West Yorkshire & Harrogate

Health and Care Partnership

Engagement and consultation mapping

May 2020

Engagement and consultation mapping report - 2020

Contents

Section 3: Appendices

Section 1: Introduction to the report

1. Purpose of the report

The report captures intelligence collected from engagement and consultation activities carried out across West Yorkshire and Harrogate during the period April 2019 to April 2020. It also includes reference to any issues raised by protected groups.

The report will support commissioners to:

- Provide information on work which has already taken place or is underway to avoid duplication
- Highlight any gaps in activity across West Yorkshire and Harrogate
- Understand some of the emerging views gathered from local people across West Yorkshire and Harrogate
- Ensure that any future plans have a baseline of engagement intelligence to support the work

The intelligence collected will ensure we meet our legal requirements, outlined later in this document, and guarantee that we:

- Consider the views of patients and the public as part of service redesign
- Ensure the feedback is considered in the development of any future options to change the way a current service is provided or delivered
- Highlight patient and public priorities and ensure that these priorities are in line with current thinking and that commissioners can consider all public views

2. Background

West Yorkshire and Harrogate Health and Care Partnership (HCP) is not a new organisation, but a new way of working to meet the diverse needs of our citizens and communities. NHS services have come together with local authorities, voluntary and community groups to agree how we can improve people's health and improve the quality of their health and care services. Our approach to collaboration begins in each of our six local places (Bradford District and Craven, Calderdale, Harrogate, Kirklees, Leeds and Wakefield). Within each local authority place are local neighbourhoods, in which GP practices work together with community and social care services to offer integrated health and care services for populations of 30,000-50,000 people. These integrated neighbourhood services focus on preventing ill health, supporting people to stay well, and providing them with high quality care and treatment when they need it.

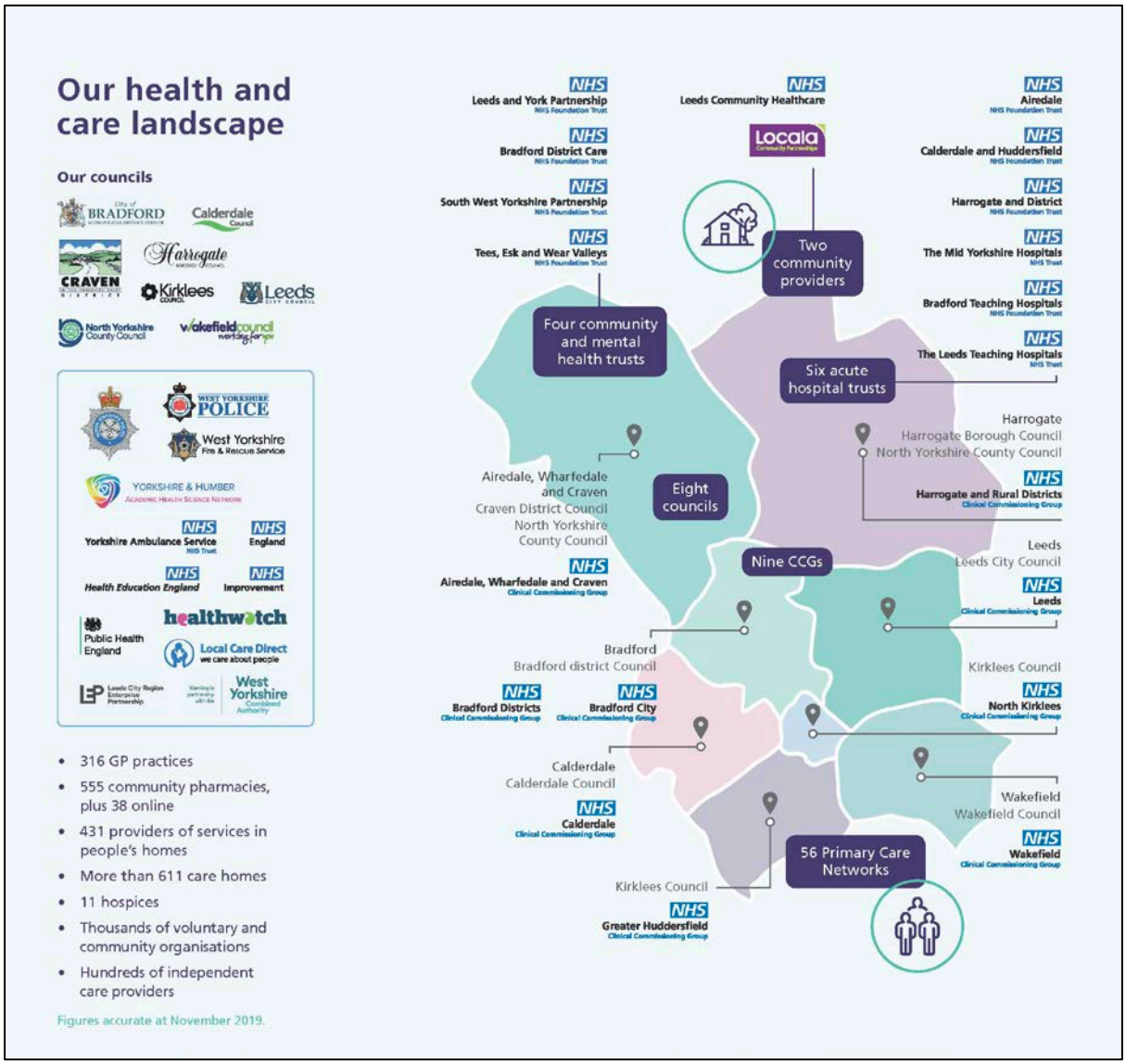
Neighbourhood services sit within each of our six local places (Bradford District and Craven, Calderdale, Harrogate, Kirklees, Leeds, and Wakefield). The focus for these partnerships is moving increasingly away from simply treating ill health to preventing it, and to tackling the wider determinants of health, such as housing, employment, social inclusion, and the environment. These place-based partnerships, overseen by Health and Wellbeing Boards, are key to achieving the ambitious improvements we want to see. However, we have recognised that there are also clear benefits in working together across a wider footprint and that local plans need to be complemented with a common vision and shared plan for West Yorkshire and Harrogate as a whole. We apply three tests to determine when to work at this level:

- To achieve a critical mass beyond local population level to achieve the best outcomes;
- To share best practice and reduce variation; and

- To achieve better outcomes for people overall by tackling 'wicked issues' (i.e., complex, intractable problems).

In February 2018 we published Our Next Steps to Better Health and Care for Everyone. In November 2019, we also published our Five Year Plan.

Below is a map of all the organisations involved in the West Yorkshire and Harrogate Health and Care Partnership.



The West Yorkshire and Harrogate HCP focuses on the delivery of its areas of priority. These areas are:

- Cancer
- Hospitals working together
- Maternity

- Mental health
- Planned care and reducing variation
- Preventing ill health
- Primary and community services
- Stroke
- Urgent and emergency care
- Capital and estates
- Digital technology
- Innovation and improvement
- Personalised care
- Learning disabilities
- Work with the community and voluntary sector
- Supporting carers
- Children, young people and families
- Housing and health
- Improving population health
- Workforce

Whenever each of these areas has featured in engagement work over the target period, it has been included in this report.

3. Process

The documents in this report were sourced via requests to the West Yorkshire and Harrogate Health and Care Partnership work stream leads, engagement leads across CCGs, Healthwatch and providers, and a review of documents held on websites of all key organisations.

Each document was reviewed, and the key themes and details were written into an evidence summary. Any specific themes raised by protected groups are also included within this document.

4. Our responsibilities, including legal requirements

Engaging people is not just about fulfilling a statutory duty or ticking boxes, it is about understanding and valuing the benefits of listening to patients and the public in the commissioning process.

By involving local people, we want to give them a say in how services are planned, commissioned, delivered, and reviewed. Individuals and groups play different roles and there needs to be engagement opportunities for both.

A West Yorkshire and Harrogate HCP Communications and Engagement Plan underpins the principles by which the engagement and consultation will operate and highlights our commitment to good practice. Engaging people who use health and social care services, and other stakeholders in service planning, is vital to ensure services meet the needs of local communities. It is also a legal requirement that patients and the public are not only consulted about any proposed changes to services but have been actively involved in developing the proposals.

5. Legal requirements

There are a number of requirements that must be met when discussions are being made about the development of services, particularly if any of these will impact on the way these services can be accessed by patients. Such requirements include the Health and Social Care Act 2012 and the NHS Constitution.

