West Yorkshire
Health and Care Partnership

Involvement and consultation mapping

May 2023

Contents

1. Introduction to the report

1.1 Purpose of the report

The purpose of this report is to refresh the previous involvement and consultation mapping report that was published in May 2022. This report includes the key themes from the May 2022 report and any additional themes from involvement and consultation activities that have taken place since the production of the previous mapping report.

It also includes, where available, details of any issues raised by protected groups.

The report will support colleagues and partners by:

- providing information on work which has already taken place, or is underway
- highlighting any gaps in involvement and consultation activity, across West Yorkshire
- helping to understand some of the emerging views gathered from local people across the area
- ensuring that future plans have a baseline of involvement insight, to support work undertaken

The insight 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 all views have been considered when making decisions

1.2 Background

West Yorkshire Health and Care Partnership (the Partnership) is a large integrated care system (ICS) that supports 2.4 million people, living in urban and rural areas. 770,000 are children and young people. 530,000 people live in areas ranked in the most deprived 10% of England. 20% of people are from minority ethnic communities. There are an estimated 400,000 unpaid carers, as many don’t access support.

Together we employ over 100,000 staff and work alongside thousands of volunteers.

Our ICS is made up many different organisations and collaboratives across West Yorkshire, including our Partnership Board which is the Integrated Care Partnership for West Yorkshire. It also contains the NHS West Yorkshire Integrated Care Board (WY ICB) which is the statutory NHS organisation responsible for developing a plan in collaboration with NHS trusts/foundation trusts and other system partners for meeting the health needs of the population. These are all supported by organisations working together across all services.

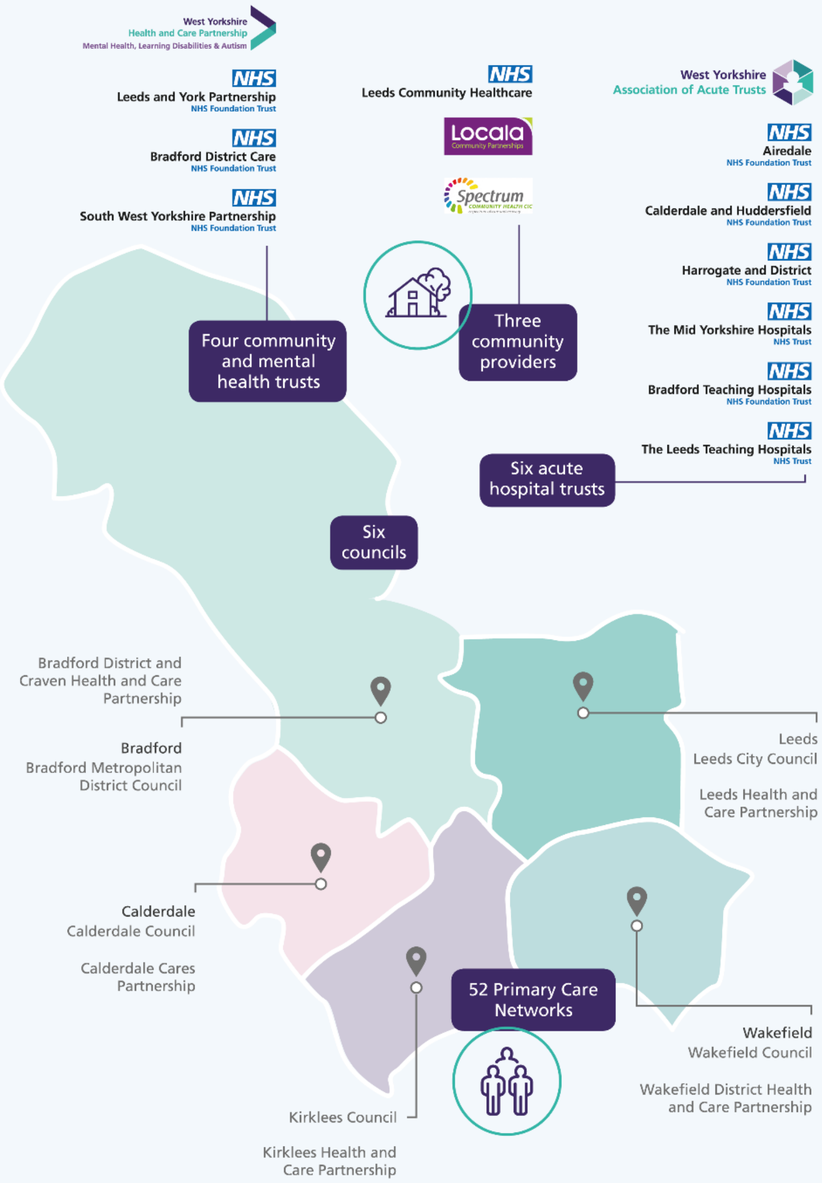
Our work begins in the neighbourhoods across West Yorkshire, keeping people, families, the health and care teams that support them within local communities at the centre of everything we do. Our five local places (Wakefield, Leeds, Calderdale, Bradford and Craven and Kirklees) support this work, coming together as partners in the place to meet the needs of local populations.

Within the Partnership we have many partners working together across the NHS, local authorities, the voluntary community social enterprise sector (VCSE), Healthwatch, hospices, and wider public sector organisations. We come together to better join up integrate health and care, to tackle health inequalities and to improve health and wellbeing for everyone.

We also come together in partnership with some of our wider partners like the West Yorkshire Mayor, the West Yorkshire Combined Authority, Local Resilience Forum and universities to maximise resources, for example buildings, skills and expertise and to work together for a common purpose of reducing health inequalities we know exist.

Our health and care landscape

Our councils



- 291 GP practices
- 547 community pharmacies, plus 38 online
- 277 dentists
- 431 providers of services in people's homes
- More than 442 care homes
- 11 hospices
- 255 optometrists
- 52 primary care networks
- Estimated 11,996 voluntary community social enterprise organisations in West Yorkshire

Figures accurate at November 2022.

We have agreed to work at a West Yorkshire level on the following priority areas of work:

[Cancer](#)

[Capital and estates](#)

[Children, young people and families](#)

[Digital technology](#)

[Hospitals working together](#)

[Improving planned care](#)

[Improving population health](#)

[Innovation and improvement](#)

[Maternity care](#)

[Mental health, learning disability and autism](#)

Our work with the voluntary, community and social enterprise sector

Preventing ill health

Primary and community care

Personalised Care

Stroke

Supporting unpaid carers

Urgent and emergency care

Workforce

Our five-year ambitions for these priorities are:

- increase early diagnosis of cancer, ensuring at least 1,000 more people have the chance of curative treatment.
- reduce health inequalities for children living in households with the lowest incomes, including halting the trend in childhood obesity
- increase the years of life that people live in good health, and reduce the gap in life expectancy by 5% in our most deprived communities by 2024
- strengthen local economic growth by reducing health inequalities and improving skills.
- reduce anti-microbial resistance infections by 10% by 2024, reducing antibiotic use by 15%
- become a global leader in responding to the climate emergency
- cost of living
- reduce stillbirths, neonatal deaths, and brain injuries by 50%, and reduce maternal morbidity and mortality, by 2025
- reduce suicide by 10% overall by 2020/21 and achieve a 75% reduction in targeted areas by 2022.
- reduce the gap in life expectancy for people with mental health, learning disabilities and autism by 10% by 2024.
- increase the years of life that people live in good health, and reduce the gap in life expectancy by 5% in our most deprived communities by 2024
- have a more diverse leadership that better reflects the broad range of talent in our area

1.3 Our responsibilities, including legal requirements

The legislation we must work to when delivering any involvement is set out below. Involving people is not just about fulfilling a statutory duty or ticking boxes for our Partnership Board or the NHS West Yorkshire Integrated Care Board, it is about understanding and valuing the benefits of listening to people and communities in the commissioning process.

There are a number of requirements that must be met when decisions are being made about the development of services, particularly if any of these will impact on the way these services can be accessed by people and communities.

Public involvement legal duties

The legal duties on public involvement require organisations to make arrangements to ensure that people are appropriately 'involved' in planning, proposals and decisions regarding NHS services.

NHS England's new statutory guidance provides the detail on these legal duties, when they are likely to apply and how they can be met. Key requirements of Integrated Care Boards (ICBs), trusts and NHS England include that they:

- Assess the need for public involvement and plan and carry out involvement activity
- Clearly document at all stages how involvement activity has informed decision-making and the rationale for decisions
- Have systems to assure themselves that they are meeting their legal duty to involve and report on how they meet it in their annual reports.

Integrated Care Partnerships (ICPs), place-based partnerships and provider collaboratives also have specific responsibilities towards participation. There are statutory requirements for ICBs and ICPs to produce strategies and plans for health and social care, each with minimum requirements for how people and communities should be involved.

A significant change introduced by the Health and Care Act 2022 is that, in respect of NHS England and ICBs, the description of people we must make arrangements to involve has been extended from 'individuals to whom the services are being or may be provided' to also include 'their carers and representatives (if any)'.

The triple aim duty

NHS England, ICBs, NHS trusts and NHS foundation trusts are subject to the new 'triple aim' duty in the Health and Care Act 2022 (sections 13NA, 14Z43, 26A and 63A respectively). This requires these bodies to have regard to ‘all likely effects’ of their decisions in relation to three areas:

- Health and wellbeing for people, including its effects in relation to inequalities.
- Quality of health services for all individuals, including the effects of inequalities in relation to the benefits that people can obtain from those services.
- The sustainable use of NHS resources.

Effective working with people and communities is essential to deliver the triple aim.

Involvement duties on commissioners and providers

To reinforce the importance and positive impact of working with people and communities, NHS England, ICBs and trusts all have legal duties to make arrangements to involve the public in their decision-making about NHS services. The main duties on NHS bodies to make arrangements to involve the public are all set out in the National Health Services Act 2006, as amended by the Health and Care Act 2022:

- Section 13Q for NHS England
- Section 14Z45 for ICBs
- Section 242(1B) for NHS trusts and NHS foundation trusts.

A requirement to involve the public is also included as a service condition in the NHS Standard Contract for providers.

Each of the organisations listed above is accountable and liable for compliance with their public involvement obligations. However, that does not mean that each organisation should carry out its public involvement activities in isolation from others within the ICS and beyond. Plans, proposals or decisions often involve more than one organisation, particularly in respect of integration and service reconfiguration, in which case it is usually desirable to carry this out in an joined up and co-ordinated way, reducing the burden on both the public and the organisations themselves.

The legal duties require arrangements to secure that people are ‘involved’. This can be achieved by consulting people, providing people with information, or in other ways. This gives organisations a considerable degree of discretion as to how people are involved, subject to the below requirements.

The Gunning Principles

Commissioners and trusts must ensure that their arrangements to involve people are fair. The courts have established guiding principles for what constitutes a fair consultation exercise, known as the Gunning principles. These four principles relate to public consultation processes and do not create a binding legal precedent for how other ways of involving the public should be carried out. However, they will still be informative when making arrangements to involve the public, whatever the form of those arrangements.

- Consultation must take place when the proposal is still at a formative stage.
- Sufficient information and reasons must be put forward for the proposal to allow for
- intelligent consideration and response.
- Adequate time must be given for consideration and response.
- The product of consultation must be conscientiously taken into account.

The Equality Act 2010

The Equality Act 2010 prohibits unlawful discrimination in the provision of services on the grounds of protected characteristics. These are: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex and sexual orientation.

As well as these prohibitions against unlawful discrimination the Equality Act 2010 requires public sector organisations to have ‘due regard’ to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct
- prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic
- and those who do not.
- And foster good relations between people who share a protected characteristic and
- those who do not.

This is known as the ‘public sector equality duty’ (section 149 of the Equality Act 2010). Working with people with characteristics protected under the Act means understanding how decisions or policies can affect them and whether they will be disproportionately affected.

An Equality Impact Assessment (EIA) will need to be undertaken on any proposals for changes to services that are developed, to understand any potential impact on protected groups and ensure equality of opportunity. Involvement and consultation 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.

Principles for communications and involvement

West Yorkshire Health and Care Partnership (the integrated care system) and partners communications and involvement colleagues co-designed the following involvement principles. Joint West Yorkshire activity should be carried out on behalf of the Partnership by following these principles.

- We will make our involvement activities accessible.
- We want to be inclusive, so we ask for help to make sure that we are. Across West Yorkshire, we will be fair to all.
- We communicate with clear, simple and meaningful messages that are open, honest, transparent and timely.
- We know that diversity is a strength, so we engage with communities to reach and target people. We work with voluntary and community groups, and local Healthwatch, to help us do this.
- We value and use your input, expertise and insight. We will tell you how your involvement has made a difference.
- We will plan and design with you and spend public money on what matters to you.
- We provide support to make involvement easier for everyone.
- We build relationships and keep in touch.
- We care. We listen. We act.

1.4 West Yorkshire involvement and consultation activity at a glance

To deliver our priorities and ambitions in West Yorkshire it is essential that partnership networks work together to understand the views of local populations.

Using the mapping exercise it is clear to see that there is already a wealth of information and intelligence that can be used to support any future commissioning decisions.

Where there are gaps in this information, we can progress to have further conversations based on what we already know. 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. In addition, work done regionally should not confuse the public who may have given their views at a local level. The communications supporting any further involvement and consultation activity needs to be managed with this mapping in mind.

The following table provides an ‘at a glance’ summary of where reports were produced for involvement and consultation activities that have taken place across West Yorkshire.

It should be noted that for all the priority areas a significant amount of work has taken place that has involved working with key stakeholders, members of the public, and staff however, this report only captures involvement or consultation activities where views have been collated and a report has been produced.

