant vehicle or face having to pay a tax (ULEZ) to drive their current vehicle!!

Although there was strong agreement with the community insight about **walking and cycling for health**, several survey comments were concerned with the implications of active travel for older people and those with mobility problems.

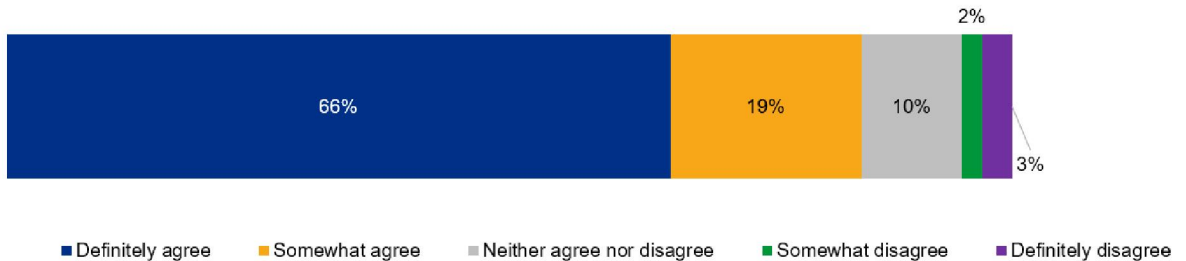
Disabled people sadly are often unable to walk or cycle. Provision needs to be made for everyone.

As a cyclist I feel elderly & people with disabilities are not listened to regarding transport. Poor bus service here. How are they to visit GP, shops etc?

I support green policies, but as an older person I am reliant on public transport and car. I could not get about on a bicycle

Ambition

For the emissions we control directly (the NHS carbon footprint), we want to be net zero by 2040, achieving an 80% reduction during 2028 to 2032; and for the emissions we can influence (our NHS Carbon Footprint Plus), we want to be net zero by 2045, achieving an 80% reduction during 2036 to 2039.



As already mentioned, the design of the survey meant that the extensive programme of often technical actions and ambitions for the green agenda were reduced to a single ambition about emissions. This almost certainly had an impact on the types of comments received. Although respondents largely agreed with the green ambition, several comments argued it was not ambitious enough and the timescale to become carbon neutral was too far in the future.

Needs to be more radical...net zero by 2045??

Not ambitious enough.

I would like you to be even more ambitious - the situation is critical.

By contrast, the same number of people commented that the green agenda should not be a priority for focus for the NHS, with about half of these comments critical of the concept of net zero.

I think the primary issue for NHS is staff shortage and underfunding and don't want you to also feel burdened with climate issues but great you want to tackle this.

Green policies should be low on your list of priorities because the health service is not a big polluter.

I feel that green travel and green buildings and green carbon footprint are excellent goals, but should be secondary to the vital services the NHS provides. Too often these goals are implemented in ways which disadvantage those who struggle with limited mobility, low income, long distances to travel etc. Where these can be implemented in a cost effective and non-discriminatory way they are, of course, welcome.

The NHS should focus on healthcare, at which it is currently really bad, instead of taking on political agendas on net zero and diversity.

Since the full green plan had been reduced to a single ambition, it was not surprising that a few people commented to say it was lacking detail and targets.

The plan is not detailed or believable.

That allows you to ignore progress meantime. Interim targets need to be set and publicised.

Additionally, several comments raised other green initiatives, such as recycling, which were covered in the longer plan. Some of the comments also suggested broader opportunities to become greener, such as waste reduction, community growing initiatives and having health services within walkable distances.

Reduce the carbon footprint by making more hospitals accessible to public transport and parking.

The vast quantities of disposable equipment and PPE is a massive contribution to landfill. Autoclave? Reusable PPE?

If you want to get people to live greener lives, you need to make it easier for people to access local medical services, first by making sure every NHS site has excellent public transport, and second by making services more local, so it is possible to walk to a pharmacy, walk to a blood-testing station, walk to a GP. I've seen the health bus come round to offer basic services in high streets and that is an excellent idea, bringing services to people, but it's barely used.

Reduction of waste and an audit of how many disposable things can actually be used again or replaced by non-disposable items eg blood test tourniquets. Make sure that recyclable material is actually recycled and not mixed in with plastic etc

Prevention is the best way to reduce the carbon footprint of the NHS. Net zero will not be sufficient; we need to adapt to our changing climate. One key approach to adaptation is building community resilience, e.g. through collaborations between NHS, local authorities, VCFSE and local communities. As an example, a community allotment enables people to grow healthy food with a much lower carbon footprint than commercially produced food, whilst giving people access to healthy food, encouraging them to do physical exercise whilst spending time in nature with other people.

A small number of respondents argued the issues involved in the green agenda were broader than the NHS could address, with suggestions about necessary changes to infrastructure and the need for issues to be managed at a national level.

Please don't employ (and pay) too many people who work for the NHS to deal with what is a national/government issue. The NHS needs all the funding it can get to deal with improving its services for patients.

Infrastructure to support e.g. electric vehicles.