The Health and Social Care Act 2012 sets out the Government's long-term plans for the future of the NHS. It is built on the key principles of the NHS - a comprehensive service, available to all, free at the point of use and based on need, not ability to pay. It sets out how the NHS will:

- Put patients at the heart of everything it does: 'no decision about me, without me'
- Focus on improving things that really matter to patients
- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services

It makes provision for CCGs to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners. It also places a specific duty on CCGs to ensure that health services are provided in a way which promotes the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- in their planning of commissioning arrangements
- in the development of proposals for changes in commissioning arrangements, where the implementation of the proposals would have an impact on how services are delivered or the range of health services available to individuals
- in decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

The Act also updates Section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The duties to involve and consult were reinforced by the NHS Constitution which stated: 'You have the right to be involved directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services'.

The Gunning Principles set out the legal context for the consultation process. Public bodies need to ensure that they are working within this framework and can withstand any scrutiny on each of the principles set out below:

- Consultation should occur when proposals are at a formative stage
- Consultations should give sufficient reasons for any proposal to permit intelligent consideration
- Consultations should allow adequate time for consideration and response
- Consultation responses must be conscientiously taken into account - there must be clear evidence that the decision maker has considered the consultation responses, or a summary of them, before taking its decision

The Equality Act 2010 unifies and extends previous equality legislation. Nine characteristics are protected by the Act: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation.

Section 149 of the Equality Act 2010 states that all public authorities must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance 'Equality of Opportunity', and c) foster good relations.

To help support organisations to meet these duties a set of principles have been detailed in case law. These are called the Brown Principles:

- The organisation must be aware of their duty
- Due regard is fulfilled before and at the time any change is considered as well as at the time a decision is taken. Due regard involves a conscious approach and state of mind
- The duty cannot be satisfied by justifying a decision after it has been taken
- The duty must be exercised in substance, with rigour and with an open mind in such a way that it influences the final decision.
- The duty is a non-delegable one.
- The duty is a continuing one.

An Equality Impact Assessment (EQIA) will need to be undertaken on any proposals for changes to services that are developed through the programme, in order to understand any potential impact on protected groups and ensure equality of opportunity. Engagement must span all protected groups and other groups, and care should be taken to ensure that seldom-heard interests are engaged with and supported to participate, where necessary.

Secretary of State's key tests

Any service change proposals are expected to comply with the Department of Health's four tests for service change. These are:

- Strong public and patient engagement;
- Consistency with current and prospective need for patient choice;
- A clear clinical evidence base; and
- Support from proposals from clinical commissioners

For significant service changes, NHS England operates an assurance process whereby they provide support and guidance to commissioners so that they can demonstrate compliance with the four tests and other best practice checks. The assurance process concludes with an assurance checkpoint at which time NHS England provides a recommendation regarding whether the tests have been met.

6. West Yorkshire and Harrogate engagement and consultation activity at a glance

In order to deliver the priority areas in West Yorkshire and Harrogate it is essential that partners work together to understand the views of local populations. A number of organisations across West Yorkshire and Harrogate have already started to host conversations about the priority areas at a local level. This information needs to be considered and used so we are not over-engaging our local populations. Using the mapping exercise included in this section, it is clear to see that there is already a wealth of information and intelligence that can be used to support any future planning decisions. Where there are gaps in this information, we can progress to have further conversations. The information in this document can also be cross-referenced with the priorities in the Better

health and wellbeing for everyone: Our five year plan to support identification of any gaps. This means that any future service provision uses what we already have, prevents duplication of existing conversations and ultimately has the public at the centre of everything we do.

	Airedale, Wharfedale Craven	Bradford City	Bradford District	Calderdale	Greater Huddersfield	Harrogate and Rural District	Leeds	North Kirklees	Wakefield	Key areas covered
Cancer	E	E	E	E	E	E	E	E	E	Initial and ongoing support; communications; cancer screening (bowel and lung); race; religion; sex.
Capital and estates				E						NHS buildings
Children, young people and families				E			E	E	E	GP services; ASD and learning disabilities; cancer screening; young carers.
Community and voluntary sector		E		E				E	E	Mental health; partnership working with the VCS; age
Digital technology	E	E	E	E	E	E	E	E	E	Uptake; barriers to accessing services; being supported; carers; disability (hearing and sight loss, mental health, dementia, autism and learning disability, physical disability); age
Hospitals working together										
Housing and Health							E			Refugee accommodation.
Improving population health	E	E	E	E	E	E	E	E	E	Mental health provision for people with learning disabilities; geographical boundaries and mental health provision; protected characteristics.
Innovation and	C	C	C	E	C	C	E	C	C	Telephone and video appointments; urgent treatment centres; specialised

improvement				C						vascular services.
Maternity							E		E	Birthing choices; seeking and receiving mental health support; communications; planning future maternity services; children born with disabilities
Mental health, learning disabilities and autism spectrum disorders	E	E	E	E	E	E	E	E	E	Seeking and receiving mental support for learning disabilities and autism; mental health provision; ASD and communication; support for parents; learning disability, ASD and digital technology; accessing care and support for mental health; mental health and prevention; staff training and awareness around mental health; mental health and communications; mental health crisis services; mental health and digital technology; refugees; disability (sensory impairment); age; race; sex.
Personalisation	E	E	E	E	E	E	E	E	E	Definitions of personalised care; mental health services; sensory impairment and the accessible information standard; language needs; race; maternity.
Planned care and reducing variation				E			E			Visual impairment and communications; telephone and video appointments.
Preventing ill health	E	E	E	E	E	E	E	E	E	Role of health services; self-care; statins; refugees; age
Primary and community care	E	E	E	E C	E C	E	E	E	E	General experiences of GP services; GP services and mental health; GP services and refugees; urgent treatment; coordinating hospital discharges with GPs; digitalisation; care homes; home care; hearing impairment; visual impairment; age.
Stroke		C		E						Awareness raising; after-care; digitalisation; communications.
Supporting carers	E	E	E	E	E	E	E	E	E	Recognition for carers; unpaid carers; decision-making; data privacy and digitalisation; mental health support.
Urgent and emergency care	E	E	E	E	E	E	E	E	E	Provision and preferences; mental ill health; communications in Accident and Emergency; quality of care in Accident and Emergency; innovation and urgent treatment centres; visual impairment; race; age.
Workforce							E		E	Maternity staff training and staffing levels; cancer support.

7. Referencing and abbreviations

For the sake of brevity, the following abbreviations are used in references:

Abbreviation	Organisation
HW	West Yorkshire and Harrogate Healthwatch organisations (joint working)
HWB	Healthwatch Bradford
HWC	Healthwatch Calderdale
HWK	Healthwatch Kirklees
HWL	Healthwatch Leeds
HWNY	Healthwatch North Yorkshire
HWW	Healthwatch Wakefield
BDCT	Bradford District Care NHS Foundation Trust
CCCG	NHS Calderdale Clinical Commissioning Group
GHCCG	NHS Greater Huddersfield Clinical Commissioning Group
LCCG	NHS Leeds Clinical Commissioning Group
NKCCG	NHS North Kirklees Clinical Commissioning Group
WCCG	NHS Wakefield Clinical Commissioning Group
WYHHCP	West Yorkshire and Harrogate Health and Care Partnership

8. Why haven't all engagement projects been included in the findings section of this report?

On page 33-36, we have listed all the engagement projects we have been told about from across the West Yorkshire and Harrogate HCP. We have not been able to detail findings for all of them for a variety of reasons:

- Not all projects have produced a publicly available report
- Not all reports were ready in time for inclusion in this publication
- Some findings cannot be shared publicly to protect patient confidentiality
- A small number of projects cover issues not included in the West Yorkshire and Harrogate Health and Care Partnership's 16 priority themes.

Section 2: Findings

Below is a summary of key findings from the consultation and engagement mapping exercise, grouped thematically using the West Yorkshire and Harrogate HCP's priorities.