Area of priority	Bradford District and Craven	Calderdale	Kirklees	Leeds	Wakefield District	WY HCP	Key areas covered
Cancer	X	X	X	X	X	X	Initial and ongoing support; communications; cancer screening (bowel and lung); COVID-19
Capital and Estates	X	X	X	X	X	X	Hospital environment
Children, young people and families	X	X	X	X	X	X	Early support; Family hubs; online parenting courses; education; experience of health services; sexual health services; social prescribing; CAMHS; COVID-19; LGBTQ+; ASC; Abuse
Coronavirus	X	X	X	X	X	X	Vaccination programme; Accessing medication; Cancer care; Maternity care; Delays to care; Care Homes; Young people; Migrants; 3rd sector
Digital technology	X	X	X	X	X	X	Experience of using digital technology; Telephone appointments; Video consultations; Text messaging; Online services; supporting people to access digital technology Accessing medication; Protected characteristics;
Hospitals working together							
Improving planned care	X	X	X	X	X	X	Delays to care; Elective recovery (Planned Care Citizen Panel); Quality of care; Leaving hospital; hip replacements
Improving population health	X	X	X	X	X	X	Health inequalities; Migrants; Homelessness; Anti-racism; Green social prescribing; Physical activity; weight related bias; diabetes; frailty; Climate change; Housing; cost of living; food resilience; public safety; sexual abuse; domestic abuse
Innovation and improvement	X	X	X	X	X	X	Cardiac and pulmonary rehab; Bradford B Positive pathways
Maternity care	X	X	X	X	X	X	COVID-19; Experience of care; What maternity care should look like; Mental health support; Breastfeeding; Information; Birthing choices; children born with disabilities; planning future maternity services

Area of priority	**Bradford District and Craven**	**Calderdale**	**Kirklees**	**Leeds**	**Wakefield District**	**WY HCP**	**Key areas covered**
Mental health, learning disability and autism	X	X	X	X	X	X	COVID; promoting positive mental health; preventing mental ill health; early intervention; Accessing care; staff training; communication; Crisis care; Forensics; Employment support; Migrants; Homelessness; Hearing impairments; Learning disabilities; Autism; Neurodiverse; dementia pathway
Other	X	X	X	X	X	X	ICB Constitution; Merger of CCGs; Transition to ICS; Joint Forward plan
Our work with the voluntary, community and social enterprise sector	X	X	X	X	X	X	Third sector resilience; COVID-19; primary care; structure, dynamics and impact of the VCSE (voluntary, community and social enterprise); support for volunteers; awareness of VCSE
Personalised care	X	X	X	X	X	X	Definition of personalised care; accessible information; Access to services; reasonable adjustments; Making decisions; Communication; Information; language needs; palliative and end of life care
Preventing ill health	X	X	X	X	X	X	Role of health services; self-care; cardiac and pulmonary rehab; communications; social prescribing; protected characteristics
Primary and community care	X	X	X	X	X	X	GP practices; Extended hours; experience of using GP practices – mental health, LGBTQ, migrants, homeless, hearing impairment, visual impairment, young people; GP practice websites; abuse towards staff; pharmacies; accessing medication; Care homes; care staff crisis; dentistry; Community Neurological Rehabilitation Service; social care
Stroke	X	X	X	X	X	X	Raising awareness; what would be different – in hospital, at home 1+ years later; aftercare; digital solutions; staff feedback

Area of priority	**Bradford District and Craven**	**Calderdale**	**Kirklees**	**Leeds**	**Wakefield District**	**WY HCP**	**Key areas covered**
Supporting carers	X	X	X	X	X	X	Experience of ethnic minority carers; young carers; direct payments; leaving hospital; palliative care; carer lanyard pilot; impact of care staff crisis; improving involvement
Urgent and emergency care	X	X	X	X	X	X	Awareness of services; Why people access services; people aged 20-29; communications in A&E; Quality of care in A&E; Alternatives to A&E; NHS 111; mental health; views of staff
Workforce	X	X	X	X	X	X	Urgent and emergency care; anti-racism campaign; stroke; maternity; health inequalities; care homes

2. Findings from involvement and consultation activity

The documents in this report were sourced via requests to the West Yorkshire Health and Care Partnership Programme leads, engagement leads across our five local places, Healthwatch and providers, and a review of documents held on websites of all key organisations including local authorities. The mapping consisted of reviewing **114 documents,** see Appendix A for a list of the documents reviewed that were published during 2022/2023.

Inevitably, there will be some involvement or consultation activities not included in this report. This report can only capture activity that we are made aware of, where a report has been produced for the involvement or consultation activity, and the report has been published at the time of producing this report.

Each document was reviewed, and the key themes and details were written up into an evidence summary. Most of the work that was sent had already been thematically analysed, and in those cases, the themes were copied. Some of the involvement and consultation reports that were reviewed had also been analysed to establish if there was any variation in the views expressed by people from protected groups. Any specific themes raised by protected groups are also included within this document.

After summarising all of the documents, the key themes from those documents were assigned to the appropriate priority area. The themes were then reviewed and cross checked with the key themes developed for each of the priority areas from the previous mapping exercise published in May 2022 to develop an overall summary of the themes raised.

2.1 Cancer

Ambition

Increase early diagnosis of cancer, ensuring at least 1,000 more people have the chance of curative treatment.

In relation to cancer, whilst a significant amount of work has been taking place with this priority no additional involvement or consultation reports have been produced since the previous mapping exercise. The themes developed for cancer from the previous mapping exercise were:

a) Public confidence in cancer care and treatment during the Covid-19 pandemic

Decision making and information:

- There was a clear 'fear of the unknown' deterring many people from accessing care and treatment. Black, Asian and minority ethnic communities in particular were feeling scared and frightened, with media coverage exacerbating the situation
- There was an overwhelming preference for people to receive information verbally - rather than by letter or leaflets. Community messaging would also be helpful

Hospital and site environment:

- Pontefract Hospital was cited as a good example of a positive model of care
- Communication from primary care could be improved e.g. GP surgeries were supposed to be Covid-safe but appointments for blood tests had been cancelled with no explanation

Distance, travel and transport:

- The best place to be treated was what matters most and generally patients said that they would be willing to travel to guarantee this
- There were concerns as to whether the clinical team would have full access to patient details when being treated at a different site

The clinical team:

- Relationships, trust and confidence in the clinical team were considered to be one of the main factors in getting people through their cancer treatment
- Regarding the idea of a West Yorkshire and Harrogate wide cancer workforce: some people felt unable to comment, whilst others felt it would not be in the interests of patients and some had concerns relating to recruitment in outlying areas

Common waiting lists:

- There were mixed views but support in principle, although people wanted more information about assessment, criteria and points of contact and how it would work
- Some of the more complex specialist cancers may not be suitable for this approach

b) Initial and on-going support

- Many patients reported that they didn't feel that their GP had explained to them what ACE (Accelerate Co-ordinate Evaluate programme) was, with some having thought they were being referred for something else
- Most patients stated that they had confidence in their clinical nurse specialist appointments, and reported that next steps were clearly explained
- Some patients felt they had more time to speak freely at a hospital appointment, rather than a GP appointment, as GP surgeries are always busy. However, some felt that it was easier to access their GP surgery in terms of location and at lower cost
- 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. However, when cancer services were perceived as slow, this could cause considerable distress
- Just over half of people with cancer were offered ongoing support. This support was generally perceived as being effective. Ongoing person-to-person support was particularly valued
- 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. Staff also believed that it was important that cancer patients and their carers could access psychological and emotional support
- 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

c) Communications

- Cancer patients were more likely report that communications with them were consistent compared to those with other long-term health conditions. However, some suggested communications between primary and secondary care could be improved

- A significant number of people said that they would prefer that materials posted to them about FIT (faecal immunochemical test) bowel cancer screening not use the word “cancer”, as this would cause fear and panic

d) Cancer screening

- The FIT 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
- For homeless people, one of the main barriers to screening was the cost of transport, which made accessing GPs difficult
- 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
- Most people 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
- 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 and agreed that they had been given information about symptoms to look out for in the future
- People reported an overwhelmingly positive experience of having a CT scan as part of lung health screening

e) 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
- A lack of English skills and a preference for non-medical, faith-based treatments can be barriers to some community groups seeking cancer treatment

- 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
- 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

2.2 Capital and Estates

In relation to Capital and Estates, whilst a significant amount of work has been taking place with this priority no additional involvement or consultation reports have been produced since the previous mapping exercise. The themes developed for Capital and Estates from the previous mapping exercise were focused on the hospital environment:

- People want all NHS buildings to be used effectively and buildings should be shared by different agencies to help keep services in a local setting
- People would like to have greenery and open spaces which would provide a peaceful haven for patients, parents and staff to use
- A quiet place for all beliefs
- A welcoming, relaxed environment
- A place that works for everyone
- People want consideration to be given to travel and transport, as people could neither afford the time to travel; the cost or find suitable parking on premises. It was felt that there should be an adequate number of parking spaces available at any site, with special focus on making sure there is enough disabled parking available. The car park should be in a safe location and the price of parking should be as low as possible. Public transport, particularly to our major hospitals, is a challenge to many people
- When developing new or improving existing sites to ensure that patients, staff and surrounding neighbours are included within the development of these plans

a) Accident and Emergency (A&E)

- Patients have diverse needs and that those needs should be provided for without compromising the treatment and experience of other patients
- Separate areas for entrance, waiting and treatment for children, particularly away from patients with substance abuse problems was considered to be important. Children’s areas were considered to be necessary, though responses differed on how appropriate separation and passive supervision could be achieved
- Quiet, calm areas for patients with dementia, mental health problems and other needs were also seen as desirable
- One of the key themes for the department was efficiency, from external signposting to the clarity and efficiency of the process at Reception

- Privacy and dignity were particularly important at Reception, with acoustic privacy raised as a priority. Privacy, dignity and passive supervision were of particular importance in triage and treatment areas, with staff and patient security also being essential
- Provision of refreshment opportunities and things to do (distractions) whilst waiting

b) In-patient wards and single rooms

- There was recognition that no single approach to ward areas would fit all scenarios and an understanding that a blend of multi-bed bays and single bedrooms would ultimately be necessary
- The design of ward areas, whether multi-bedded bays or single bedrooms should provide good visibility into the rooms from the Nurse's Station or 'Touchdown' to achieve passive supervision of patients. It was also important to users that colleagues were visible to the patients
- Accommodation for a family member or carer to stay with patients, particularly patients with additional needs such as children, elderly or frail patients and patients with mental health challenges
- Patient privacy and dignity were considered to be essential at all points in the patient journey, which was communicated across several aspects of the design from ensuite toilets, toilets with lobbies, and rooms for patients with learning disabilities and mental health issues
- Whilst lack of privacy was voiced as a key concern, the ability to interact 'socially' with fellow patients was considered to be essential
- The provision of natural daylight within the ward areas was seen to be beneficial to all users
- Multi-bedded bays were deemed to provide additional 'security' as patients can be seen, as well as providing increased social interaction
- Visual and acoustic privacy was highlighted as being important. For some, this meant a desire for a 'private' side room or single bedroom and for others an offset design for multi-bedded wards
- Sufficient space around beds was identified as being essential for private conversations and storage of belongings, but also to facilitate the use of equipment at the bedside
- Social spaces on the ward for interaction with other patients, colleagues or visitors were also seen as desirable
- External views and natural daylight were seen as important to patient wellbeing

c) Waiting areas

- Reception areas and waiting areas should be welcoming with a range of seating options available and, where possible, a view to an external area
- Accessibility and inclusion for those with a disability or impairment
- Quality, arrangement and design of the seating to ensure that patient needs could be met
- A welcoming environment together with clarity and consistency of information available to those waiting
- The use of technology as a call system
- Access to natural light, plants, calming colours and ‘quiet areas’

d) Signposting

- Information should ideally be presented at a variety of heights and should allow for a range of physical and sensory disabilities, such as hearing and visual impairment
- Colours and symbols and ‘lines’ were preferred to text-only based systems
- Clear and simple language, avoiding overtly technical medical terms was preferred
- A means of confirming that a patient or visitor was ‘on the right track’ were also seen as important
- Concerns for patients with dementia and recognised that the condition can affect visual interpretation of colours and shadows

e) People with a disability

- Hospital buildings should be wheelchair accessible and the signs in the buildings and departments are available at a suitable height for wheelchair users
- Places should be autistic-friendly, this includes having quick, well-signposted routes to give stress-free access to departments and to have quiet areas with dimmable lights where an autistic person could wait or de-stress if needed

f) People with sensory impairments

Places should be fully accessible by blind and visually impaired people without the need to involve sighted guides

g) Children and young people

- Ability to personalise each bed space by incorporating lots of plants, art and pictures, to more inventive ideas such as telescopes for stargazing and a performance space for live music
- Access to indoor and outdoor space to play
- Older children highlighted the importance of having their own area to relax or play computer games and including furniture that was appropriate for all ages

2.3 Children, young people and families

Ambition

Reduce health inequalities for children living in households with the lowest incomes, including halting the trend in childhood obesity

In relation to children, young people and families, **twenty-eight** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to children, young people and families. The themes developed for children, young people and families from the current and previous mapping exercise were:

a) Early support

- Early support should be prioritised for those families who need it, and that support should not be diluted by being available for everybody
- Concern raised regarding young people and how we can ensure that Early support is available to them
- Mental health found to be the most important area that people would want support with
- The importance of intervening early from preparing to become a parent in pregnancy through the toddler years and preparation for school
- Want safe places to go to meet other new parents in particular young parents, to talk to staff and for their small children to play with other children
- Support for dealing with children's behaviours, emotions, transitions and conflicts both with parents and with young people
- More activities, including holiday and after school activities for children and young people with additional needs in particular safe outdoor spaces.
- Support for young adults with additional needs 19+ and support for employment
- Early years development has become a concern for some parents, who have noticed the impact of Covid on their child's development including language skills. Some noted there are long waiting lists for Speech and Language Therapy

b) Family hubs

Current gaps:

- Cost of services / cost of parking and travel to venues
- Communication / Promotion to capture an audience - Timetable of support to be available and well promoted

- Open access hubs / Drop-ins – rather than referrals, parents want to access early interventions to prevent escalation of issues
- Connections with school around support and directing parents to support
- Services and support for parents and children in the 5 – 10-age group
- Sessions for older children i.e., Youth club provision
- Activities and classes for SEND children / parents / sibling
- Need more parenting classes

Suggestions for development / wants and needs:

- Coffee mornings for parents - rota basis in different parts of the district for parents to attend
- Parents / Carers to volunteer as group session leaders
- Taster days for parents and/or children
- Family (parent and child) activities – such as all age groups: family play, family craft session, after school baking, cook and eat sessions
- Donation area/lending library - donate items and then pay as you feel donations
- Group for SEND children, more sensory, crafts, singing and dancing with other children with SEN needs – also explore combined offers
- Clubs after school to stimulate child and offer support for parents

Parenting classes:

- Health visitors/ midwifes for pre-natal and post-natal support
- Support for parents with children with behavioural issues / SEN
- Mindfulness / Mental Health support
- Support for grandparents and wider family network
- Healthy lifestyle, healthy eating for parent and child
- Support for Dads - online support for those unable to attend the face-to-face classes

c) Online parenting courses

- The majority of parents had positive experiences with online learning. Parents reported the benefits of the flexibility afforded by online learning as well as the useful information accessed
- Parents gave examples of how they had put into practice what they had learned and of improved communication and relationships with their children

- They also reported an increased sense of confidence and a reduction in stress levels from improvements in their child’s behaviour
- For a few parents, the content of the course was insufficient or not stimulating enough.
- Two parents expressed more limited an impact due to not having sufficient early help support whilst completing the programme
- For parents with children with additional needs, in particular, a greater level of support was required

Service leads and practitioners reported many benefits of online learning, namely:

- Increased accessibility which particularly benefitted those communities who struggled to get to face-to-face provision for reasons of cost, travel implication or practicality issues
- The flexibility of learning allows people to learn at a pace and time that suited them and also enabled partners to be involved in the learning
- Increased efficiencies afforded to services and staff, namely from avoiding venue set-up costs and time, a greater time available for practitioners to carry out casework at their desks, and increased retention levels amongst the parents being reported

Challenges of delivering online learning need to be considered in any future planning. These included:

- Digital exclusion with some parents and communities having poor quality or no access to online learning, and some having a low level of skills to interact sufficiently online
- The ability to build positive relationships between practitioner and participants, so affecting parents’ level of engagement in the content
- Safeguarding concerns of both participants and children during online learning times
- Challenges in supporting peer-to-peer online discussions and support

d) What is important to children and young people?