2.1 Cancer

Initial and on-going support

- The vast majority of cancer patients surveyed said the initial support they received met their needs and that all stages in their care journey were fast or very fast. (HW, *Long Term Plan*, p. 73 and p. 77) However, when cancer services were perceived as slow, this could cause considerable distress. (p. 78)
- Just over half of people with cancer were offered ongoing support. (p. 80) This support was generally perceived as being effective (p. 82). Ongoing person-to-person support was particularly valued. (p. 83)
- Professionals reported a lack of clarity about support options available to patients, and that support could sometimes "drop off" once the initial diagnostic process was over. (Leeds Cancer Programme, *FIT Test Engagement Summary*, p. 4) Staff also believed that it was important that cancer patients and their carers could access psychological and emotional support. (p. 5)
- The vast majority of health service users and staff felt there was a need for a community cancer support service. One in two people said they would prefer to access support at their GP practice, with a smaller number being interested in home visits. The biggest reported barriers to accessing community cancer support (for the general population) were the time the service was available, work commitments, transport issues and health issues. (Leeds Cancer Programme, *Community Cancer Support End of Engagement Summary*, p. 2)

Communications

- Cancer patients were more likely report that communications with them were consistent compared to those with other long-term health conditions. (HW, *Long Term Plan*, p. 87) However, some suggested communications between primary and secondary care could be improved. (p. 66)
- A significant number of people said that they would prefer that materials posted to them about FIT bowel cancer screening not use the word "cancer", as this would cause fear and panic. (Leeds Cancer Programme, *FIT Test Engagement Summary*, p. 4-6)

Cancer screening

- The FIT test is a test that GPs can offer to patients within a specific age bracket who present with certain symptoms of bowel cancer. The main barrier that participants said could prevent them from taking the test was the "embarrassment" factor as well as a "lack of courage" and "awareness". Several cited having to physically perform the test as a barrier. (Leeds Cancer Programme, *FIT Test Engagement Summary*, p. 5)
- For homeless people, one of the main barriers to screening was the cost of transport, which made accessing GPs difficult. (p. 5)
- The main method that participants suggested would help to promote FIT testing were home visits to patients, as well as visits to existing community groups, "person-friendly" venues or clinics to raise awareness. (p. 5)
- Nearly three-quarters of people in Wakefield who attended lung screening said that this was because of the original letter that they received. Of those who declined to attend, a fifth said the reason for this was because they had never smoked. (HWW, *Checking Lung Health: Wakefield District Citizens' Thoughts and Experiences of the Lung Health Check Programme*, pp. 7-8)

- The vast majority of people who attended a lung check found it easy and said they would recommend friends and family do the same. Almost all would attend a check again. (p. 8)
- 85% of people who had a lung check agreed with the statement, "I have been given information about symptoms to look out for in the future". (p. 8)
- People reported an overwhelmingly positive experience of having a CT scan as part of lung health screening. (p. 9-11)

Cancer and protected characteristics

- Among certain cultural groups, cancer is considered a "death sentence" and the word "cancer" itself is sometimes so taboo that it is avoided altogether. Some faith groups might consider cancer a "punishment for past sins", which provokes fear among families about being ostracised from the community. There can also be a lack of understanding of signs and symptoms. Some cultural groups say that it would be helpful to meet people from their own faith/culture who had had survived the disease to show people that cancer can be treated. (Leeds Cancer Programme, *FIT Test Engagement Summary*, p. 2-3)
- A lack of English skills and a preference for non-medical, faith-based treatments can be barriers to some community groups seeking cancer treatment. (p. 3)
- Men from some ethnic backgrounds would not be willing ask for help and information about cancer because of shame and embarrassment, but women are viewed as key players in disseminating important messages to the men in their life. (p. 3)
- Some female respondents from the South Asian community suggested that being able to attend a clinic to complete a FIT bowel cancer test rather than completing it at home would encourage greater uptake. (p. 3)

2.2 Capital and estates

- People want all NHS buildings to be used effectively and said that buildings should be shared by different agencies to help keep services in a local setting. (CCCG, *Community Services Engagement and consultation mapping*, p. 7)

2.3 Children, young people and families

For information about services for children and young people with autism spectrum disorder, please turn to page 18.

For information about the experiences of children aged 10-11 while visiting the GP, please turn to page 28.

For information about the importance of families regarding the take-up of cancer screening, please turn to page 12.

For information about young carers, please turn to page 29.

2.4 Community and voluntary sector

- People who had sought mental health support from the third sector in Leeds generally reported a positive experience. (HWL, *Mental Health Crisis in Leeds*, p. 1)
- Voluntary services working in mental health and other areas of health and wellbeing are widely considered valuable, particularly because they offer support that is "closer to home". (HWK, *Community Services Engagement and consultation mapping*, p. 8) (HWK and HWC, *The*

experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale, p. 18-19)

- Older people living in Leeds said they found Age UK a helpful place to go for information and support. (Age Friendly Leeds, *Healthy Ageing and Frailty in Leeds What matters to you? Engagement with older people*, p. 12)
- The voluntary and community sector in Bradford would be interested in collaborating with health systems and finding local solutions, so long as funding is genuine, appropriate and distributed appropriately. (WYHHCP, *Long Term Plan, Voluntary and Community Sector Engagement Showcase Event*, p. 8).

2.5 Digital technology

Uptake

- Around three quarters of people surveyed in the region said they would like to be able to access their medical information (including results) and book appointments digitally. Around half would be willing to have online video-call appointments with health professionals. (HW, *NHS Long Term Plan*, p. 31) (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 24)
- More people said they would prefer to access digital services using a mobile phone than a computer. (CCCG, *Community Services Engagement and Consultation Mapping*, p. 12) Some people reported being more distrustful of websites when they access them on the computer, although PCs and laptops were considered more practical for information-gathering tasks. (Greater Huddersfield and NKCCG, *Report of findings from all the engagement which has taken place on: 'NHS Long Term Plan and Kirklees Operational Plan'*, p. 9)
- Most people who were already using digital services to access healthcare reported a positive experience. The services were mostly used for booking appointments and organising repeat prescriptions. Repeat prescription services appeared to be particularly effective, whereas appointment booking tools seemed comparatively less helpful. (HW, *NHS Long Term Plan*, p. 41) (Greater Huddersfield and NKCCG, *Report of findings from all the engagement which has taken place on: 'NHS Long Term Plan and Kirklees Operational Plan'*, p. 9)
- Reasons cited for not taking up digital service offers include:
  - Not enough services or information to access, especially regarding appointment booking
  - Services not being user-friendly
  - IT systems being unreliable and prone to crashing (HW, *NHS Long Term Plan*, p. 42-44)
- The vast majority of potential service users considered it essential that they could trust their data was being managed safely. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 24)

Barriers to accessing digital services

- Not having access to technology has been the most frequently cited barrier to using digital services. A preference for personal contact was also cited, as well as fears around data safety. (HW, *NHS Long Term Plan*, p. 34-36) (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 24-26) (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments*, p. 6) (Greater Huddersfield and NKCCG, *Report of findings from all the engagement which has taken place on: 'NHS Long Term Plan and Kirklees Operational Plan'*, p. 10)
- Some areas of the region still have limited internet access and the cost of data was considered prohibitive by many. (CCCG, *Community Services Engagement and Consultation Mapping*, p. 12-13)

- Some people were worried that digitalising healthcare services would increase health inequalities because particular groups would find them harder to access than others. These groups included:
  - Older people
  - People with low or no income
  - The homeless
  - People with limited reading skills
  - People who find computer use daunting due to mental health conditions or learning disabilities or difficulties
  - People with sensory impairments
  - People with limited movement in their hands (due to arthritis, for example) (HW, *NHS Long Term Plan*, p. 36-38)
- Limited English skills presented a significant barrier to some people. (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments*, p. 8)

Being supported to use digital services

- Around a quarter of people stated that they would need help to access healthcare services digitally. (CCCG, *Community Services Engagement and Consultation Mapping*, p. 12) (HW, *NHS Long Term Plan*, p. 31)
- A significant minority of people stated that they did not feel confident using technology and that this would put them off trying to access digital services. (HW, *NHS Long Term Plan*, p. 32)

Digitalisation and protected characteristics

- People with hearing impairments reported being notably reluctant to use digital technology such as audio/video appointments. (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments*, p. 5). They stated that the following barriers would prevent them from accessing digital healthcare solutions:
  - Apps which require users to speak are not suitable for all hearing-impaired people
  - Users of British Sign Language are not always confident in their English skills. Unlike English, BSL is a “3D language”.
  - NHS Apps do not necessarily enable users to book interpreters
  - Speech-to-text features for non-signing people are imperfect. (Idem, p. 9) (LCCG, *Improving British Sign Language Interpreting Services in the NHS in Leeds*, p. 7-8)
- Generally, the older people get, the less likely they are to want to access digital services and the more likely they are to require assistance to do so. (HW, *NHS Long Term Plan*, p. 38)
- People with sight loss are likely to be reluctant to access digital services, particularly if they are video-based. (p. 39) (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments*, p. 10) (Greater Huddersfield and NKCCG, *Report of findings from all the engagement which has taken place on: ‘NHS Long Term Plan and Kirklees Operational Plan’*, p. 10).
- When it comes to people living with mental health conditions accessing digital services, the picture is complex. Some prefer to use online services over face-to-face services, while others avoid using online services altogether. Some worry that digital services will increase feelings of isolation, whereas others would be pleased to be able to avoid the stress and anxiety that face-to-face contact can bring. There is some evidence that telephone appointments would be preferred over video calls among this group. (HW, *NHS Long Term Plan*, p. 45) (HWC, *Outpatient*

clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments, p. 14)

- People with dementia and memory difficulties would face significant barriers to getting online, with many of their carers saying using digital services could cause upset and confusion. (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointments*, p. 11)
- There are also suggestions that people who have suffered stroke may find digital services confusing and frustrating to use. (p. 12)
- Most people with physical disabilities would be willing to take telephone and video call appointments, but a small number would be unable to do so because of their impairments. (p. 12)
- People with learning disabilities and their carers were particularly likely to cite concerns about the cost of technology, with younger people being far less likely than other, non-disabled people in their age group to have a mobile phone. (p. 13 and p. 15)
- Some people with a disability (of any kind) say that the use of digital services would increase their reliance on carers. (p. 15)

2.6 Hospitals working together

We could find no engagement or consultation work relating to hospitals working together between April 2019 and April 2020.