- Children and young people want to feel their identity and individuality is accepted and celebrated in all areas of their life. And they do not experience bullying and discrimination
- Children and young people want to feel safe in their communities, have safe spaces to play, hang out and have fun
- Children and young people want to feel their futures are important and that they have choice and opportunity that is fair for all
- Children and young people want to feel their health is taken seriously, that they are listened to, and that it is easy to access mental health support. And to have the support

and information needed to make healthy choices, and opportunities for regular physical activity

- Children and young people want to feel their education gives them confidence in their future, that they all are represented, and that they have the same opportunities and access to further education. And all children and young people are in learning settings that meet their needs
- Schools / Colleges need to know and be more aware of knowing more about the experiences of different communities and groups of young people and where support is available. e.g. do schools know about local services for young carers?
- Schools / colleges need to educate young people, so they are more aware of the lived experiences of different communities and groups of young people
- Young people want to have access to a wide range of work experience, employment and volunteering opportunities
- Children and young people want to express their views, feel heard and be involved in decisions that affect their lives
- Children and young people want everyone to take more action to protect the environment from climate change
- Children and young people want to be able to travel around safely and easily
- Children and young people want to know about the different things to do and places to go. They want to be able to enjoy different cultural experiences including art, music, sport and film
- They want to live in a city / town that reduces the impact of poverty and helps families who need it
- They want to live in a city / town that is inclusive for children and young people with special educational needs and disabilities

e) Transition to high school

Suggestions on how to improve the transition to high school:

- Raise more awareness of what support is available around transitions. Help and support needs to be more visible in schools and colleges e.g. in corridors, classrooms, bathrooms. Raise awareness that anonymous support is available for students who feel embarrassed
- Schools and colleges need to be aware of how to improve experiences for students who are transitioning from education settings, by being able to spot the signs of individuals that are struggling with transition. If the majority are happy with, and confident with

transition processes, schools need to target those who are not. There are lots of services on offer to support students

- Schools and colleges need to do their own surveys on transition, on an annual basis and use the feedback to improve next year's transition process – students should be aware of how schools/colleges will be using their feedback and also tell students about what support is available to them

School transition for young people with Special Educational Needs and Disability (SEND)

- The issues/ anxieties faced by young people with SEND in relation to transition are similar to those of mainstream schooled young people, particularly in relation to friendships, homework, moving around school etc
- Raise awareness of some of the barriers that students with Special Educational Needs and/or Disabilities (SEND) have experienced and consider how to overcome these barriers – e.g. students with hearing impairments have struggled with communication, as other students and teachers are required to wear masks and they are unable to lip read
- Raise awareness of what additional support is available for students with SEND
- A longer transition period and personal transition plans play a key role to a successful transition from primary to high school settings

f) Young people who had experience of alternate provision

Young people who had experience of alternate provision struggled to see how they could remain in 'school' unless there were radical changes to:

- Buildings. These being inclusive in design, with break out, outdoor learning and quiet spaces. There was a desire for vocational skill-based areas and facilities
- Curriculum being condensed, refined, and tailored to individual need
- Flexibility in timetables and approaches to assessments
- 'Rules' and expectations being manageable and achievable. Supporting young people with a key worker and using lots of energy to work on behaviours, may mean doing other things at the same time is very hard
- Relationships- student-teacher-peer relationships being balanced/cohesive
- 'Holistic support' is crucial for life challenges. This is as important as academic achievements. Being a young carer, having care experience, frequent moves of home, mental health challenges or health difficulties are all impactive

g) Accessing health services

- Young people were mixed in confidence in accessing healthcare themselves
- If it is an urgent medical need, they would want a parent/adult to be with them
- If it was a sexual health need, they would NOT want a parent to be with them
- Some knew what a GP was but did not know what symptoms they'd need to go to see a GP
- They would prefer phone/video appointments rather than having to travel somewhere and wait
- They would chat to a doctor on the phone
- They would be happy telling a doctors' receptionist why they needed to speak to someone - they thought it might help them be seen by the most suitable clinician
- Pharmacy: they would NOT want to speak in a shop-like environment about medical needs. But they would speak to a pharmacist in private

h) Experience of using GP practices

- **Health concerns -** children/young people concerned about their health behaved differently, depending on age. Those 16 and under were more likely to discuss issues with a family member, whilst those 17-25 much preferred going online, using an App or calling NHS 111
- **Booking appointments -** although most appointments were made by phone, again age range was a factor, with those 16 and under having an appointment booked for them in part, due to not wanting to have to discuss the reason for their appointment with a receptionist
- **Availability of appointments -** most young people did not find it difficult to access appointments, although some would prefer a more flexible, easy to use booking system with shorter waits to be seen. Both same day and advance appointments were considered important
- **Communication -** most respondents felt that they had been able to understand what they'd been told and that the doctor/health professional had used simple terms
- **Treatment -** many respondents felt that they had been listened to and provided with the care/support that they needed but some felt that their doctor/health professional didn't understand their condition/take the time to listen to their concerns or answer their questions
- **Respondents identifying as LGBTQ** (lesbian, gay, bisexual, transexual or questioning) - expressed a much higher preference for seeking digital information, via Google and

other online websites and Apps. Felt that GPs/health professionals did not have an adequate understanding of LGBTQ issues especially those around gender

- **Young carers -** indicated a strong preference for using NHS 111 or discussing concerns with a friend

i) Sexual health services in Bradford district

- Most use the more traditional methods of accessing sexual health medical support such as GP practices and the family planning clinic
- Convenience is a hugely important aspect to young people in access to sexual health services. Opening times before or after school/college/work are preferred
- Weekend availability is also important, as well as the availability of drop in-clinics
- People would like to get more information about sexual health through websites, social networking sites and peer education talks
- Asian men and African men's groups all highlighted the need for better bilingual leaflets (Swahili, Arabic, Amharic, Somalian, Hindi, Bengali, Punjabi) and online information (including videos)
- A preferred method of accessing appointments and information was via telephone conversations rather than face-to-face meetings
- The men's groups all highlighted stigma, peer pressure and a lack of education as barriers to accessing services and felt that education was the best way to tackle this
- There is a need for more training to be provided within school, college and community settings
- Services tailored to the specific needs of LGBT+ and particularly trans people were highlighted as a priority, along with more cultural awareness of ethnically diverse communities when supporting them with their sexual health
- A lack of awareness of both sexually transmitted diseases and exactly how and where to access support
- A need for more education and information about issues including consent, rape and abuse and tackling stigma around accessing services
- They would like to access education and information about sexual health issues and access to services, in schools and colleges (with an increased focus on non-heterosexual issues) and direct engagement with communities through events to provide education and tackle stigma through material available in a range of community languages and formats, including video

j) Child and adolescent mental health

Prevalence of child and adolescent mental health

- Mental health issues are a growing issue among young people, and they have increased over the past years due to COVID-19
- The loss of routine, lack of school structure, social isolation, and prolonged uncertainty are thought to be key factors in the increase in pandemic related mental health issues
- School pressures, social pressures, family life, and the impact of social media and their online life are all identified as being key factors impacting young people's mental health

Low level mental health issues and violence

- Mental health issues are worse for girls than for boys by the time they are in their teens, and almost all the young people being referred to support services are girls
- It is likely that boys are also having problems following the pandemic, facing the same challenges of social isolation and loss of routine, but don't seem to be reporting problems or accessing services
- Low-level mental health issues can lead to violent outbursts or misbehaviour through a frustration response and poor emotional regulation skills
- Young people with low-level mental health issues are more vulnerable to peer pressure and to being targeted by gangs
- Experiences of violence exacerbate mental health issues, and people with mental health issues are more likely to be victims of violence as they are more vulnerable
- Home life can impact mental health and influence experiences of violence

Accessing support

- People reported long waiting lists when trying to access mental health support. This was a concern, especially for those who are already at crisis point when they initially seek support
- The lack of support available when young people move from crisis support to longer-term support was mentioned as another area that needs to be addressed. It was suggested that more support needs to be provided while people are waiting, such as signposting to where useful online resources can be accessed
- There is also a lack of accessible mental health services in rural areas and that this need can't simply be addressed through more NHS or Local Authority staff, as more services are just not viable for such a sparse population. Therefore, the need to look at strengthening community support through building peer support networks for not only

children and young people, but their parents and the professionals who work to support them

Children and young people told us:

- Help us develop our self-care and coping skills, so we can help ourselves. We want to know how to plan to feel well rather than things becoming overwhelming or a ‘crisis’. Time-framed support and therapy might not work because it takes time for us to open up. Support options need to be more flexible
- Need to provide prevention and early intervention, not just focus on those that are in crisis
- We need it to be easier to find and ask for help. When we do ask, we need to know how to manage while we wait and not wait for too long for a service to help us
- Young people want services to be easy to access, with short waiting times. The delays for assessments and treatment for counselling were too long and had a detrimental effect on mental health
- Recognising that ‘one size doesn’t fit all’ is important and as much as online support is important, there needs to be additional ways in which people can access the services
- They want to be seen by someone who will listen to them and have continuity of care, so they don’t have to repeat their story
- They need to be able to trust the service and know that it is confidential
- Some don’t seek support for their mental health and well-being concerns as they feel embarrassed or don’t want to burden others with their problems. Others said they thought they could manage on their own or felt their problems were not severe enough to ask for help
- Developing trust with professionals can be a barrier, as can worries about being a “burden”. Youth groups and support networks beyond school counselling were suggested as ways of mitigating these barriers
- Community groups for young people appear to have a positive impact on mental health when they are used. Young people can find enjoyment and purpose leading projects on their interests and passions e.g., gender neutral toilets, climate change
- While many youth groups are inclusive to all types of young people, many need a referral based on certain qualifying criteria. This can be a barrier to access as it relies on that need being identified and the referral given, and often referrals are a ‘bottle neck’

Accessing support in school

- People highlighted that more is needed to help students cope with the stress and pressures they are experiencing and the earlier in education this starts the better. This could help provide young people with the tools to cope with their mental health and well-being issues before they reach crisis point
- Some people said colleges would benefit from a team of identified staff who have had training and are available to help with mental health and well-being issues in a timely manner. Some people said the staff at their college are very helpful, but they aren't available very often, which means people have stopped going to them. Having a dedicated space in educational settings for people to use when they need some space or time away was also suggested
- Schools often offer mental health and wellbeing support, but their time and resources are stretched
- There is increasing pressure on schools to do more: education, mental health support, family and community support. Pressure and demands on schools have been and continue to increase but it never (or rarely) comes with more time or more funding
- Most schools and staff are supportive of CPD and training on mental health and supporting young people, though levels of interest vary between individual teachers. Senior leadership teams have a big influence on the ethos of a school and its treatment of mental health and violence
- Training is available, but resources are stretched, and teachers are stressed so time and budget are the barriers to access
- Some schools now have staff specifically for wellbeing and pastoral care, as it is too much to expect teaching staff to do this in addition to their educational roles

Emotional wellbeing service

Children and young people told us:

- Mental health services should be 24 / 7 and include mindfulness and wellbeing support
- Some young people that had received counselling had withdrawn when they started to feel better but actually, they would have benefited from completing the treatment; if they could go back, they wouldn't withdraw
- The people to be accessed for help were family followed by school/college and youth groups. This was closely followed by GP, someone to talk to / someone who would listen was noted as a key theme

- Young people would find it easier to find help if there was more awareness about support available and more promotion including during assemblies, lessons in schools; hearing from people that are experiencing / have experienced mental health issues; access to a confidential service / being anonymous; familiarity of a person noted together with face to face, drop in, text, phone, group chat etc
- Young people, parents and professionals value the provision of an out of hours crisis service for young people. Texting was the most popular method used to access the service
- It was suggested that more needs to be done to guarantee services work effectively together and to ensure better crisis support is provided and consistent
- That long-term support is provided so a relationship can develop between the young person and the mental health practitioner. Some respondents said they were left with no support after their limited number of therapy sessions had been used
- The gap in support provided by colleges over the summer holidays was also mentioned as an area that needs to be addressed
- Concerns were also raised around the transition between child and adult mental health services, with a number of respondents saying the support they were receiving stopped when they reached 18 years old, with no other support being offered in the interim while they were in the process of moving to a different service
- Young people who identified themselves as having a special educational need and or a disability highlighted that they had struggled accessing services to support their mental health due to their disability or condition

Parents wanted:

- Up to date, clear accessible information to help parents/carers and family members know what is available for children and young people
- More support for year 6/7 students in helping them with transition from primary to secondary school
- Free young people’s sessions to help them with their emotional health and wellbeing.
- More support for students in school
- Education and training for children/young people/parents and professionals
- Clear referral systems into services
- Right support at the right time in the right place
- Reduced waiting times
- More family support sessions

- More support focused on primary aged children
- Direct support to parents/carers and family members in order to enable them to support their children at home

Professionals wanted:

- Up to date, clear accessible information to help professionals know what is available for children and young people
- More support for children under 5 particularly around bereavement
- Free counselling for young people aged 16 – 18
- Clear referral systems into services
- Reduced waiting times
- Reduced waiting times particularly for an ASD assessment
- A more joined up approach between services and professionals
- Further training opportunities for all professionals
- More support for students in schools
- More support for staff in schools
- Sustainability of services
- Targeted emotional health and wellbeing support for the most vulnerable children and young people

k) Autism spectrum conditions

Mid Yorkshire Hospitals

- Inconsistent information from secretaries/admin teams regarding waiting times for ASD assessment
- Families feeling isolated and left with no support once the referral has been made into the ASD pathway/ no contact following referral
- Complicated outcome reports. Parents feeling they do not have a chance to discuss/understand
- Long wait for assessment
- Letters need to be understandable and useful for parents
- Some ADHD traits present in Autism. Parents noted issues with some schools where schools don’t support the child until diagnosis of autism is given. Find though that when you get a diagnosis of autism first; felt that schools are reluctant to provide ADHD support. For the parent and the child, a diagnosis of ADHD being shared with the school would have been beneficial for school to recognise the need to provide support

- Parents commented that it is unclear that the ASD pathway is a needs-based assessment, and not diagnosis led. Many families feel that as soon as a diagnosis is given (or not) support disappears and many do not know where to go for advice/help and this is not the expectation beforehand. People usually expect that a diagnosis = constant support
- Once you get a diagnosis you have to understand what it means, and some parents have said it feels like a grieving process

Education

- More support is needed from teachers in relation to the EHCP process, parents feel as though they are constantly fighting a battle to get their children what they need at school
- Majority of teachers are unaware of what provisions need to be in place or they ignore them and do not appear to understand the needs of SEN children
- Timetables for SEN children need to be more flexible to help with needs i.e. regular breaks, quiet time when needed
- In addition to this, numerous parents commented that referrals into health have been done incorrectly which wastes time
- There is a need for trusted staff members that parents can approach when they have concerns. These staff members should be able to ensure that parents' worries are addressed and where possible, resolved. Having dedicated staff who are trained in this area would ensure a better relationship between school and families and build the trust and communication that participants felt is severely lacking
- SEN children would benefit from having a 'key contact' at school who knows and understands the child and their needs
- Further general training for all school staff to increase knowledge and awareness of SEN was suggested
- Key information in relation to the child should be shared between parents and schools i.e. incidents at home/school, change of behaviours, provisions that have worked or not
- There was an ask that all professionals involved with EHCPs should be more mindful that children with SEN can present differently in different settings and behaviours can change
- Parents have asked for recommendations of books and other sources that may help
- Emotional Based School Avoidance (EBSA) needs to be clearly marked if this is the reason for a child's absence. A lot of parents feel that this is not recorded properly, and it appears that their child is just 'not going to school'

- Schools do try to put good support mechanisms in place, but the newly qualified teachers don’t seem to have access to this

Suggestions from participants:

- For parents and school to complete referrals together to ensure correct information is captured
- For health professionals to explain to children more about their diagnosis. It is currently the parent’s ’job’ and they do not feel they know enough themselves to explain.
- Include parents in the evaluation
- Transition into high school with accompanied visits, also buddies at new schools are things done in other areas
- Secondary schools to have a team of people for ‘wellbeing’ to support all children whether that is autism or anxiety or anything else

Positives

- It was felt that the Autism Education Trust training has been really well received. There have been many parents that have already attended or planning to in the near future
- Advice line has been helpful
- Some participants experienced good support in school

General

- Better access to mental health support services is crucial. Many families are not sure who they can get in touch with if they need help or advice
- More support is needed throughout the whole process from making a referral to the outcome of the assessment. Parents’ voices and feelings need to be validated and they should be involved with decisions made and communicated with at all times
- Training for children around autism so that peers have understanding would be good. Children learn and accept better. Start early with the information, just as we do with other aspects, but then consider the transition into high school which is very stressful

Support

- More support for parents and children is needed following a diagnosis
- There needs to be more support for parents that isn’t “patronising, generic and parent shaming”
- There should be more consideration for support of siblings and families

l) Young people and COVID-19

- **Mental health -** More than half said their mental health had been negatively affected. Many young people expressed that they missed their friends and family, their social activities, and their usual routine. Uncertainty about the future was frequently mentioned. A small minority said the disruptions had affected their mental health in a positive way
- **Progress with learning -** just less than half felt that their progress with learning had been negatively impacted since their return to school in March 2021, with many identifying the limitations of remote learning. A small number felt that there had been a positive impact on their progress with learning. Many said that they had not been able to keep up with the schoolwork they had been asked to do at home and were worried that they were now behind. They were worried that they had been away from school for so long that they had forgotten 'vital things' and that they would fail. The thought of going back to school after a long period away from it was daunting for some, and those due to start secondary school felt 'unprepared' and nervous about it
- **Friendships -** just less than half said the disruptions caused by covid impacted negatively on their friendships. Enforced segregation within school was a common theme as well as a lack of opportunities to connect outside of school. A small number said their friendships had improved. Social anxieties were frequently reported, with feeling worried that being with their friends would not be the same due to social distancing measures. Some described anxieties around friends not liking them anymore, people laughing at them, trying to fit in, getting their feelings hurt and being bullied
- **Physical activity -** just less than half said their physical activity levels had been adversely impacted due to covid disruptions. A fifth experienced positive impacts.
- **Confidence with learning -** a third felt that their confidence had been affected negatively by disruptions to learning. A small number had been positively affected
- **Health anxiety around Covid-19** - with children worrying about themselves or members of their family becoming ill and dying, particularly their parents, grandparents and family members who worked for the NHS. There was also anxiety about lockdown easing and being in crowded places, as well as concern about wider society and when the pandemic would end
- **Diet -** snacking at home and restricted menu at school were factors for a fifth feeling that their diet had been negatively impacted. A small number had a positive impact. Some reported being worried about having put on weight and not having done enough exercise during lockdown

- **Benefits** - They had more time to spend playing on their Playstation/Xbox, doing hobbies like painting and baking or going out for walks and bike rides. They seemed to have benefited from being able to contact and speak to their friends through online games, social media and on the phone. They described enjoying spending more time with their family, and many children said that they had found it more relaxing being at home, not having to stick to such a strict schedule and had enjoyed time on their own. Some had also enjoyed being able to stay up later and sleep in longer

m) Young people's social prescribing

Feedback from young people on their experience of young people's social prescribing programme:

- **Build Positive Relationships:** A very high percentage of young people made improvements towards this outcome. More than half linked this to their family relationships and just under half linked this to their education setting. Throughout the service young people demonstrated a willingness to improve relationships recognising the positive impact this would have on their overall health and wellbeing
- **Feel more connected to community:** Despite the pandemic a high percentage of young people felt more connected with their community. Through improved relationships, increased confidence and self-worth, young people accessed new activities, made new / improved friendships, and re-engaged with their education setting to improve their overall health and wellbeing
- **Loneliness and Isolation:** More than half the young people supported through the pilot, experienced a reduction in their feelings of loneliness and isolation. For some young people this was the first time they acknowledged having friends and being part of social group, for others this provided an opportunity to improve relationships. Young people accessed a range of different social opportunities both online and face to face. This enabled new friendships to form, new skills and interests to develop and stimulated peer to peer support

n) Young people who identify as LGBTQ+

Young LGBTQ+ people told us that emotional health and well-being was their highest priority. They told us that the struggle to be accepted especially for young nonbinary people, the impact of homophobia (particularly at school), being treated like a social outcast, the lack of recognition in services of gendered terms and pronouns particularly in health services, the underlying inequality they experienced, the lack of gender-neutral facilities and a lack of 'non-traditional sex education' had an impact on their overall mental health and well-being.

They also told us that young LGBTQ+ people have mental health problems due to bullying and loneliness and as a result are likely to feel depression. Some felt that some trans people needed support because of body dysphoria. Other said that "*expectations in the gay tribes*" can cause emotional problems. Other highlighted that many young people had trouble with parental acceptance.

Young people felt there is a need for group and one to one services specifically for young people who identify as LGBTQ+.

A lack of awareness of the existence of services, anxiety about what to expect such as using the right terms to identify themselves and a previous bad experience with a group might deter some young people and waiting lists act as barriers to services.

In addition, young people raised that group work needs to be age appropriate (as there is a difference in the needs and interests of 13- and 19-year-olds) whilst others felt that young people between 20-25 years also need support.

The need to promote services to people with cross sectional protested characteristics such as young LGBTQ+ people form BAME communities, young people who have Specific Educational Needs and Disability, asylum seekers, to children who are home educated and to children who are looked after was highlighted by stakeholders and young people.

o) Sexual exploitation, physical and emotional abuse of children and young people

Awareness of child exploitation

- When surveyed most young people did not know what child exploitation was, of those that did most described it as gangs targeting children to get them to do things, e.g. carry drugs, sexual acts, steal things
- Those that had heard of it the majority had done so through school. Those that hadn't would like to know more about it, with the preferred method being via school
- Most young people didn't feel that it was an issue where they lived, of those that did they felt that the main issues were drugs, gangs and knives

Prevalence of child exploitation, physical and emotional abuse

- That sexual harassment/abuse incidents are so commonplace, there is a lack of reporting
- Online sexual abuse and harassment is more prevalent than adults would believe
- Sexual violence occurs most frequently in unsupervised areas out of school. However, some non-consensual touch occurs on school corridors
- Most girls have experienced sexual abuse/violence – always older boys and men but none have ever reported because they know they will be blamed/made to feel responsible – common knowledge that prosecutions are rare
- Girls harassed by older males in vehicles even when wearing school uniform – some that park up outside their schools and offer lifts/gifts – report these to schools but nothing is done
- Across ages many have seen a huge decline across more deprived areas/social housing estates, poverty links to how girls are targeted by potential abusers
- Online grooming mentioned – worse during the pandemic as children were already isolated so more vulnerable to 'kind' words from strangers online – parents often unaware of online dangers – young girls feel it's their own fault so unable to tell a parent until it's too late
- Discussion about children's clothing – girls sexualised from a young age by clothing industry – leads to victim blaming even when there are few options for girls
- Concern also that boys are being groomed online to hold extreme views against/about women and girls – online forums for boys discussing hate and how to deal with problem women, all made worse by extreme/violent porn
- Online exploitation of girls – groomed into having Only Fans accounts while still at school to perform for men for money – targets vulnerable girls and women with promises of high earnings

Key factors of victims of violence and exploitation

- **Lack of parental supervision** - Children with parents who work multiple jobs and are away from home are more vulnerable
- **Familial involvement in crime** - Young people are being drawn into gangs and criminality if a family member is already involved - often young people are recruited by their own family in this scenario
- **Girls are more likely to be victims of sexual exploitation than boys** - Although stakeholders noted a rise in sexual exploitation of young men, young women are more often victims of sexual exploitation

- **Excluded from school** - Stakeholders noted a link between being excluded from school and being involved in a gang - but the causality is hard to determine
- **Boys are more likely to be criminally exploited than girls in West Yorkshire** - However, stakeholders noted that when girls are involved in gangs, criminality and violence, they are less likely to be caught by police
- **From economically deprived backgrounds** - Young people from lower income families were considered to be more likely to get involved in violence. Often to support their family or to buy the things they want
- **Not engaged with services** - Some children choose not to engage; others don't have a choice as they feel there are no appealing youth services in their area
- **Unemployment** - Young people who struggle to find a job are more likely to get involved in criminality and potentially violence due to a lack of options to make money

Key factors of perpetrators of violence and exploitation

- **Girls' involvement is different than boys'** - Girls who are involved in violence, exploitation and crime are most commonly on the periphery
- **From economically deprived backgrounds** - Young people with less money are more likely to be perpetrators, according to stakeholders. They tend to get involved in crime initially to support their family or buy the things they want
- **Social network involved** - If a young person's social network, including their family and peer group is involved in violence and crime, it is much more likely that they will become involved too
- **Often victims themselves** - Stakeholders highlighted that young perpetrators of violence and crime have often experienced trauma or have been exploited themselves
- **Poor attainment at school** - Stakeholders noted that young people who fail to achieve good qualifications at school have a higher likelihood of being involved in crime and violence as they have fewer opportunities
- **Lack of support from parent or role models** - Stakeholders noted that young people who lack parental support or role models are more likely to be perpetrators of violence and crime
- **Young people who are destitute** - When we spoke to a representative of young asylum seekers, they told us that young people who have no legal option of employment (destitute) are more vulnerable to getting involved with crime and violence

- **Not engaged with services** - Stakeholders noted that the young people involved with violence, crime and exploitation are often the young people not known to/engaged with services such as sports clubs
- **Women and girls face specific challenges and pressures** related to self-worth and wellbeing which may make them more vulnerable to exploitation. Young female stakeholders say Covid-19 has heightened feelings of low self-worth
- The stakeholders we spoke to highlighted the importance of service provisions for young people which focus on gender-specific intervention

Neurodiversity and violence - the experience of neurodiverse young people

- Experiences of violence are often through bullying, though some young people have experience of perpetrating violence through lashing out to gain attention for a specific need
- There is a concern that figures in authority (such as police or airport security staff) are not trained in responding to someone with a neurodivergent condition, which could provoke misunderstanding
- Aggression from figures in authority (e.g. police) towards a neurodiverse person can escalate a situation very quickly
- Not all support from specific neurodiversity support workers is as good as it could be
- Training and awareness, support like quiet spaces, and information on coping strategies for people who work with or may encounter neurodiverse young people would help to improve the situation for young people

What ‘Neglect’ means from a child and young person’s perspective

- Young people are able to clearly identify the difference between ‘want’ (having desirable items) and ‘needs’ (things that are important to their well-being)
- Having a supportive, caring network of family and friends, access to good education and the opportunity to get involved in activities were some of the things they described as being important to aspects to keeping them happy and healthy
- Low self-esteem, not achieving academically, engaging in criminal activity, depression and suicidal thoughts were all things young people felt could be the consequences of them not having their basic needs met during childhood

Education/prevention in schools, colleges, universities

- Adults in education provisions underestimate the prevalence of sexual harassment/abuse and violence within the provision, especially online occurrences
- Work to educate boys needs to start from Early Years in schools that there is no excuse for abuse of girls/women and must be reinforced throughout all stages of education. Agreement that there is still a culture of ‘boys will be boys’ and questioning girls about what they did to make a boy ‘hit out’ – victim blaming is experienced in our schools
- Fears about regular news stories about the huge increases in sexual assault/harassment in schools – saying that every time it’s mentioned the statistics are worse but there is never any visible action to address it – concerns raised about mixed sex facilities ignoring the specific needs of girls and women
- All agree that male staff in education need to demonstrate the behaviours that boys need to see – recognition that male role models are needed especially where there is/has been domestic abuse/violence in the home
- Need for spaces for girls/support services for girls to be safe so that they can talk without the pressure of a man in the room
- Relationship Sexual Health Education (RSHE) doesn’t cover peer on peer sexual harassment and harm holistically. Therefore, children and young people are seeking support and understanding via their peers and the internet
- Need for education to cover the harms of the kinds of porn/sexual material that boys and men are seeing from a young age that normalises violence and abuse of women and girls – cited that girls as young as 13 believe that the bruises inflicted on them are ‘love bruises’ and talk about being choked/breath play, spat on and slapped as normal sex that they feel they ‘have’ to do. Also coercion into providing nudes – fear of rejection/exclusion/bullying is often worse than fear of images being shared

2.4 Coronavirus

In relation to coronavirus, **five** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to coronavirus looking at either the vaccination programme or the impact that coronavirus has had on people's experiences of accessing NHS services. The themes developed from the current and previous mapping exercise have been presented here for ease, however where appropriate the themes also appear in other sections of the report, such as cancer, maternity etc.

a) Vaccination programme

Vaccine hesitancy

- People in the 18-34 age group were significantly more likely to be hesitant than those aged 35 and above. The primary reasons cited for hesitancy were concerns about the safety of the vaccine and a lack of research. Some people also had concerns around the long-term effect of the vaccine on fertility, pregnancy and breastfeeding
- Hesitant people were significantly more like to rely on their GP, their family and their own independent research to find trustworthy vaccine information. A much larger proportion of hesitant people agreed that they felt pressured into accepting the vaccine and that healthy people do not need to be vaccinated
- Some people told us they wanted to wait before making a decision about getting the vaccine. Younger people wanted to weigh up the potential risks of being vaccinated vs. not being vaccinated, as they perceive the risk of becoming seriously ill from Covid to be lower to them
- Confusion about why people feel ill after receiving a flu or COVID-19 vaccine
- A sense that receiving vaccines would not make a difference, or prevent people from contracting a virus or prevent the viruses from spreading
- Limited knowledge of the viruses themselves, including symptoms and how they are transmitted
- Concern about the effects of vaccines – both in terms of headaches and dizziness in the immediate wake of the vaccine being administered and perceived longer-term effects such as new allergies/illnesses, changes to monthly cycle etc
- Of those that originally had not intended to get vaccinated, the main influence in terms of their 'change of mind' was around the restrictions tied to not being vaccinated.
- 'Family and friends' were also a major influencer – either pressure from them for individuals to get vaccinated, or concern from individuals about protecting others