2.7 Housing and health

For information about how Syrian refugees' health is affected by their accommodation, please turn to page 25.

2.8 Improving population health

For information about mental health provision for people with learning difficulties and autism, please turn to page 18.

For information about how geographical boundaries can make affect people's experience of mental health care, please turn to page. 18.

Each section in this report includes references to protected characteristics (whenever such data has been gathered in the region). Please refer to these for further information about how health inequalities and protected groups.

2.9 Innovation and improvement

For information about engagement done in connection with Calderdale and Huddersfield NHS Foundation Trust's plan to introduce telephone and video appointments to some of their outpatient clinics, please go to page 14.

For information about engagement done in connection with the NHS in Leeds plans to provide five urgent treatment centres, please go to page 29.

2.10 Maternity

Birthing choices

- Nearly three-quarters of expectant mothers were given a choice of where to give birth. Of those who were not offered a choice, this was mainly because they needed consultant-led care or were referred to specialist care as a precautionary measure. Most felt there had been enough information to help them (or their family member) make the choice. (WCCG and Mid Yorkshire Hospitals NHS Trust, *Maternity Services in Wakefield District: Independent analysis of engagement*, p. 13-14)
- Accessibility was one of the key considerations when people were choosing where births should take place, with "closer to home" and "easier to travel to" being the most frequently mentioned reasons for choosing a place of birth. (p. 16)
- Most women gave birth in the place that they had planned to. (p. 17)
- The presence of consultants and doctors as opposed to midwife-led care can impact on women's choices around where to give birth. (p. 19)

Seeking and receiving mental health support

- More parents reported having a difficult experience of seeking perinatal mental health support compared to those reporting an easy experience. (HWL, *Maternity Mental Health Services in Leeds*, p. 3) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 11 and p. 27)
- Women who had a difficult experience immediately before, during or immediately after their pregnancy (such as miscarriage, fertility treatment or a traumatic birth) reported not being systematically offered support. (HWL, *Maternity and Mental Health Focus Groups: Understanding People's Experiences of Accessing Mental Health Support Before, During and After Pregnancy*, p. 3-4)
- Parents most commonly received perinatal mental health support from their GP. (p. 8) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 12).
- While relatively few parents reported getting mental health support from midwives, those who did were the most likely to be satisfied with their care. (HWL, *Maternity Mental Health Services in Leeds*, p. 4)
- Some women found it difficult to recognise mental ill health in themselves and to start conversations with health professionals about their mental well-being. They reported feeling ill-informed about the difference between "baby blues" and mental illness. (HWL, *Maternity and Mental Health Focus Groups: Understanding People's Experiences of Accessing Mental Health Support Before, During and After Pregnancy*, p. 3) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 28)
- Proactive, open-ended and frank conversations about the subject were felt to be more effective than "tick-box" style questions. (HWL, *Maternity Mental Health Services in Leeds*, p. 4)
- Peer-support groups provided useful support, but information about them was not given out consistently. (HWL, *Maternity and Mental Health Focus Groups: Understanding People's Experiences of Accessing Mental Health Support Before, During and After Pregnancy*, p. 3 and p. 5) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 29)
- Some parents reported not receiving help despite it being offered it because services were not appropriate to individual needs or simply did not materialise. People said that professionals did not frame conversations in ways that encouraged parents to talk openly about their mental health; and that there was a general lack of awareness of and stigma around mental health issues. (HWL, *Maternity Mental Health Services in Leeds*, p. 3)

- Parents said they were looking for perinatal mental health care that is received early, consistent, and is available for as long as they need it. (p. 4)
- Parents reported it being unlikely they had a care plan that considered both their maternity and mental health needs. People without a care plan were more likely to report having a poor or very poor experience of receiving mental health support, and were less likely to feel involved in their care. Almost half of parents with a mental health diagnosis had not had a formal review. (p. 4) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 14).

Communications

- Women reported that relationships with health professionals were sometimes negatively affected when they felt their concerns about their children's health were being dismissed. (HWL, *Maternity and Mental Health Focus Groups: Understanding People's Experiences of Accessing Mental Health Support Before, During and After Pregnancy*, p. 3)
- Women commonly felt that the conversations they had with their health visitors about their well-being were "tick-box" exercises, rather than real prompts to reflect on and disclose their feelings. People felt that it was very rare for conversations with health visitors to act as a starting point for accessing mental health support. (p. 4) (HWW, *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*, p. 26)

Planning future maternity services

- Three areas have been identified as priorities when planning future maternity services:
  - making sure there is sufficient high-quality staffing in hospitals and in the community,
  - making sure all women have access to safe and high-quality care close to their home,
  - making sure women can give birth at a place of their choice.

  (WCCG and Mid Yorkshire Hospitals NHS Trust, *Maternity Services in Wakefield District: Independent analysis of engagement*, p. 17)

- Staff based in the community were less likely to say their job allowed them to maintain their level of skill than staff based in hospitals. (p. 26)
- More staff and greater stability around staffing cover were cited as the most significant ways of improving staff members' experience of their role. (p. 29) Professionals also felt that staffing levels should be a key consideration during service planning. (p. 35 and p. 39)

Children born with disabilities

- People reported little specialist support being offered to parents of children born with learning disabilities. People also said that signposting to specialist third-sector organisations was not consistent. (HWL, *Maternity and Mental Health Focus Groups: Understanding People's Experiences of Accessing Mental Health Support Before, During and After Pregnancy*, p. 5)
- Parents cited that the way health professionals talked to them about their child's additional needs could affect their well-being. It was commonly felt that health professionals focused on the problems associated with their child's health conditions, rather than viewing their new baby as a positive addition to parents' lives. Health professionals rarely asked parents about how they were coping personally. (p. 5-6)

2.11 Mental health, learning disabilities and autistic spectrum disorder (ASD)

Seeking and receiving support

- Most people surveyed said the initial support they received when they approached health care services about their autism or learning disability was not sufficient. (HW, *NHS Long Term Plan*, p. 73) (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 11)
- People reported that waits for initial support and assessments were often long (with most people waiting one or two years), which sometimes provoked distress. (HW, *NHS Long Term Plan*, p. 74 and p. 78) (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 15) (HWNY, *NHS Long Term Plan: What would North Yorkshire do?*, p. 35) (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 9)
- There was perceived to be a lack of knowledge among GPs about autism. (HW, *NHS Long Term Plan*, p. 74)
- Accessing on-going support after diagnosis of ASD was generally perceived to be difficult, and when it was accessed it did not consistently meet expectations. (p. 81 and p. 83) (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 16)
- Most young people were referred to autism services by their school. (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 9)
- Nearly half the families of young people surveyed contacted more than one organisation to get a referral to autism services. (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 10)
- People who reported a good experience of getting a referral for autism services cited speed as a key factor. (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 11)
- Around half of parents of children with autism received their child's diagnosis at the assessment stage (47%). The most common way in which parents found out about their child's diagnosis was face-to-face (78%). (HWW, *Children and Young People's Autism Spectrum Disorder Survey*, p. 15)
- Just over half of parents whose child had been diagnosed with autism felt they had a good understanding of their child's condition. (HWW, Children and Young People's Autism Spectrum Disorder Survey, p. 17)
- Parents highlighted that if their child is home educated would the ASD referral be rejected as no school information would be available. (WCCG, ASD Parent Feedback, p.1)
- Parents highlighted some schools and academies need more SEND support from the Local Authority and SEND, ASD EWB training. (WCCG, ASD Parent Feedback, p.1)