- People that chose to have the vaccine were significantly more likely to trust the medical safety and dietary / religious compliance of the vaccine and were also much more likely to trust the government data

People with disabilities

- There was a mistrust because of the lack of accessible information explaining the vaccine
- People used the internet and accessed misinformation, such as work and films on American websites
- There was a lot of worry about what they saw as the quick construction of the vaccines
- Rumours discussed on WhatsApp, Facebook and twitter producing elevated negatives
- People felt the vaccine had foetus material or pork in it and was not halal
- People thought that they would develop allergies if they had the vaccine
- People felt the Pfizer jab could make slight changes to their genetics, majorly affecting their disabilities
- Some people thought it could change their chances of getting pregnant
- People thought the vaccine could give them blood clots

Vaccine uptake in Bangladeshi and Pakistani communities

- Knowing the halal status of vaccines was very important to people when making their decision about whether to have them
- Offering drop-in vaccinations at local community locations within walking distance and providing interpreters would help encourage people to get vaccinated. Additionally offering vaccinations on evenings and weekends was seen as helpful
- People felt that employers giving time off work to get the vaccine and recover would help people get additional doses of the vaccine. This was also important for people who needed to help older family members get to appointments as they helped not only with practicalities like transport but also with translation if the person didn't speak English. During the pandemic, there had been a perceived increase in flexibility and understanding from employers to enable this to happen, but people felt that this was no longer there
- Being able to book vaccinations by phone or face-to-face rather than via a national website. Would prefer this to be via their GP rather than via a national call centre. This was particularly an issue for those who did not know how to use or have access to any technological devices such as a smartphone, computer, or tablet. For those that were online, text reminders containing a booking link were helpful

- Acknowledged that family members do play an important role in influencing decisions. People generally agreed that if they were told by people of status (e.g., a doctor, a social worker, an Imam) to get the vaccine, they would be more likely to
- Although some members of the Pakistani communities reported that they were offended and incensed by the use of imams in the roll-out of the COVID-19 vaccine, saying they felt "religiously manipulated". Although they said that despite this, once their imam gave their advice, they did mostly follow it and get vaccinated. However, members of the Bangladeshi community said they felt grateful for the imams getting involved in endorsing the COVID-19 vaccination roll-out, and as soon as their imam advised them to have the vaccine, none questioned it
- Across both communities there was a lot of concern, both from men and women, over changes to women's cycles and other gynaecological issues after they were given the second vaccine. This mass shared experience left them feeling as though the government was hiding things from them
- Some people said they had chosen not to be vaccinated because they didn't trust how quickly it had been developed and that it had only been around a short time

Access to vaccinations

- Most people found the booking process easy to use and would have liked to be able to book their second vaccination at the same time
- Carers told us they were worried about the people they care for if they hadn't been offered the vaccine
- People wanted to get their vaccine, but said work was a barrier to being able to go and get it
- Most felt that it was easy to travel to the vaccination centre, with many saying the site was close to home or in a convenient location and that they could drive there easily. Negative comments generally related to traffic and parking difficulties
- People wanted to be vaccinated in their own communities - pop ups / walk in clinics.
- Most people reported having a positive experience when attending for their vaccination, and talked highly of the friendly, well-trained staff. Negative comments received were:
  - The vaccine centres were very busy, and people sometimes needed to queue outside
  - It was sometimes difficult to socially distance at the vaccine centres
  - It was sometimes difficult to know where to go when you arrive at the vaccine centre
  - Some people did not receive a card explaining which vaccination they had received

    - Some people would have felt safer waiting in the clinic (rather than their car) in case they had a reaction to the vaccine
    - Some people did not receive enough information about the vaccine at their appointment. This included not receiving any literature after the appointment and not having the opportunity to ask about things like side effects
- Need to ensure that there are adequate facilities for disabled people, for example, adequate seating
- Need to ensure that adequate translation services to meet the needs of diverse communities and improve representation

b) Accessing medication during the Covid-19 pandemic

- Due to the reduction in face-to-face appointments with healthcare staff, some found it more difficult to obtain medication in a timely way
- Some were happy to have a medication review on the phone, whereas others would have preferred a face-to-face appointment and there was some frustration around the limited amount of communication regarding medication reviews
- People were generally impressed with the way pharmacies adapted their services in response to challenges presented by the pandemic with some starting to offer home deliveries for the first time. Some people now find it easier to order medication online and have medication delivered
- Periods of shielding and self-isolation meant that people who were previously managing their own medications suddenly had to start requesting and relying on support from other sources such as family, friends, neighbours and volunteers. South Asian people were twice as likely to rely on family and friends to collect medication, which they hadn't done previously. The pandemic often brought out the very best in people; a great deal of compassion and good will was extended towards others who might be struggling but some people, understandably, did not like being dependent on others for things like medication ordering and collection
- Some people have faced additional barriers relating to access, communication and digital technology and these are areas which could be improved in future to ensure good quality, equitable access for people who need medication during the continuing challenges presented by the Covid-19 pandemic and beyond

c) Cancer care and treatment during the Covid-19 pandemic

Decision making and information

- There was a clear ‘fear of the unknown’ deterring many people from accessing care and treatment. Black, Asian and minority ethnic communities in particular were feeling scared and frightened, with media coverage exacerbating the situation
- There was an overwhelming preference for people to receive information verbally - rather than by letter or leaflets. Community messaging would also be helpful

Hospital and site environment

- Pontefract Hospital was cited as a good example of a positive model of care
- Communication from primary care could be improved e.g. GP surgeries were supposed to be Covid-safe but appointments for blood tests had been cancelled with no explanation

Distance, travel and transport

- The best place to be treated was what matters most and generally patients said that they would be willing to travel to guarantee this
- There were concerns as to whether the clinical team would have full access to patient details when being treated at a different site

The clinical team

- Relationships, trust and confidence in the clinical team were considered to be one of the main factors in getting people through their cancer treatment
- Regarding the idea of a West Yorkshire and Harrogate wide cancer workforce: some people felt unable to comment, whilst others felt it would not be in the interests of patients and some had concerns relating to recruitment in outlying areas

Common waiting lists

- There were mixed views but support in principle, although people wanted more information about assessment, criteria and points of contact and how it would work
- Some of the more complex specialist cancers may not be suitable for this approach

d) Maternity services during the Covid-19 pandemic

- They received less contact from maternity services, many maternity and community/voluntary services they could normally access were closed or operating only

online. They were unable to meet with friends or their extended family. Many felt more isolated and anxious as a result
- The impact was often greater on women living in poverty or deprivation as they had less access to the internet to access online services. Women who do not speak English were also disadvantaged as they often found communicating online or by phone more difficult
- Disjointed midwife support and a lack of face-to-face appointments left the individual feeling a lack of professional support and the inability to build rapport with the professionals
- Partners not being able to be present during the whole of labour, so large parts were spent on their own without support
- Partners not being allowed on the ward to bond with their baby and to help and support the new mum
- Feeling lost in the system and feeling lonely and isolated during their pregnancy journey
- The importance of face-to-face service provision, as opposed to virtual consultation
- Black, Asian and minority ethnic communities were the most dissatisfied with services
- LGBTQ partners voiced concerns that they were not recognised as ‘partners’ in the same way as heterosexual couples

e) Delays to care during the Covid-19 pandemic

- **Access to services -** people reported having difficulties making appointments to see GPs face-to-face, not receiving expected follow-up care or diagnostic tests in a timely manner and delays in accessing specialist services
- **Communication -** some people experienced a lack of communication about waiting times and next steps for treatment, which led to them feeling abandoned or overlooked. Poor communication led to missed opportunities to empower people to better manage their own health conditions
- **Quality of care -** some people highlighted the need for service improvement to support people with psychological and mental health needs, brain injuries and long-term illnesses
- **The impact of delays to care on individuals** – people reported severe deterioration in their physical, mental and emotional health, with high levels of anxiety and worry amongst people, even more so where people were living with mental health conditions
- **The impact of delays on family members** – delays don’t just affect the individual needing care or treatment, but also have a ‘knock on’ effect to family members as well

- **The importance of support from friends and family** - over half of people reported seeking help from family and friends to help them manage everyday tasks, supporting people physically and mentally, and were there to listen and provide emotional support
- **Travelling further for care** - most people would travel further or be willing to access services at a private hospital (as an NHS patient) if this meant they would be seen sooner. However, people had concerns about transportation difficulties and caring responsibilities if they had to travel further afield
- **Pandemic healthcare changes** - access to services, improving services and improving communication were the things people would change. People liked the quietness of waiting rooms and praised the phlebotomy service for improving during the pandemic
- **Improving health and wellbeing** - pain management, pain affecting health and wellbeing and impacting on sleep. People told us an improved way to contact consultants; making online booking easier and allowing greater advanced bookings would have improved their experiences

f) Impact on care homes

Impact on residents

- Deterioration in physical and mental wellbeing of care home residents as a result of prolonged severely restricted contact during the pandemic
- Impact on emotional wellbeing of family carers who have had little or no contact with loved ones for long periods of time
- Concerns raised about quality of care and safeguarding when family members hadn't been able to play informal 'monitoring role' through visiting regularly
- Fear of repercussions on resident care or even eviction if concerns raised or complaints submitted
- 14-day isolation rule after admission to care home detrimental to wellbeing of residents

Visiting care homes

- Huge variation throughout the pandemic and continuing in terms of how different care homes have enabled contact and meaningful visiting
- Lack of involvement of family carers in making visiting arrangements and doing person-centred individual risk assessments to consider residents' wishes and needs regarding visiting

- Huge variation in terms of how regular contact/communication with family members was maintained when face to face visiting was restricted
- Variation over what care homes were ‘allowing’ in terms of visiting at the end of life despite guidance saying that end of life is the last months of someone’s life not the last days and visiting should be permitted as much as possible
- Lack of awareness amongst care homes and families and/or reluctance amongst care homes to enable ‘essential care giver’ role as outlined in the current guidance on care home visiting. Blanket visiting policies e.g. half an hour once a week for everyone in a designated room, irrelevant of individual needs
- No visiting allowed on evenings or weekends

Mandatory vaccinations

Many care homes did indicate a positive sentiment towards fully vaccinating staff. However, the majority of feedback highlighted the uncertainty, difficulty, and perceived unfairness of the legislation’s application.

g) Impact on young people

- **Mental health -** more than half said their mental health had been negatively affected. Many young people expressed that they missed their friends and family, their social activities, and their usual routine. Uncertainty about the future was frequently mentioned. A small minority said the disruptions had affected their mental health in a positive way
- **Progress with learning -** just less than half felt that their progress with learning had been negatively impacted since their return to school in March 2021, with many identifying the limitations of remote learning. A small number felt that there had been a positive impact on their progress with learning
- **Friendships -** just less than half said the disruptions caused by covid impacted negatively on their friendships. Enforced segregation within school was a common theme as well as a lack of opportunities to connect outside of school. A small number said their friendships had improved
- **Physical activity -** just less than half said their physical activity levels had been adversely impacted due to covid disruptions. A fifth experienced positive impacts
- **Confidence with learning -** a third felt that their confidence had been affected negatively by disruptions to learning. A small number had been positively affected
- **Diet -** snacking at home and restricted menu at school were factors for a fifth feeling that their diet had been negatively impacted. A small number had a positive impact

h) Impact on migrants

- Increased social isolation, lack of activity, and lack of Wi-Fi, leading to increased anxiety, depression and other mental health issues
- Difficulty accessing appropriate public health information about Covid-19 in a variety of languages and appropriate formats
- Challenge of staying safe when housed in houses of multiple occupancy, where individuals have no control of what others in the house do, for example bringing friends in, seeing others outside the house but not complying with public health guidance
- Increased risk of exposure to Covid-19 in initial accommodation centres
- Being housed in contingency accommodation where accessing initial health screening and health services is more difficult
- Some work situations made it difficult to socially distance and stay safe
- Loss of income for working refugees during lockdown
- Difficulty accessing Covid-19 testing
- Reliance on phone / internet-based methods of communication for testing and vaccination which requires data that migrants in vulnerable circumstances may not have
- Restrictions and closure of some services, including statutory and voluntary sector support
- Some GP practices have developed new online systems which can be difficult for those with limited English and impossible for digitally excluded people

i) Impact on the Third Sector

Positives highlighted were

- Resilience and adaptability of the third sector, this was shown in the way it adapted services, innovated and supported communities through very challenging times
- The fast tracking and flexibility of service commissioning and delivery between health, local authorities and the VCS (voluntary and community sector), meaning services could respond quickly and everyone worked together to make things happen at greater pace

Finance

Many VCSE organisations had experienced a loss of income and were concerned that they would not be financially stable. However, over time there was more confidence about financial resilience, continued flexibility from funders and newly developed partnerships that remain.