Mental health provision

- People with learning disabilities reported that specialist provision was not always in place for them when they were seeking mental health care. (HWL, *Mental Health Crisis in Leeds*, p. 20) (HW, *NHS Long Term Plan*, p. 4) (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 5) (HWK and HWC, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 15)
- Parents reported that they felt their child had to be in crisis before services accepted that they needed support. (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 6)

Communication

- Communications during and after diagnosis of ASD, ADHD or ADD were frequently felt to be inconsistent or lacking and not always tailored to people's individual needs and circumstances. (HW, *NHS Long Term Plan*, pp. 88-90) (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 7)
- Some parents of people with autism and learning disabilities felt that they were not included in communications when this would have been helpful. (HWNY, *What's Important to you?*, p. 10)
- One in two people were not informed how long their child could expect to wait to get care and support for their learning disability. (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 4)

Support for parents

- Little specialist support appears to be available for new parents of children born with learning disabilities. For more information, please see section on Maternity on page 12.
- Delays in their child receiving support and assessments can have significant negative effects on parents' employment, finances, health and relationships. (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD, or ADD*, p. 9)

Learning disabilities and ASD: Digital

- People with learning disabilities were somewhat more likely than not to be willing to have medical appointments over the phone or by video call. For some people with learning disabilities and autism, digital appointments would be easier particularly if they had issues around travelling and mobility. However, concerns were raised about the support some would need to get online and the related costs. (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointment*, p. 13-14)

Mental health: accessing care and support

- Most people felt the initial support they were given for their mental health needs was insufficient. The most common reason for this was that waiting times were distressingly long. (p. 73 and p. 78)
- About half of people were offered ongoing support for their mental health condition, but this support was generally considered hard to access and ineffective. (p. 80-83)
- Differences between local authorities (such as Leeds and Harrogate) can make people who live in boundary areas feel that they are not always getting a "full package of care". Services need to be better joined up. (LCCG, *Developing community mental health services for Harrogate and Rural Districts, Wetherby and its surrounding areas (Wetherby Area Report)*, p. 23)
- In North Yorkshire, people felt that provision was patchy, with residents living in different areas getting different support. (HWNY, *What's Important to You*, p. 2)
- Different services (i.e.: services looking after physical health and those looking after mental health) do not always join up. (p. 3) (HWNY, *Access to Mental Health Services A Conversation with Service Users and Carers February 2019*, p. 3-4)
- There is a preference for locally accessible services. Public transport can be a barrier when it is limited and costly. (LCCG, *Developing community mental health services for Harrogate and Rural Districts, Wetherby and its surrounding areas (Wetherby Area Report)*, p. 23)
- Faster access was cited as the most important way of improving mental health services. More than half of people surveyed also wanted a mental health emergency support service that was available 24 hours a day, seven days a week. (HW, *NHS Long Term Plan*, p. 53-54)

Mental health: prevention

- The third most popular way of looking after one's own health in North Yorkshire was to join social groups and other activities designed to boost mental health. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 12)

Mental health: staff training and awareness

- Mental health service staff are vital for recovery. People would like to see investment in staff so they are supported enough to carry out their job and there are enough workers to cover need. (LCCG, *Developing community mental health services for Harrogate and Rural Districts, Wetherby and its surrounding areas (Wetherby Area Report)*, p. 23) (HWNY, *What's Important to You?*, p. 1)
- People want staff to be friendly, approachable, understanding and empathetic. They want staff to listen well and give them plenty of time to discuss their issue. (HWL, *Mental Health Crisis in Leeds*, p. 1 and p. 12) (HWL, *NHS Long Term Plan*, p. 56) (HWK and HWC, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 12)
- People would like to see all health care staff given training in how to identify mental health issues in patients and refer them appropriately. (HW, *NHS Long Term Plan*, p. 59)
- People with hypermobility conditions expressed concerns that they have been unnecessarily diverted into mental health care pathways, rather than getting the diagnosis they require for their physical condition. Partial diagnoses of physical conditions can also lead to mental health issues such as anxiety and depression. (HWC, *Feedback on Health and Social Care Services from Adults with Hypermobility Syndromes across Yorkshire and the Humber*, p. 26-31 and p. 33)

Mental health: communication

- It is not always clear what services are available to people locally. People would like to see more promotion of services, and for staff to be better trained about what is available in the local area. (LCCG, *Developing community mental health services for Harrogate and Rural Districts, Wetherby and its surrounding areas (Wetherby Area Report)*, p. 23)
- Communications about mental health care were not generally found to be consistent. (HW, *NHS Long Term Plan*, p. 88)

Mental health: crisis services

- Almost half of people experiencing or supporting someone in crisis for the first time said they would not know where to go for support. (HWL, *Mental Health Crisis in Leeds*, p. 1)
- GP surgeries were the most contacted service; the second was the "Crisis" (or Single Point of Access) service. Crisis, Acute Liaison Psychiatry Service (ALPS) and Accident and Emergency receive more negative feedback than positive feedback. (p. 1)
- Having someone to talk to was highlighted as being the most important and helpful thing during a crisis. (p. 1)
- People perceived some mainstream services as having a lack of understanding of mental health crisis. (p. 1)
- Quicker access to support when in mental health crisis is repeatedly cited as a way of improving services. Waiting times were felt to be lengthy in various parts of the region. (Idem, p. 1) (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 31)
- Less than half of people were told about post-crisis support. (HWL, *Mental Health Crisis in Leeds*, p. 1)

- The most common reasons why people said they did not seek help in a mental health crisis were:
  - They did not know where to go
  - They were not sure they were experiencing a crisis
  - They had used a service before and not found it to be helpful or had a poor experience (Idem, p. 1)
- Promotional leaflets about mental health crisis services should avoid excessive amounts of information, so that people can find the contact details they need quickly. They should also be discreet and avoid giving an unrealistic expectation about what support services can provide (including regarding opening times). (HWC, *Feedback from workshop 30 July 2019*, p. 7)
- A good Single Point of Access service is described by people as being:
  - Responsive and accessible 24 hours a day
  - Reassuring and empathetic (HWK and HWC, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 10)
  - Flexible enough to adapt to the needs of people with autism and learning disabilities. (Idem, p. 15) (HWL, *Mental Health Crisis in Leeds*, p. 2) (HWNY, *What's Important to You?*, p. 4)

Mental health: digital technology

For information about how digitalisation affects people seeking support from mental health services, please go to the Digital Technology section on p. 10.

Mental health and protected characteristics

- People with hearing impairments have reported difficulties communicating with mental health services. It is particularly difficult to get quick access to interpreting services during an emergency. (LCCG, *Improving British Sign Language Interpreting Services in the NHS in Leeds*, p. 5-7) (HW, *NHS Long Term Plan*, p. 58)
- Past trauma affects Syrian refugees' mental health. Because finding employment can often be difficult for this group, people have said that they have "too much free time" to reflect on their experiences which can sometimes resulted in "severe" mental health difficulties. Reported barriers to accessing mental health support include the following:
  - Stigma attached to mental health issues within the Syrian community.
  - Reports of authorities within Syria using mental health services as a mechanism for monitoring citizens, which prompts fears about accessing mental health services in the UK.
  - Lack of early screening for mental health issues, meaning that mental health concerns are not attended to until they become more acute.
  - People being unsure as to whether they needed support or not. (LCCG, *Syrian Refugee Health Priorities*, p. 11)
- Young people (and boys in particular) reported that peer pressure can make it difficult for them to report mental health difficulties, as can a lack of understanding of how to assess the severity of their mental ill health. Developing trust with professionals can be a barrier, as can worries about being a "burden". Youth groups and support networks beyond school counselling are suggested as ways of mitigating these barriers. (WCCG, *Build our Futures Summit 11 May 2019, themes and feedback*, p. 1).
- Young people also suggested mental health services should be 24/7 and include mindfulness and wellbeing support. (HW, *NHS Long Term Plan*, p. 63)
- Fewer people from BAME backgrounds accessed SPA or the Crisis service compared to white British people. People from minority ethnic groups were more likely to report the police

responding during their mental health crisis than white British respondents. Communication was more likely to be cited as a barrier to accessing services by people from BAME backgrounds. (HWL, *Mental Health Crisis in Leeds*, p. 22)

- When asked what they did to stay generally healthy and well, activities designed to support mental health were frequently cited by people from BAME backgrounds. One group of elders from the black Caribbean community mentioned "playing dominoes, singing, dancing, painting and laughing" as well as reminiscing about the past and attending social groups. Social gatherings are also considered good ways of reducing loneliness and isolation by two groups of people from South Asian and Hindu backgrounds. (HW, *NHS Long Term Plan*, p. 15)
- To read more about the experiences of women seeking perinatal mental health support, please go to the section on Maternity on page 12.

2.12 Personalisation

What does personalisation mean to people?

- Over half of people surveyed described personalised care as follows:
  - It was about the individual and what matters to them.
  - The person is at the centre and a key partner in all aspects of their care.
  - It takes a holistic approach to physical and mental health, as well as other factors such as housing, family and support networks. (HW, *NHS Long Term Plan*, p. 63)
- Some people also described personalisation as relating to choice and control over care being shared between patients and professionals. (p. 64) (Greater Huddersfield and NKCCG, *Report of findings from all the engagement which has taken place on: 'NHS Long Term Plan and Kirklees Operational Plan'*, p. 11)
- More than half of people agreed that the following statements are important:
  - Choosing the right treatment is a joint decision between me and the relevant health and care professional
  - I make the decision about where I will go to receive health and care support
  - I make the decision about when I will receive health and care support
  - My opinion on what is best for me counts
  - I have time to consider my options and make the choices that are right for me. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 15-16)
- Of all these statements, the one most commonly considered important was: "Choosing the right treatment is a joint decision between me and the relevant health and care professional". (p. 15-16)

Personalisation and mental health services

- People accessing crisis services such as the Single Point of Access were sometimes concerned that advice was very generic. (HWL, *Mental Health Crisis in Leeds*, p. 8) (HWK and HWC, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 12-13)
- Carers of people who had experienced a mental health crisis sometimes experienced a lack of support, information and follow-up. They said that they were not always involved in conversations about the care. (HWL, *Mental Health Crisis in Leeds*, p. 19)

Personalisation, sensory impairment and the accessible information standard

- The majority of people with visual impairments reported that they had never been asked about their communication needs, or that their communication needs had not been met. This was

particularly the case for people from older age groups. Appointment letters were felt to be especially inaccessible. (HWL, *A snapshot of people with visual impairments' experiences of accessing health and care services in Leeds*, p. 6-7)

- A lack of access to interpreters was also a significant issue for members of the deaf community across a wide range of services. (LCCG, *Improving British Sign Language Interpreting Services in the NHS in Leeds*, p. 22-24)

Personalisation and language needs

- The vast majority of people who needed English language support did not get access to interpreting. This generally had a negative impact on their experience. (HWNY, *Policy vs Reality: Interpreting in Health and Social Care Services*, p. 13) (LCCG, *Syrian Refugee Health Priorities*, p. 10)

Personalised care and protected characteristics

- People from BAME backgrounds and young people under the age of 15 were particularly unlikely to be able to define the term "personalisation". (HW, *NHS Long Term Plan*, p. 64)
- For information about personalisation and maternity, please refer to the section entitled Maternity on p. 12.

2.13 Planned care and reducing variation

- Appointment letters were not always accessible to people with a visual impairment. (HWL, *A snapshot of people with visual impairments' experiences of accessing health and care services in Leeds*, p. 6)
- For information about engagement done in connection with Calderdale and Huddersfield NHS Foundation Trust's plan to introduce telephone and video appointments to some of their outpatient clinics, please go to page 10.

2.14 Preventing ill health

The role of health services

- Having timely access to necessary help and treatment and to professionals who listen were considered key ways in which health services could help people to live a healthy life. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 8) (HW, *NHS Long Term Plan*, p. 26)
- When asked what the NHS and its partners could do differently to help people stay healthy and well, people most commonly suggest changes to access and appointments. In particular, people wanted it to be easier to book appointments and more time to be available to them when they were talking to health professionals. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 12) (HW, *NHS Long Term Plan*, p. 16)

Self-care

- Exercise was the most common thing people did to stay healthy, followed by eating a healthy diet. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 12) (HW, *NHS Long Term Plan*, p. 14)

- Members of the public said it would be helpful to have more face-to-face contact with people who can help navigate the large amounts of information available about prevention. (CCCG, *Community Services Engagement and consultation mapping*, p. 7)

Prevention and protected characteristics

- Engagement work conducted with Syrian refugees indicated that ill health could be better prevented in the following ways:
  - Improving the quality of housing provision
  - More effective promotion of existing support services
  - More access to low-cost exercise options as well as more sex-specific provision in gyms and swimming pools
  - Cheaper fresh produce (LCCG, *Syrian Refugee Health Priorities*, p. 9-11)
- For older people living in Leeds, connecting with others was cited as a valued way of preventing ill health (although accessibility, support and cost could be a barrier to this). Small amounts of exercise were also considered useful. (Age Friendly Leeds, *Healthy Ageing and Frailty in Leeds What matters to you? Engagement with older people*, p. 7)

2.15 Primary and community care

GP services – general experiences

- People in the region felt that easier access to GP appointments would help them stay well. This would include:
  - An easier booking system
  - More appointments being available
  - Being able to see a GP quicker (HW, *NHS Long Term Plan*, p. 15) (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 9, p. 12 and p. 18) (HWNY, *What's Important to North Yorkshire?*, p. 5) (CCCG, *Community Services: Engagement and Consultation Mapping*, p. 7) (Age Friendly Leeds, *Healthy Ageing and Frailty in Leeds What matters to you? Engagement with older people*, p. 7)
- People said they would like GPs to:
  - read their medical notes before their appointment
  - introduce him or herself and invite the patient to ask for a clearer explanation if they do not understand
  - make eye contact and actively listen
  - keep their computer use to a minimum
  - give patients time to explain their assessment of their own health
  - document the appointment notes and give them a hard or digital copy, according to their preference (HW, *NHS Long Term Plan*, p. 29)
- Some people reported a lack of knowledge among GPs regarding autism and other long-term health conditions. (Idem, p. 74) (HWC, *Feedback on Health and Social Care Services from Adults with Hypermobility Syndromes across Yorkshire and the Humber*, p. 25 and 32)
- People with hypermobility syndromes largely considered that the care their GPs provided for their condition was not adequate, which in turn made them less likely to access GP care. (p. 34-35)
- In North Yorkshire, people were interested in specialist support being available in GP surgeries so that they would not be obliged to travel to distant hospitals. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?,* p. 45-46)

GP services – mental health

- People seeking support for a mental health crisis said they most commonly contacted their GP. Over a third (38%) report a positive experience, just under a third (29%) report a negative experience, and the remaining third (33%) have had a mixed experience. Those who have had a positive experience mentioned quick referrals as well as understanding, patient GPs. (HWL, *Mental Health Crisis in Leeds*, p. 7-8)
- Along with Accident and Emergency, GP surgeries are particularly likely to be described as not taking mental ill health seriously or not understanding it. (p. 13)
- Some people felt that GPs were too quick to prescribe medication for mental health conditions and should be more knowledgeable about referring people for other support. (HW, *NHS Long Term Plan*, p. 59) (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 41-42)

GP services – refugees

- Syrian refugees reported preferring to see the same GP to help them develop a trusting relationship. (LCCG, *Syrian Refugee Health Priorities*, p. 10)
- Refugees in North Yorkshire reported that it was unlikely they would receive interpreting services when they attended the GP. Those that did get interpreting services were considerably more likely to report a positive experience. Sex-appropriate interpreters were preferred, and appointments need to be longer to accommodate interpreting needs. (HWNY, *Policy vs Reality: Interpreting in Health and Social Care Services*, p. 14 and p. 17)

GP services - miscellaneous

- People seeking urgent treatment were more likely to be dissatisfied with the service they get from out-of-hours GPs than from any other service. 27% report a negative experience of getting urgent care. (HW, *NHS Long Term Plan*, p. 5)
- GPs were sometimes not informed when their most vulnerable patients had been discharged from hospital, leaving those patients without the support and follow-up they needed. (CCCG, *Community Services: Engagement and Consultation Mapping*, p. 12)
- For information about digitalising GP services, please go to p 10.