Digital technology

- Demand for services to move online. Some services had been able to move to this, using platforms like ‘Zoom’, but others had faced difficulties in reproducing the same service online
- Digital exclusion presented significant challenges and had an impact on the ability of people to access VCSE organisations during the pandemic
- Digital working reduced the need for travel
- Organisations came together online and worked jointly, where they would not have otherwise had the chance to do so
- Opportunities to interact with others they would not usually encounter

2.5 Digital technology

In relation to digital technology, in response to the pandemic and the increase in the use of online tools and digital solutions a significant amount of work has been taking place with this priority. In terms of involvement activities, **four** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to digital technology. The themes developed for digital technology from the current and previous mapping exercise were:

a) Overall experience of using digital technology

- Whilst many valued the convenience of moving to more online and telephone appointments, people feel that digital access should be one of the available options, so it can be used where appropriate. Each option should have equal priority and responsiveness and at no time should there be a two-tier system which works better for those who have digital access/can use digital methods
- Many are keen on ensuring that face to face appointments continue to be available and feel that for many conditions this is the only way to receive an accurate diagnosis
- Pre-pandemic, people’s experiences tended to be limited to booking appointments and ordering repeat prescriptions. Whilst they found this useful, they did want to be able to access more services online
- Of those people that had had an appointment either over the phone or through video conferencing, the majority reported a positive experience. And would choose to use the service again and recommend it to their friends and family
- People wanted to be given a time for their appointment rather than being expected to wait around all morning or day
- People wanted to be provided with information on how to access digital technology on a range of devices
- Smartphones and tablets were the most common devices used by people, with most using them to text and email. People also used their devices to do online banking, watch videos, and use video calls

b) Phone appointments

- From the range of digital methods that people can now use to access services, when they have an urgent health need the most common used by people is a phone consultation / appointment

- People valued being able to talk to someone about their condition, with many commenting on the convenience of not having to leave home, arrange childcare or take time off work to attend their appointment
- Some people felt that telephone and / or video appointments are suitable for triage or minor ailments and if medical professionals have access to notes and history
- Many commented that they had been seen quickly and felt that they had received the appropriate care / treatment. Although, some people said they had concerns about the quality of care they get and felt that appointments over the telephone / video felt rushed or impersonal

c) Video appointments

- For those that have used it, many felt that it worked better than using the phone as they were able to show the clinician the physical symptom but where a physical examination was needed a face-to-face appointment would still be required
- Convenience of not having to leave home, arrange childcare or take time off work to attend their appointment
- Not having to travel to the GP practice / hospital
- Quality of the picture and audio had been poor for some people
- Not everyone has privacy or feels safe conducting a video consultation at home
- Some reported that they hadn't been offered this and whilst some would be willing to try it others wouldn't want to, either because they don't feel they would be able to receive an accurate diagnosis, or they are unable to use the technology
- Virtual waiting room would be beneficial for informing patients on delayed appointments
- Would like to be able to share/forward the video consultation links with family/friends to invite multiple people using different devices
- Video appointments have meant clinic rooms don't have to be booked, no travel to rural locations creating an agile working approach for staff
- Equipment has been a large issue in community nursing, signal loss and getting others to log on properly has resulted in more nursing hours logging people on and fixing technical issues

d) Text messaging

- People have mainly used text messaging to receive reminders about an upcoming appointment or to book their Covid vaccine

- Some people had also been sent links to further information to manage their condition
- It was felt that text messaging would not be an appropriate method to use for an appointment
- Some people mentioned that they wouldn't respond to a text message as they had concerns that it could be a scam or insecure

e) Online service via GP practice website e.g., eConsult, Engage Consult

- Those that had used an online service such as e-consult had found that it worked well when seeking advice for a non-urgent condition; requesting repeat prescriptions; and booking appointments
- Some found it was convenient as they were able to complete the form at a time that suited them, and some valued being able to upload photos
- Some people found the forms difficult to complete
- Some reported that the response from the GP practice wasn't always the same day, so not ideal for anything that is urgent
- People felt that it was reliant on having a good internet connection; ability to use technology; and the ability to describe in writing what their symptoms are, which not everyone is able to do
- Some people mentioned that their practice limits the times when e-consult is available

f) Concerns about using digital technology

- Whilst telephone appointments were convenient for some, others were worried that their health issues would not be accurately diagnosed and would prefer face to face appointments especially when presenting with a condition for the first time
- People were more concerned about having a video or telephone appointment with a health professional that they did not know
- Some people expressed concerns about using technology with some being unsure about how secure it is; not having the skills to use it; not having access to the internet; challenges of using certain technologies due to hearing impairments; and English not being their first language

g) Supporting people to use digital technology

- Not everyone has a private space for an online video consultation. Pharmacies, community assets and general practices could be utilised for patients

- With a push in utilising online services across the NHS, practices should consider that not all patient groups will be able to book online, and alternative access is key to avoid widening health inequalities
- There is a need for support and resources for user groups to be able to access remote consultation platforms and benefit from them. This includes factors such as: costs for patients to access remote video consultations; a need to consider language barriers and accessibility functions; one to one support (e.g. from administrators / digital champions)
- Live captioning / transcription - people try and make notes and take everything in. A video being transcribed in various languages would help for record keeping and in understanding what is going on
- Video appointments need to be easy to access with a useable interface, benefit potentially in standardising the interface of the software such as a single solution across primary, secondary, community etc

h) Medication

- Some people are happy to have a medication review on the phone, whereas others would prefer a face-to-face appointment
- Some people find it easier to order medication online and have their medication delivered

i) Digital technology and people with protected characteristics

- People with hearing impairments reported being notably reluctant to use digital technology such as audio / video appointments. 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 (BSL) 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
- Some platforms (e.g. e-consult) doesn’t get picked up by screen readers and are therefore inaccessible
- 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
- People with sight loss are likely to be reluctant to access digital services, particularly if they are video based

- 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
- 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
- There are also suggestions that people who have suffered stroke may find digital services confusing and frustrating to use
- 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
- 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
- Some people with a disability (of any kind) say that the use of digital services would increase their reliance on carers
- People unable to speak English or who do not have English as their first language. Issues include:
    - tackling language barriers: with no means of offering translation into other languages
    - members of the Black, Asian and minority ethnic population may need interpreters or family members included in digital appointments, to offer support
    - staff must have the technical knowledge to facilitate this and ensure that it is as well communicated as possible

2.6 Hospitals working together

In relation to Hospitals working together, whilst a significant amount of work has been taking place with this priority no involvement or consultation reports have been produced that could be included as part of this or the previous mapping exercise published in May 2022.

2.7 Improving planned care

In relation to improving planned care, **six** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to improving planned care. The themes developed for improving planned care from the current and previous mapping exercise were:

a) Patients' views on elective recovery

Themes included:

- Patient and public communications, personalised care, shared decision-making, clinical validation, prioritisation of patients, proposals for creating additional elective capacity, and the current pressures on accident and emergency services
- One of the most important themes was around helping patients to stay well during their wait for care so support services, such as patient information and guidance, social prescribing options and activities provided by the VCSE sector were also covered

b) How delays to care during the Covid-19 pandemic have affected people

- **Access to services** - people reported having difficulties making appointments to see GPs face-to-face, not receiving expected follow-up care or diagnostic tests in a timely manner and delays in accessing specialist services
- **Communication** - some people experienced a lack of communication about waiting times and next steps for treatment, which led to them feeling abandoned or overlooked. Poor communication led to missed opportunities to empower people to better manage their own health conditions
- **Quality of care** - some people highlighted the need for service improvement to support people with psychological and mental health needs, brain injuries and long-term illnesses
- **The impact of delays to care on individuals** – people reported severe deterioration in their physical, mental and emotional health, with high levels of anxiety and worry amongst people, even more so where people were living with mental health conditions. Others had seen a financial impact or been unable to work.
- **The impact of delays on family members** – people clearly showed that the delays don't just affect the individual needing care or treatment, but also had a 'knock on' effect to family members as well
- **The importance of support from friends and family** - over 55% of people reported seeking help from family and friends to help them manage everyday tasks, supporting people physically and mentally, and were there to listen and provide emotional support

- **Travelling further for care** - most people would travel further or be willing to access services at a private hospital (as an NHS patient) if this meant they would be seen sooner. However, people had concerns about transportation difficulties and caring responsibilities if they had to travel further afield
- **Pandemic healthcare changes** - access to services was listed as the priority of people, with others listing improving services and improving communication as the things they would change. People liked the quietness of waiting rooms and praised the phlebotomy service for improving during the pandemic
- **Improving health and wellbeing** - many of the comments in this section related to pain management, pain affecting health and wellbeing and impacting on sleep. People told us an improved way to contact consultants; making online booking easier and allowing greater advanced bookings would have improved their experiences

c) How to support people who have experienced delays due to the pandemic

- Healthcare services must understand how these delays are affecting people mentally as well as physically and the ‘not knowing’ or ‘feeling forgotten’ only makes the situation worse. This can be alleviated with regular contact and updates
- Basic communications with patients should include where they are on the clinical pathway, what will happen next, who will see them, what the approximate waiting times are, what they need to do to look after themselves whilst waiting and who to contact if they deteriorate or need help
- Make sure that people know about social prescribing services in their area
- Many patients would be happy to travel further afield if it meant that they could be treated sooner. Consider all options for accessing services across West Yorkshire and beyond. If people are given the option to travel further away from their home to be able to access treatment sooner, that service should include transport to and from the site because not everyone has a car or can use public transport. We must not penalise people who are unable to make their own way there
- For some people, the wait for treatment is causing massive money worries. People are worried that they're going to lose their jobs. If you can signpost effectively to people who might be able to help with things like benefits and claims, it could improve their wait

d) Improving planned care

- **Consistency in the quality and availability of care, treatments and ongoing support across the patch** - this consistency of care should be wider than just NHS and local authority services and should include the services provided by the voluntary and community sector; they don’t want a postcode lottery
- **Provide more care closer to home** - people want to see more care closer to home and in a variety of community settings, delivered by the right staff. They see GP practices and community buildings as convenient locations at which to receive services, as getting to them reduces travel times and costs. Although they would travel further for urgent or specialist care
- **Deliver flexible services that offer the right care at the right time in the right place** - people want to improve access to services and appointment systems, with greater availability at evening and weekend. There also needs to be some variety in the way that appointments can be booked and how services are accessed, like drop-in centres, telephone and video appointments, and online booking. People with long-term conditions want to be able to self-refer directly to services
- **Ensure that hospital discharge is well planned and timely** - patients want to have a thorough assessment prior to being discharged, to ensure that they are ready to go home, and if they are, to have all the appropriate aids, adaptations and home care support in place prior to them being discharged. This should include assessing the needs of the whole family, especially in situations where the patient had previously been a carer for either their own children or partner
- **Provide seamless, holistic care that links all aspects of care together and wraps around a person’s needs** - people expressed frustration that different parts of their care don’t run smoothly together, instead they face gaps between services and a lack of clarity of which services to access to get the care they need. Care pathways should encompass all of the care needs of the patient, not just their condition, and should support patients at all stages of their health care journey, including reviews, follow-up and ongoing support
- **Improve communication about patients both within and between organisations involved in their care** - patients want their healthcare records to be shared by organisations, to enable health and social care professionals to be able to make a more informed decision about their care and so they don’t have to repeat their story. To ensure high standards of care, efficiency and good patient experience there is a need for all organisations who are involved in their care to communicate with each other to ensure that the patient receives a seamless service

- **Increase the involvement of the voluntary and community sector** - support available through the voluntary sector was praised. People said there should be more groups to support people
- **Provide services that meet the needs of a diverse population** - we have a diverse population, and we need to consider all our population when designing new services, current services still don't address patient needs in terms of access, culture, information and communication

e) Quality of care in Hospital

Healthwatch have reported that they have started to hear about negative experiences of people staying in hospital. People have told them that staffing seems to be an issue, where staff are busy and overstretched and there appears to not be enough staff to deal with patients on the ward. This has resulted in people not always being treated with care and compassion and their dignity being compromised.

f) Leaving hospital

We have been hearing about people's experiences of hospital discharge. People told us about their experience of being discharged too early from hospital and not feeling prepared. The reasons for this included not having been informed it was going to happen or that it felt rushed or happened at very short notice.

Others talked about not feeling involved in the process and this is even more of an issue for family members and carers.

Where discharge had worked well, people cited good communication, feeling involved in the process, involvement of their family members where applicable, and good coordination and quality of after-care as key reasons for this.

People discharged home were more likely to be dissatisfied than those sent to a community care or other residential setting. The reasons given for this were a lack of follow up and people feeling that they had been left to sort things out for themselves, sometimes with no contact details of who to call if they needed anything.

Communication about discharge was highlighted as a concern, especially for those people being discharged home. People spoke about wanting better communication with family carers and more accessible information on discharge papers which they could easily understand and use to inform the person’s ongoing care.

g) Factors that influence people living with hip pain to seek hip replacement

- **Lack of understanding about the procedure** – some people had misconceptions about the procedure, which put them off
- **Anxiety around hospital environments** – some people said they were still worried about entering hospitals as they felt they were more likely to catch COVID-19 in these settings
- **Impact on work** – people told us that not being able to work during the 12-week recovery period after a hip replacement operation would have a negative impact on them, financially and in their work life
- **Impact on caring role** – we heard from people with a caring role that the 12-week recovery period after a hip replacement operation would have a negative impact for them
- **Impact on family life** – people told us that that the 12-week recovery period after a hip replacement operation would have a negative impact on their family life, as they were relied upon for childcare, domestic duties, transport etc
- **‘Worst-case scenario’** – people said they had been told the ‘worst-case scenario’ by healthcare professionals in terms of pain levels, recovery times and outcomes, and had consequently decided against the procedure
- **Length of appointments** – some people told us that they didn’t feel they had long enough during the appointment with the orthopaedic consultant
- **Trust in consultant** – people told us that it was important to them that they trusted the person operating on them
- **Public perception** – people told us they had a perception of hip replacements as being a major operation, high risk, and with a long recovery time
- **Length of time on pathway** – people told us that the length of time between seeing their GP for the first time and having the operation had an impact on their decision-making
- **Health prior to the operation** – people told us that they felt more confident about having the operation if they felt healthy and strong

2.8 Improving population health

Ambitions:

- increase the years of life that people live in good health, and reduce the gap in life expectancy by 5% in our most deprived communities by 2024
- strengthen local economic growth by reducing health inequalities and improving skills.
- reduce anti-microbial resistance infections by 10% by 2024, reducing antibiotic use by 15%
- become a global leader in responding to the climate emergency
- cost of living

In relation to improving population health, **twenty-five** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to improving population health. The themes developed for improving population health from the current and previous mapping exercise were:

a) Health inequalities

- **Improve the provision of information on self-care and prevention** - people want to be given the information they need to help manage their own health and wellbeing and considers their own personal circumstances. They want more focus on prevention and innovative opportunities to keep themselves well. They feel that more information about healthy lifestyle choices should be available with professionals being provided with the relevant skills and knowledge to advise and support individuals with any changes they may wish to make. Physical activity, eating well and access to social activities were the main things that people felt would help them live more healthy lives
- **Provide services that support the reduction of health inequalities** – when we are looking at changing how or what we provide people want us to consider the impact those changes can have on people from deprived communities and to look at how we can improve services to help reduce health inequalities
- **Provide services that meet the needs of a diverse population** - we have a diverse population, and we need to consider all of our population when designing new services, current services still don't address patient needs in terms of access, culture, information and communication
- **Impact of poverty on accessing health and care** - this ranges from digital exclusion to being charged for letters, not getting some health care and treatments such as dentistry

because NHS services are simply not available to them, through to other interventions that cost money

- **Digital inclusion** - as we have moved to delivering services remotely, we need to make sure that we do not further exclude people with inequalities

b) Health inequalities – migrants

Healthy behaviours

Some people were keen to adopt healthy behaviours:

- To have a healthy diet and awareness of good foods to eat
- To participate in exercise, particularly walking

However, barriers faced when trying to adopt healthy behaviours include:

- The high cost of fresh produce
- High cost and limited accessibility of exercise sessions
- Lack of gender-specific provision at gyms and swimming pools
- Poor weather conditions in the UK which prohibit participation in outdoor activities

Housing

Numerous issues relating to poor housing were identified:

- Too small and overcrowded
- Poor quality furniture
- Vermin-infested
- Not fit for purpose – for example steep steps for mother with pram
- Not conducive for socialising, and presenting a challenge to build relationships and integrate into the community

Education, skills and employment

- Lack of English language and literacy skills makes people feel isolated and makes life challenging
- Lack of meaningful activities or employment while waiting for processing of their asylum claim
- Accessing ESOL (English for Speakers of Other Languages) classes is very difficult due to high demand and financial pressures and there are long waiting times between courses
- There is a lack of childcare support to enable access to education, skills development and employment