Care homes and home care

- Care home managers reported that hospitals often indicated a time when patients would be discharged, but then released the patient either too early or too late. (CCCG, *Community Services: Engagement and Consultation Mapping*, p. 12)
- Almost a quarter of people who received home care did not know all the care workers that visited them. Only a quarter say they have a key worker. (HWL, *Care at Home: Review of People's Experiences of Care Provided in their Homes*, p. 3)
- Over a quarter of people reported their home care workers routinely did not arrive on time. Half said their home care agency did not keep them informed of any changes to their care. (p. 3)
- The vast majority of recipients of home care felt that the service keeps them safe, and most were satisfied with it. Front-line staff were often praised for their caring attitude, but home care agencies were sometimes felt to be impersonal and unresponsive. (p. 12, p. 15 and p. 19)

Primary care and protected characteristics: hearing impairment

- Hearing impaired people reported difficulties getting access to interpreters for their GP appointments. Some found that interpreters were "fully booked", that they were not available

when they needed them (especially for on-the-day appointments), or that bookings were simply not made by GP surgeries when requested. They also reported having to rely on family members to interpret for them. (LCCG, *Improving British Sign Language Interpreting Services in the NHS in Leeds*, p. 11-13)

- Most under-18s reported relying on parents to interpret for them. (Leeds CCG, Improving British Sign Language Interpreting Services in the NHS in Leeds, p. 15)
- It was sometimes felt that GPs and their receptionists talked to the carer or interpreter, rather than the patient. (p. 17 and p. 20)
- Deaf people suggest that staff in GP surgeries would benefit from having greater deaf awareness. (p. 12 and p. 17)

Primary care and protected characteristics: visual impairment

- People with visual impairment will most commonly go to their GP for information about care. (HWL, *A snapshot of people with visual impairments' experiences of accessing health and care services in Leeds*, p. 11)
- Most people with visual impairments said they would like to see an improvement in how their communication needs were met and supported in GP surgeries. (p. 12)
- People with visual impairments reported it was rare to be asked by their GP if they would like to receive correspondence in a large font. (p. 7) Some visually impaired people struggled with the digital displays used in some GP surgeries or hospital waiting areas to notify them about their appointments. (p. 8)

Primary care and protected characteristics: age

- Children aged 10-11 said they sometimes felt scared when they went to the GP, but that they knew they had to be brave. Many found going to the GP boring. They would like waiting rooms to be more colourful and would like doctors to explain things to them in a way that they can understand. (HWK, *Primary School Workshop*)
- Changes to medication (e.g. changes in the colour of tablets or packaging) were not always appropriately communicated to patients, which could be confusing and dangerous for some older people. (Age Friendly Leeds, *Healthy Ageing and Frailty in Leeds What matters to you? Engagement with older people*, p. 11)

2.16 Stroke

Raising awareness

- People recommended raising awareness of the signs and symptoms of stroke with the public and health professionals. It was felt that the FAST campaign had raised awareness but that it should go further and talk about prevention and the whole care pathway. (CCCG, *Community Services Engagement and Consultation Mapping*, p. 8)
- Any awareness-raising campaign should have a co-ordinated approach across all organisations, including the voluntary and community sector. (p. 8)

After-care

- People praised the high level of care they had received in hospital following their stroke, and said they wanted to receive this standard of care once they had been discharged. (p. 8)
- People wanted rehabilitation services to be quickly accessible. (p. 8)

- Post-stroke, people said they needed to be able to access appropriate levels of emotional support and advice, and where necessary have access to psychological therapies. (p. 8-9)
- Support and activity groups were appreciated (including those run by volunteers and targeted at specific groups, such as younger people). (Idem, p. 9) (HWB, *Stroke Ambassadors: How We Make a Difference*, p. 3)

Stroke and protected characteristics

- People living with the effects of stroke faced the following barriers to accessing digital healthcare services:
  - Memory loss issues
  - Communication (listening, speaking and following a conversation in detail) (HWC, *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust*, pp. 11-12)

2.17 Supporting carers

- Carers said they would like to be recognised for the work they do and supported with regular offers of help for themselves as well as health check-ups. (HW, *NHS Long Term Plan*, p. 30) (WYHHCP, *Report of Findings, Long Term Plan, Unpaid Carers Engagement Event*, p. 9)
- Carers reported that they sometimes find it difficult to access digital healthcare services because of restrictions around data privacy. (p. 41)
- It was important to carers that they were involved in decisions about their loved one's care. (p. 60) (WYHHCP, *Report of Findings, Long Term Plan, Unpaid Carers Engagement Event*, p. 10)
- Carers did not always feel their concerns about their loved one were taken seriously by SPA services in the Calderdale region. (HWC and HWK, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 16)
- Carers of adults and children with mental health conditions frequently reported not receiving the support they needed. (HW, *NHS Long Term Plan*, p. 60) (HWC, *Feedback on Calderdale CAMHS from families of children displaying signs of ASC, ADHD or ADD*, p. 3) (HWC and HWK, *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*, p. 16)
- Emergency care planning could be improved, with stronger links between services and families and quicker response times. (WYHHCP, *Report of Findings, Long Term Plan, Unpaid Carers Engagement Event*, p. 10)
- Better support for working carers would include flexible working hours and clear communications with employers about the benefits of supporting carers. Self-employed carers would also like access to the same support available to employed carers. (WYHHCP, *Report of Findings, Long Term Plan, Unpaid Carers Engagement Event*, p. 11)
- The majority of young carers at an event in Kirklees and Calderdale would be interested in a career in health and care. (WYHHCP, *Couldn't Care Less, Young Carers Engagement Event Report*, p. 8)

2.18 Urgent and emergency care

Where people go for urgent care

- The most popular places people said they contacted for advice prior to attending Accident and Emergency were GP practices and 111. This contact was usually made up to 24 hours before attending Accident and Emergency. (CCCG, *A Week in Accident and Emergency Engagement Report*, p. 3-4)

- Just over half of people who contacted their GP practice felt that they received the support they required. There was a higher satisfaction rate amongst those who contacted 111. (p. 3-4)
- Half of the people who sought advice before attending Accident and Emergency say they were referred to Accident and Emergency by the place they had gone to for advice. (p. 3-4)
- Half of the people who attend Accident and Emergency said they did so because they were unable to get an appointment with their GP. About 70% of these people say there is nothing that could have been done to prevent them from presenting at hospital. (p. 3-4) (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 17)
- When people were referred to Accident and Emergency by another service, they did not always understand why. They also commented that their notes were not shared across services, which meant tests sometimes had to be repeated. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 17-18)
- Suggestions about how to reduce the numbers of people attending Accident and Emergency included:
  - Same-day GP appointments available early morning, evenings and weekends
  - GP practices to undertake diagnostic testing such as blood tests, x-rays and scans and to treat minor injuries
  - A minor injuries unit or a 24-hour walk-in centre. (p. 5)

Comparing services

- Other than their GP or Accident and Emergency, most people said they would call NHS 111 for urgent medical assistance. Walk-in centres or Minor Injuries Units were the second most popular choice in Leeds. (HW, *NHS Long Term Plan*, p. 46) In North Yorkshire, the pharmacy was considered the second port of call after NHS 111. (HWNY, *NHS Long Term Plan: What Would North Yorkshire Do?*, p. 29)
- There were also strong indications that people favoured going to their GP over Accident and Emergency in the case of a medical emergency. This is because GP practices were familiar, convenient environments. (LCCG, *What do people think about the proposals for urgent treatment centres in Leeds?*, p .17)
- Out of all urgent treatment options, 999 and pharmacies reported the highest levels of satisfaction in Leeds. (HW, *NHS Long Term Plan*, p. 50-52) In Leeds, 999 and Accident and Emergency are considered most effective, closely followed by GP out-of-hours services. (p. 30)

Urgent care for mental ill health

- Most people who attended Accident and Emergency for a mental health crisis reported having a negative experience. The most frequently cited reasons for this were long waiting times; the busy, clinical environment; and a sense that Accident and Emergency was more equipped to deal with physical rather than mental health issues. (HWL, *Mental Health Crisis in Leeds*, p. 9) (HWNY, *What's Important to You?*, p. 2)
- Some people suggested that there should be a space in Accident and Emergency which is less busy and chaotic for those in crisis, as the atmosphere in the emergency department may worsen symptoms. (HWL, *Mental Health Crisis in Leeds*, p. 13) (HWNY, *Access to Mental Health Services A Conversation with Service Users and Carers February 2019*, p. 4-5)

Communications in Accident and Emergency

- People had a mixed experience of communication in Accident and Emergency settings. Those who reported a positive experience felt they understood what was happening at every stage of

their care, including what would happen next. Those who reported a negative experience said that they did not get this information. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 8)

- Where staff did not communicate with patients in Accident and Emergency, patients said this could affect how they made decisions about getting transport home and other aspects of their experience. (p. 18)