- There is a need for digital skills training
- There is the need for more support to enrol children in school and some children may need additional support in school
- More support is needed to access employment

Transport

- High prices make public transport inaccessible
- Driving lessons are also not affordable
- There is a lack of awareness about how to navigate public transport

Income

Many migrants in vulnerable circumstances are experiencing extreme financial hardship and depend on the goodwill of individuals or charities to access basic requirements such as food or healthcare

Community integration

Participants identified the need for support for a range of issues relating to integration into the community including:

- Understanding life, laws and culture in the UK
- How to make social connections
- Signposting to local support organisations
- How to navigate the local area

c) Experience of contingency accommodation for people seeking asylum

Food

- Some of the residents who had been living in the hotel since it had opened as contingency accommodation (for three months) commented on the improvement in the quality of food since their arrival. Initially the food was too spicy; residents complained and this issue was resolved
- Some residents still feel the food could be better: sometimes the same thing - or leftovers - are served on consecutive days or reheated, which gets boring
- Some residents would like to be involved with cooking. They cooked at home and it was a large part of their social lives

Families

- People with young children have found it difficult to manage in the hotel as there is very little space for children to play as the hotel has a lack of communal areas
- There are many children living in the hotel and two people with young families commented on older children playing at night, which often disturbs younger children
- The hotel rooms can also be quite full, with up to four people from a family in one room
- One single mother felt that having people around was a helpful support system for her and her child and that other people in the hotel helped her

Safety

- Most people felt safe living in the hotel and had felt safe since arriving
- Some single women did not feel safe due to factors such as living in mixed accommodation, feeling trapped/jailed, feeling other people were judging them or they would tell others in their home country where they were

Staff

- Most people found the security guards, the Mears staff and the kitchen staff to be very polite and friendly
- A few people mentioned issues with members of the security staff, but some were worried that they may be able to influence their asylum claim, so were afraid of complaining
- Housekeeping come into the rooms whilst people are; this sometimes makes people worried as everything they have is in the room
- For some there was a fear of discussing issues with staff as worried it might impact on their claim or quality of life in the hotel

Culture

- Cultural difficulties in living with many people from different countries and different backgrounds
- Many remarked that they felt the hotel was safe but it wasn’t comfortable. Some felt it was improving and staff were listening to them when they reported issues

GP

- Many residents highlighted issues with GP registration, Mears had informed some people they were registered but it took up to two months to be able to make appointments with the GP. Some people weren't warned of the long wait times
- Some had difficulties in collecting prescribed medication as their name wasn't on the system
- Many interviewees reported that Mears staff had been very helpful in arranging appointments and transport to appointments, making access much easier

Schools

- Many of the children in the hotel had been registered with schools, but some were unregistered for up to two months after arriving. It was difficult to access schools initially, it was very difficult to keep children entertained in their rooms and it was very noisy
- Some families said that the school their child had been registered with was very far away and difficult to get to. This is even more difficult for families with children at different schools or who have young children they need to take with them

Housing

- Some single women did not want to be housed with people from the same city as them, citing the importance to them of protecting their safety and identity
- Some people did not understand the system or why they couldn't have their own houses. Many residents said that having their own house would improve their quality of life, especially those with children. The freedom of cooking their food of choice was cited as a reason
- One person said there should have been more explanation around moving people from different hotels

Studying

Some people said they wanted to take up further study or placement opportunities, they had not managed to get further information on how they could go about this.

d) Health inequalities – homelessness

- **Prioritising health -** financial barriers and the stresses of homelessness often prevented health needs from being met. A lack of access to nutritious food worsened existing health conditions

- **Access to dentistry -** a lack of information about access, and the challenge of remaining registered while homeless, meant that few participants had seen a dentist in the previous year, despite a clear need to do so
- **The effects of the pandemic on relationships with GPs -** the frequent need to change GPs when insecurely housed, coupled with restrictions on face-to-face appointments, exacerbated existing difficulties with establishing trusting relationships with GPs. Those who had maintained long-term relationships with an individual doctor reported the most positive experiences
- **Patient-led treatment** - feeling listened to and involved in treatment were highly valued. Many participants felt uninformed about treatment, test results and diagnoses, resulting in feelings of disconnection and disempowerment
- **Positive relationships with pharmacies** - consistent relationships with pharmacy staff were sustained throughout the pandemic and these staff were highly praised, particularly for their non-judgemental attitudes and personalised advice
- **Stigma of drug and alcohol dependencies -** Accident and Emergency units and GPs were often identified as exhibiting discriminatory behaviour towards those with addiction issues
- **Addiction as a barrier to accessing mental health services** - participants experiencing drug and alcohol dependency were less likely than others to successfully access mental health services. They felt that GPs and mental health services often misunderstood the relationship between mental health and addiction
- **Untreated mental health conditions affecting trust in health services** - expectations of GPs' role in referring to mental health services were high. When these expectations were not met, it could lead to a loss of faith in the NHS and a consequent disengagement from services. In turn, this led to a worsening of physical health conditions
- **Unmet mental health needs leading to homelessness** - around half of participants thought that their homelessness could have been prevented if their health needs had been better met beforehand. Women were twice as likely as men to believe this. The unmet needs discussed in relation to this almost exclusively related to mental health
- **Praise for specialist homeless services and peer support** - dedicated health outreach services, especially in homeless daycentres, were positively regarded. Some support and advocacy, however, exposed power inequalities and feelings of helplessness. Support from people with lived experience of homelessness and addiction was enthusiastically supported as a solution

e) Tackling health inequalities for ethnic minority colleagues and communities

An independent review was commissioned by WY&H HCP, aimed at tackling health inequalities for Black, Asian and minority ethnic (BAME) communities and colleagues. Key themes for the review were:

- improving access to safe work for BAME colleagues in West Yorkshire and Harrogate
- ensuring that the WY&H HCP leadership is reflective of communities
- population planning - using information to ensure services meet differing groups' needs
- reducing inequalities in mental health outcomes, by ethnicity

The review set out recommendations, against each of these four themes - aiming for services to be culturally competent and contribute towards reducing inequalities identified.

f) Anti-racism movement – campaign development

In the planning of this movement, over 100 ethnic minority colleagues from across the Partnership come forward to share their experiences of racism and help their colleagues and other organisations to act. The themes raised were:

- **Systems of oppression -** these factors manifest in the systems such as education, health and public services and affect progression and opportunities, resulting in a lack of representation, particularly at senior level. Some participants described a glass ceiling, that despite qualifications such as master's degrees and PhDs, stopped any further progression. People pointed to data which acknowledged gaps in access to services, particularly mental health provision. Government policies around immigration were acknowledged to disproportionately affect people of colour
- **Adopted behaviours -** behaviours or survival mechanisms that people of colour must adopt to minimise suffering, mistreatment or discrimination. The hyper vigilance, exhaustion and paranoia people of colour suffer, constantly feeling the strain of racism and having to pre-empt and prepare for any instances of it. People spoke of not being able to be themselves - having to play a role - and how they were conditioned to simply put up with and accept their treatment. Some people referenced hierarchies of ethnic groups, based on patterns of migration, historical context and colourism
- **Appearance/Perception -** how racism appears overtly, and how outwardly, people of colour are perceived. This appearance or perception that comes with racism, manifests in a range of ways, from tokenism - using people of colour in particular roles for optics - to the isolation many people of colour feel. People spoke of the awkwardness they had

encountered and in particular, an avoidance, with people in higher hierarchical roles becoming defensive over their refusal to acknowledge the experiences of people of colour and instead relying on their own knowledge and understanding of communities

g) Green social prescribing funding programme

Five health and wellbeing outcomes emerged:

- **Peace & restoration**; interviewees referred to the restorative and replenishing effects of being in nature on the participants
- **Self-determination**; participation supported autonomy and self-determination and there was evidence of ‘up-skilling’ and education
- **Curative**; natural environments were considered to aid recovery, support overall health as well as ‘rekindle’ a zest for life
- **Social cohesion**; combatting isolation and supporting community cohesion was a benefit of the projects
- **Biophilia**;1 facilitating an innate connection with nature.

Interviews with service providers indicated positive environment impacts which were:

- Learning to grow food
- Distributing food that was grown to local population
- Learning to cook fresh produce
- Developing environmental awareness and sustainable behaviours
- Supporting sustainable models of healthcare
- Creating and enhancing greenspaces

h) Physical activity

- People told us that access to cheaper exercise and more accessible walks in the countryside would be beneficial
- People told us that they value quality of greenspace, citing a multitude of other health outcomes being addressed as well as physical activity (mental health, air quality)
- People told us that driver behaviour (particularly close-passing and speeding) discourages both cycling and walking

i) Weight related bias and / or discrimination

- Over half of the responders felt they had experienced weight related bias and/or discrimination

- Individuals who had experienced weight related bias and/or discrimination were more likely to have accessed tier 3 and 4 weight management services
- Individuals who had experienced weight related bias and/or discrimination were more likely to actively pay for goods and services regarding weight management
- They were also more likely to have sought/ needed multiple levels and types of support.
- Weight related bias and discrimination enhanced weight anxiety and lowered confidence regarding weight, in social settings
- Weight related bias and discrimination affected individuals priorities and beliefs regarding the importance and value of their weight within society
- Over 90% of participants that experienced weight related bias and/or discrimination felt they had been negatively judged because of their weight
- 45% of individuals stated that their first experience of weight bias and/or discrimination was before they were 16 years old in a school setting either from a classmate or teacher
- 54% of individuals experienced weight bias and/or discrimination within General Practice settings
- When visiting the GP or healthcare professional's individuals felt that every health problem was blamed on their weight, even those not related to weight such as a sore throat
- Individuals felt that GP's and healthcare professionals need to demonstrate more compassion towards weight issues
- Participants believed to feel comfortable with their weight they 'needed to lose weight' and 'improve mental health', independent of experience with weight bias and discrimination
- Weight related bias and/or discrimination made individuals feel that they could not manage their weight on their own and that they required assistance from healthcare professionals to become comfortable with their weight
- Weight related bias and/or discrimination had a long-lasting impact on individuals leading to preventable behaviour disorders such as agoraphobia, binge eating and drug abuse
- Healthcare professionals should develop their consideration towards the psychological impact of weight management
- Healthcare professionals should better support and encourage the use of beneficial weight management pathways

j) Diabetes in South Asian Communities

Lifestyle

- Challenge is with the younger generation who are moving away from the traditional Bangladeshi foods and instead are eating takeaways on a regular basis
- Need to educate children and young people
- Promote healthy takeaways over those that have poor nutritional ratings
- Traditionally women from the Bangladeshi community are often indoors and need to get people involved in activity sessions or access lifestyle services as well as volunteering opportunities

Diet

- Lifestyle is a key issue such as diet – what people eat and when people eat which is often late in the day
- The Bangladeshi diet consists of oily food and ‘there’s cruelty in love’ where people offer food to excess thinking this is being kind. People need to move away from this culture of generosity at the expense of health
- Diet plans need to be something that people can relate to, some of the advice people receive is really good in terms of broader lifestyle, but the suggested menus are not relatable so what people need is practical advice that considers the Bangladeshi/Asian palette
- The typical Bangladeshi diet consists of curries complemented with generous portions of rice
- Historical issues where modern-day Bangladesh experienced significant famine during British rule. This has resulted in a carbohydrate heavy diet; the key is to do sensible swaps and reduce portion sizes
- Consistent theme emerged of rice being a key part of the diet

Exercise

- Consider the sensitivities to give advice and confidence to Bengali women to exercise during the day
- To address health conditions in the South Asian community, it has to be a whole family/community approach
- Impact of lockdown on people reducing the amount of exercise people do
- Intergenerational issues and cultural confidence where older women lack confidence to attend a gym where younger women will be present

Wider community issues

- Education is helpful but more important is how the message is delivered
- Have a number of people working in trades where movement is limited, leading to a more sedentary lifestyle
- The focus needs to be on the older generation, who have well established views and habits
- Need to ensure we don't create a stereotype that only people who are overweight get type 2 diabetes
- Not only do we need culturally appropriate information, but it needs to be delivered in different formats

k) Frailty

- **Information** - The challenges of getting the right information at the right time – for people living with frailty and their families / carers, and also for staff so that they know what services are available for people, and how to contact or refer to them
- **Person-centred care** - Some barriers to person-centred care – having to repeat the same information to different professionals and the importance of taking 'the whole person' into account
- **Wider determinants** - relating to travelling into town and to using public transport were raised, including worries associated with using buses, and pointing out that taxis are often not suitable for people living with frailty
- **Digital access** - a lot of information is now only online, so for people who don't have or don't want good online access this can be a barrier. Similarly, as a consequence of the Covid pandemic, some other types of support, like peer support groups, went online and haven't reverted back to face-to-face. So people who are not online are still missing out
- **Health inequality** - For those who can still access face-to-face support or social activities, getting there is the challenge, especially for people living in areas of higher deprivation. Issues re buses and taxis is mentioned above, but also the important lifeline services like the Access Bus offers, particularly to people who would otherwise be very isolated

l) Climate change

- Few people were aware of the net zero target, but when told of it, staff, patients and citizens strongly support it. They need some contextualising information to illustrate the contribution that the NHS reaching net zero will make, for example the proportion of vehicles removed from the road

- Many staff were proud to work in an organisation that has made this commitment, and staff who completed the survey are highly motivated to make changes
- People need to be reassured that the changes will not adversely affect clinical outcomes
- Leaders and senior managers need to show what they are doing personally to reduce their carbon emissions and encourage others to make similar changes
- The organisations that make up the Partnership need to show what they are doing to make it easier for staff, patients and citizens to behave more sustainably
- The ideas of how to tackle climate change that received the strongest support were arranging appointments that minimise the need for patients to travel, showing patients and clients how to be more sustainable, a website with carbon emissions targets and progress towards them, taking carbon awareness training, and sustainability not being the last list item on agendas

m) Housing

Housing and community

- People made a broad range of comments about housing, with improved access to affordable homes being the most common. Suggestions include the need to replace social housing that has been sold off in previous years
- People mentioned the lack of maintenance and upkeep of community spaces. They talked about ‘caring’ for local spaces, which seems to suggest both the council and residents taking care
- People raised concerns about the cost of local rental properties
- There were some positive comments about the variety of quality homes, which meet people’s needs
- People highlighted their concerns about the development of housing and about protecting green spaces, indicating a preferred use of brownfield sites and the use of empty buildings as alternatives
- Other comments were about anti-social behaviour in communities and a lack of cohesion or neighbourliness. Several people said they are concerned about mixing of younger and older people in social housing, and how this has a negative impact on residents

Social housing and community

- Most participants said that they would like to see more investment in their home. Issues mentioned include roofs, space heating, kitchens (including extraction), bathrooms, windows and doors. A small number of participants mentioned providing solar panels. Some participants would also like to see investment beyond their home, including better communal entrances and environmental improvements