Quality of care in Accident and Emergency

- In general, people were broadly positive about the care they received in Accident and Emergency, with many commenting that staff understood their needs and looked after them well. People tended to report a negative experience when they felt that they were not being listened to or taken seriously. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 14)
- Waiting times were felt to be lengthy in Accident and Emergency departments. (HWNY, *What's Important to You?*, p. 9) (HW, *NHS Long Term Plan*, p. 68)
- While the vast majority of people were pleased with the care they received in Accident and Emergency in the Calderdale area, they felt that staff were rushed, which had an impact on service. They suggested increasing staff numbers would improve this. (CCCG, *A Week in Accident and Emergency Engagement Report*, p. 4-5)
- People said they would appreciate being given an indication of how long they could expect to wait and having more comfortable seating. (p. 4-5) Food provision was widely felt to be lacking. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 19)
- People who spent a long time waiting in Accident and Emergency frequently made no comment about the length of their visit if they were pleased with other aspects of their experience, particularly communication and quality of care. Long waiting times were generally accepted to be a part of the experience. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 10 and p. 12)
- Patient comments about staff attitudes in Accident and Emergency were overwhelmingly positive. (HWW, *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*, p. 13)

Innovation in emergency services: urgent treatment centres (UTCs) in Leeds

- Most people in Leeds felt that they would have the confidence to select the right emergency service to attend. (LCCG, *What do people think about the proposals for urgent treatment centres in Leeds?*, p. 20-21)
- Most people thought that the introduction of urgent treatment centres would improve emergency care because:
  - It would give them a clearer idea of where to go
  - It would provide greater choice and capacity
  - They would serve as an alternative to GP practices
  - They would be convenient (p. 20-21)
- Reasons people give for not introducing UTCs in Leeds include:
  - It is already easy to get urgent care
  - UTCs would be inaccessible (they would largely require people to take a bus from their home to the city centre, then a second bus to the UTC)
  - They would not change anything or solve underlying issues such as understaffing
  - Adding another option would be confusing (p. 23)

- Other suggestions for ways in which urgent care could be improved often relate to transport and accessibility. People want treatment centres to be closer to where they live, to have good transport links, ample parking and taxi ranks. (. 26)

Urgent care and protected characteristics

- When asked about a proposal for Urgent Treatment Centres, people with visual impairments responded that services should be on regular bus routes; be located on the ground floor, with no stairs; and as local as possible. (HWL, *A snapshot of people with visual impairments' experiences of accessing health and care services in Leeds*, p. 23)
- People with visual impairments also suggested that Urgent Treatment Centres use bold signage and that 24-hour access and volunteer assistants be on hand. (Idem, p. 24)
- People from BAME backgrounds, aged 80+ or with physical or mobility impairments were particularly likely to report that they did not know where to go for urgent treatment except Accident and Emergency. (HW, *NHS Long Term Plan*, p. 49)

2.19 Workforce

For information about staff views on the support options for cancer patients, please turn to page 11.

For information about maternity staff based in the community and their assessment of their skill level compared to their hospital-based colleagues, please turn to page 16. For information about their views as to how their experience of their role could be improved, please turn to page 16.

Section 3: Appendices

List of documents reviewed

The list below details the engagement reports we were made aware of as part of this engagement mapping work. They are either publicly available to view on organisation websites, or organisations informed us of them individually.

CCCG (May 2019), *A week in Accident and Emergency - engagement report*

CCCG (2019), *Report of Findings on the pre-consultation engagement of APMS (Alternative Primary Medical Services) contracts in Calderdale*

CCCG (August 2019), *Community Services Engagement and consultation mapping*

CCCG (January 2020), *Report of findings on the consultation, Alternative Primary Medical Services (APMS) in Calderdale*

CCCG (August 2019), *Children and Young People's Experience of their local GP practice*

GHCCG (April - May 2019), *Report of findings from all the engagement which has taken place on: 'NHS Long Term Plan and Kirklees Operational Plan'*

GHCCG (November 2019), *The Nook Group Practice Consultation report of findings*

GHCCG (May 2019), *Report of Findings on the engagement for The Nook Group Practice*

NKCCG (March 2019), *Engagement event report March 2019*

NKCCG (July 2019), *Engagement event report July 2019*

NKCCG (October 2019), *Engagement event report October 2019*

NKCCG (February 2020), *Engagement event report February 2020*

WCCG (May 2019), *Build our Futures Summit 11 May 2019, themes and feedback*

WCCG (2019), *General practice performance and development: draft strategic objectives and project plan to March 2020*

WCCG (April 2019), *Maternity Services in Wakefield District Independent analysis of engagement carried out by NHS Wakefield Clinical Commissioning Group and Mid Yorkshire Hospitals NHS Trust*

WCCG (February 2019), *Adult Hearing Loss February 2019*

WCCG (Nov 2019), *ASD Parent Feedback (from workshops)*

BDCT (April 2019), *Consultation with parents on the breastfeeding strategy*

BDCT (Sept 2019), *Annual Members Meeting - Hear about service improvements and give your views on service developments*

BDCT (Sept 2019), *National changes to NHSE Friends and Family Test*

BDCT (April 2019), *Your Voice Matters – Involvement Strategy*

BDCT (November 2019), *Service user and Carer involvement in BDCFT Estates Strategy*

HW (April 2019), *NHS Long Term Plan*

HWB (2019), *Stroke Ambassadors: How We've Made a Difference*

HWB (May 2019), *"Recall Matters" – appropriate dental recall intervals for people with good oral health*

HWC (July 2019), *Feedback on Health and Social Care Services from Adults with Hypermobility Syndromes across Yorkshire and the Humber*

HWC (November 2019), *Feedback on Calderdale Child and Adolescent Mental Health Service (CAMHS) from families of children displaying signs of autistic spectrum condition (ASC), attention deficit hyperactivity disorder (ADHD), or attention deficit disorder (ADD)*

HWC (November 2019), *Outpatient clinics at Calderdale and Huddersfield NHS Foundation Trust Feedback from people with certain protected characteristics in relation to the use of telephone and video healthcare appointment*

HWK (August 2019), *Feedback from workshop 30 July 2019*

HWK (August 2019), *The experience of people who contact the Single Point of Access (SPA) for adult mental health services in Kirklees and Calderdale*

HWK (2019), *Primary school workshop*

HWL (March 2019), *Mental Health Crisis in Leeds*

HWL (March 2019), *Maternity and Mental Health Focus Groups*

HWL (July 2019), *Maternity Mental Health Services Leeds*

HWL (March 2019), *A snapshot of people with visual impairments' experiences of accessing health and care services in Leeds*

HWL (awaiting publication), *HIV and Dentistry*

HWL (February 2020), *Care at Home: Review of People's Experiences of Care Provided in their Homes*

HWNY (February 2019), *Access to Mental Health Services A Conversation with Service Users and Carers February 2019*

HWNY (January 2020), *Policy vs Reality: Interpreting in Health and Social Care Services, insights from refugees in North Yorkshire*

HWNY (July 2019), *Scarborough Acute Services Review Is this out of catchment?*

HWNY (2019), *What's Important to you?*

HWNY (August 2019), *NHS Long Term Plan: What would North Yorkshire do?*

HWW (2019), *Healthwatch Wakefield and Leeds Maternity and Mental Health Report 2019*

HWW (August 2019)*, Children and Young People's Autism Spectrum Disorder Survey*

HWW (January 2020), *Checking Lung Health: Wakefield District Citizens' Thoughts and Experiences of the Lung Health Check Programme*

HWW (February 2020), *What Matters to People Using Accident and Emergency: A Report for the NHS Clinical Review of Standards*

Leeds Cancer programme (February 2019)*, Community Cancer Support End of Engagement Summary*

Leeds Cancer programme (March 2019)*, Leeds Cancer Programme Engagement Summary*

Age Friendly Leeds (2020)*, Healthy Ageing and Frailty in Leeds What matters to you? Engagement with older people*

Leeds Teaching Hospitals Trust (2019), *Listening Week Outpatient Services 23rd - 27th September 2019*

West Yorkshire and Harrogate Health and Care Partnership (April 2019), *Report of Findings, Long Term Plan, Unpaid Carers Engagement Event*

West Yorkshire and Harrogate Health and Care Partnership (June 2019), *Couldn't Care Less, Young Carers Engagement Event Report*

West Yorkshire and Harrogate Health and Care Partnership (May 2019), *Long Term Plan, Voluntary and Community Sector Engagement Showcase Event*

Contact details

Tel: 01924 317659
Email: Westyorkshire.stp@nhs.net
Visit: www.wyhpartnership.co.uk

This information was published May 2020.