- Anti-social behaviour and fear of crime were highlighted as concerns by many participants. Issues mentioned include dealing with anti-social behaviour, evicting nuisance tenants, more police presence and the control of drug use. Some said they would feel safer if better doors and CCTV were provided. Many people commented on the need for working more closely with the police, especially in relation to drug dealing and nuisance motorbikes
- Lot of participants mentioned grounds maintenance, including grass cutting (concerns include the frequency of grass cutting and the clippings not being taken away) and the general upkeep of estates (concerns include poor maintenance of footpaths and overgrown hedges). Garden maintenance issues were frequently mentioned. Some tenants are struggling to maintain gardens due to poor health or for age related reasons, and some are finding that tree management is too big a job or is too expensive
- Many participants mentioned household waste management, recycling facilities and garden waste collections. A small number of people said they would like support with dealing with garden waste. This suggests that some tenants may not know about the garden waste collection scheme or that the cost of the collections is an issue
- Car parking was a relatively common theme, with suggestions including more road parking and installing driveways as well as allocated parking bays
- A few people mentioned the poor condition of highways and footpaths, sharing concerns about slips and falls. Participants who mentioned repairs commented on the quality of work not being good enough
- Many people commented on their relationships with Housing Officers, including how often they see officers, their role and whether action is taken. A number of people said that they would like officers to check in with tenants more frequently both to see if tenants are safe and well and to take tenancy action where appropriate due to untidy gardens and the condition of a property
- Tenants also mentioned working closely with residents to make estates better places. A number of people commented about engagement and communication with tenants. There’s need for a range of different communication methods to be used for making contact, to suit the needs of tenants. People would like more opportunities to engage with other tenants and officers. Other comments included tenants not knowing what services

they can access and the need for regular engagement between tenants and Area Housing Managers

Suggestions on what could be improved

- Dedicated neighbourhood teams to include staff and residents all working together to improve estates. Tenants should have more say on the look of estates
- Loans of equipment or use of gardening equipment for a small hire fee would make gardens easier to maintain (this could work for lawnmowers, wallpaper steamers, drills etc)
- Regular estate walkabouts with our Estate Management Officer to give a chance to discuss any problems that may arise and to request works that would improve the look of the area
- A yearly review on how a tenant feels about things, either with their home or the community they live in
- More services available for disabled people and more properties adapted for vulnerable and disabled people. Checking up on elderly people more to make sure they are OK
- Recycling facilities for high density housing
- More secure gates and fencing should be installed along with cameras “so that us older people can feel safe alone in our homes”
- Efficient enforcement of tenancy rules. Stricter measures imposed on those causing anti-social behaviour
- Check that the work workmen do in homes is done to council standards
- Email contacts to each department, “particularly for those like me with mental health issues or people using the phone this would be invaluable”. A named person to contact: “Sometimes we can be unsure of what to do about a problem, i.e. when the really heavy rain fell a few months ago”
- Young people want to be engaged through social media – Tik Tok, Snapchat and YouTube. Decision makers need to put faith in young people – their input is important
- Opportunities to give quick feedback through commenting on content. More questionnaires and newsletters. Help people to speak more as a community

Housing needs of older people from South Asian and African / African Caribbean communities

- A cultural shift in family structure – more older people from ethnic minorities are now living alone, and this will be more prevalent in the next 10-15 years. This could be through choice, where an older relative wants to live independently from their family, but also in some cases it is a necessity, for example where the family are working/live far away and are not able to look after an older relative

- The majority want to stay where they are but there was a significant proportion of older people from ethnic minorities that were seeking to move to alternative accommodation
- Many older people from ethnic minorities are living in properties that will not be suitable for later life because the homes are not accessible or easily adaptable and lead to some people being socially isolated or lonely
- Older people are seeking a range of housing options and homes that will be suitable throughout their life course. This is about being able to adapt existing properties as well as designing new builds that are 'future proof'
- Both 'downsizing' and 'rightsizing' are important. Whilst some older people from ethnic minorities want to move to smaller, more manageable properties as they get older, others prefer a larger home where they can live with family or have family to stay for later life
- There are several barriers that prevent older people from ethnic minorities moving to 'housing for older people'. For example, existing stock is not culturally and/or religiously situated, there is stigma within some communities, it is associated with a care home, or there is a lack of information and advice
- Older people from ethnic minorities are seeking 'housing for older people' and services that are culturally and/or religiously competent
- Whether living at home or in specialist housing, more high quality, culturally and/or religiously competent support/care is needed
- More cultural/religious competent service providers to better meet the needs of ethnic minorities
- Access to cultural and/or religious amenities is crucial to combat social isolation and loneliness
- Whilst homeownership is seen as aspirational, a number of older people from ethnic minorities are also experiencing financial insecurity in later life so a range of tenure types are needed
- There is a significant lack of awareness of housing and support options and a strong view, that local community organisations/the third sector are best placed to deliver this
- People are seeking better opportunities for collaboration and to be involved in decision making around future housing which will help to build trust between the council and community

Housing related support service

- Having a safe and secure environment
- Having private space
- Having well trained, reliable and proactive support workers
- Having a recovery focused service with specialist provision
- Having a joined up, person centred approach
- Need for a befriending service to combat loneliness and isolation.
- Groupwork for promoting independent living and budgeting
- An advocacy service, especially for YPASS (young people's housing related support)
- To combat digital exclusion and provide access to IT equipment
- The need for the young people's YPASS service age range to be 16-25 years
- Need to 'tell your story once' and have an accessible single point of access

Views of landlords from the private rented sector

- Landlords would not consider tenants that came without deposits and references and saw no reason to do so
- Most landlords claimed to take an active role in selecting tenants, with many wanting to meet tenants personally and relying heavily on "gut instinct" in making judgements on tenant's suitability. Most see deposits and rent in advance, references and even guarantees as essential precursors to granting a tenancy and were unwilling to consider tenants unable to provide these
- The category of tenant that most sought to avoid were heavy drinkers and alcoholics – seen as unreliable payers and deeply problematic tenants
- The tenant type that most were keenest to avoid were heavy drinkers and recovering addicts or alcoholics. Such tenants were regarded as not only likely to be unreliable in terms of making rental payments but likely also to be disruptive to other tenants
- Those who had taken on tenants with alcohol or drug addiction issues, in the most part unknowingly, reported that tenancies broke down rapidly and that properties were returned in an unacceptable condition
- Those who had taken on vulnerable tenants were keen not to repeat the experience
- Many letting agents do not accept tenants who are receiving benefits, while some landlords are prohibited from letting to them by mortgage and insurance policies

Impact of Covid on housing

- During Covid Social Landlords stopped providing an active offer to let vacant properties. Although active letting has now commenced it has meant that there are less properties available especially given the current ban on evictions. This eviction ban has also reduced the number of private rented properties coming to the market. Both types of landlord are therefore able to be more selective of tenants
- Due to the pandemic it has proven to be even more problematic to secure funding from charities that help with furniture/bedding and/or rent in advance due to the increased number of applications and the lack of funding. Some charities have had to change their application process from ‘open all year round’ to operating ‘windows of funding opportunities’ to cope with the demand and are struggling to award all applications. The decision of awarding those applications that are likely to be successful are also taking much longer

n) Cost of living

People told us that the increased cost of living has negatively impacted their ability to access health services, ability to manage their own or others’ health conditions and negatively impacted the health and well-being of people who would usually be considered healthy.

Digital access - Not everyone can afford a computer or smartphone which is a barrier to booking GP appointments online. There is also an added cost of maintaining use such as topping-up phone credit to make calls.

Transport - Some people are unable to attend appointments because of the cost of travelling to get there. The rise in fuel costs has meant that people are reluctant to drive and use expensive public transport. Students in particular travel further than others depending on whether they are registered at home or a GP practice near the university housing and where they are residing at the time. One person said they only book online because of the cost of travel.

Treatment - Some people are reducing the frequency of treatments that they must pay for due to the costs. People told us dental treatment is very expensive.

Prescriptions -The cost of prescriptions has gradually risen and those who need multiple prescriptions are finding the cost to be too much. Some are thinking of prioritising one medication over another.

Food

Many people told us they had noticed food prices going up. We heard from different people that they are:

- Reducing the food, they buy to the minimum.
- Struggling to buy fresh fruit and vegetables.
- Prioritising feeding their children and reducing their own meals.
- Buying food that will be filling first and foremost, rather than nutritious or tasty.
- Avoiding using gas to cook food.

Occasionally, people – younger people in particular – told us they were choosing to get takeaways rather than turn on the oven. We have also heard concerns from one person about their medication being less effective because it needed to be taken with food, something they cannot afford.

Heating - People told us they are limiting their use of heating at home. This is affecting people’s mental health as their home is no longer a nice environment to live in and impacts people's physical health and long-term health conditions.

Socialising & self-care - Some people told us they aren’t socialising with friends as much because they can’t afford to go out, can’t afford to have people at home because of heating costs, or because they are having to work longer hours. Some described how they lived with worry about money, with a few making a link between their declining mental wellbeing and fears for their financial future.

Some told us that they no longer do the self-care activities they used to do, such as going to the gym.

Childcare / education - Concerns were also raised for parents who are struggling with childcare costs and are finding it hard to keep up with school expenses such as school bus fares and school dinners.

Impact on people with long term conditions - People with long term conditions, such as people with asthma, Alzheimer's disease and arthritis are even more affected by the cold. Also, people with specific dietary needs must buy food that is often more expensive. There is also the concern that some people who have a long-term condition or disability are unable to go out and therefore unable to access the provision (such as warm spaces) that lots of organisations are offering.

We also heard from stroke survivors about the impact of the cost of living on their recovery. They talked about the importance of having access to physical activities to support their recovery and wellbeing, but this was becoming limited due to cost.

What would people like services to do?

- More funding for community organisations and groups that support people locally was suggested as they are providing invaluable support to the people who need it most but are struggling for resources and funding to keep running
- A one stop phone line that could help people to find and access the services they need
- Further support for people who need to access services but live rurally
- More information about the support available
- More education about how to eat healthily on a budget
- More financial support with energy costs
- Cheaper fitness activities
- Support with travel costs and/or more local services that are easy to get to
- Vouchers for essentials such as food
- Consideration for costs incurred on carers as well as the patient
- Students in particular faced issues with travelling, between university and home, to access their GP and commented that it would be financially better to enable students to have more than one GP
- Some people also said they would like people in power to understand their situation more and really listen to them

o) Food resilience

- People trust the organisations they are part of but are wary of external input
- People are living with financial pressures meaning they are looking to feed their families in the most cost-effective way

- People are living chaotic lifestyles, where routine and regular mealtimes isn’t always possible
- There is a lack a greater understanding of nutrition
- People want their children to eat and be full. Full tummies is a bigger priority over health and nutrition
- Some families do cook however it needs to be more nutritional and other families don't at all and rely on takeaway meals
- Within the school setting, there is support taking place for children and their families to develop more nutritional eating habits. The older the children the more external factors come into play with regards to children’s eating habits e.g. peer to peer pressure
- There was no association between household income and how often people eat out or have takeaways
- Families with a higher income eat more vegetables

p) Impact of COVID-19

- Many families are struggling financially with 1 in 4 worried about paying the rent/mortgage, 1 in 4 not being able to afford to buy the food they needed and 1 in 10 worried about losing their home and having to skip meals because there wasn’t enough food. Many families also live in poor housing conditions: 2 in 5 families lived in overcrowded homes and 1 in 4 families live in poor quality housing (e.g. mould/damp, vermin problems, major repairs needed)
- Those who belong to non-White British ethnic groups are more likely to be struggling financially, with those in the most deprived areas and younger age groups also more likely to be finding it difficult to manage financially
- Difficulty in encouraging residents to attend events to receive support and guidance on managing their finances. Concern that stigma attached to seeking help
- People seeking help tend to be older and / or disabled

South Asian communities

- Reduction in income likely to have a major impact on families. The self-employed and small businesses are particularly affected
- Reported problems in access financial support packages from the government
- Accessing services, including those tackling food insecurity
- Families not using services which may be available (e.g. food banks), due to stigma, and / or difficulties of referral system

- There is reduced capacity of voluntary and community sector organisations to deliver services as many are reliant on volunteers who are now not able to help due to lock-down restrictions

White communities

- Financial poverty was a key concern, and it was felt this would be made worse by the current crisis
- Families not being able to afford ‘essential’ items e.g. sanitary products, soap, toothpaste with these items are not always available in food parcels
- Families may not be able to access free school meals for children
- Local business whose income has dropped are struggling to afford rent
- Many families do not have reliable internet access or not able to keep phone in credit
- Individuals who have problems with addiction who may have resorted to criminal means to pay for their addiction via shop-lifting or other petty crimes and can no longer do so may turn to more extreme methods if not given help

Eastern European Roma communities

- Many people within these communities have ‘cash-in-hand’ jobs or agency work and are not eligible for benefits. They may fall through the cracks in terms of receiving support.
- Larger family sizes mean more of a struggle to feed / food poverty
- Face to face access to organizations for support with welfare and housing has been curtailed and this is usually how most people gain access to these services
- Financial issues a particular concern potentially increasing poverty

q) Public safety

Personal safety for women

- Many women report never going anywhere alone, even to their local shops, because of previous experience of harassment or abuse
- Of those who feel okay going out alone through the day, many do not leave the house alone in the evening – citing the experience of street harassment, often from younger men/teens
- Most feel that there are no go areas of the district – anti social drinking/drug use/driving mentioned as reasons as well as harassment and this includes town/city centres

- Women talked about giving up running/walking/cycling in parks and along canals and in woodland – many have been a victim of indecent exposure and those who haven't themselves know someone close to them who has and it "puts them off"
- All women talk of constantly being on edge, risk assessing, walking with their keys in hand etc. when they do have to walk anywhere alone, this is described as worse in evenings and winter months
- Up skirting still an issue: and is not just experiences by young women – same with catcalling – abuse from vehicles including being followed by men in cars
- Many women report no longer feeling safe in changing rooms as they will see males in or hanging around them – also stating that they don't feel safe letting children in public changing rooms citing regular news stories about hidden cameras or increases in sexual abuse in mixed sex spaces/toilets etc

Safety in the workplace for women including travel to/from on foot/using public transport/accessing safe car parking

- Avoidance of multi storey car parks – fear of getting in the lift alone but equal fear of using the stairs alone – having to walk the full length of poorly lit car parks – worse in evenings/winter months – this is also an issue in large ground level car parks – poorly lit and often potential hiding places that make women feel unsafe – discussed idea of having women only spaces in similar way to disabled and parent and child spaces – so closer to entrances / lower floors of multi storey
- Public transport is unreliable – women often having to stand alone at bus stops for a long period of time – Hall Ings was cited as a particular problem area especially in evenings
- Women avoid using subways due to feeling unsafe when people are hanging around in them drinking/using drugs or behind the courts – a number have experienced indecent exposure in these areas
- Indecent exposure on buses/trains – being touched inappropriately – worse at busy times – again this happens to women of all ages – anti social behaviour on public transport again leaves many women feeling unsafe with many feeling that 'nothing is done' even when reported
- Issues raised by some who work in customer facing roles within the VCS and health sector that abuse/sexual harassment and threats are everyday occurrences but complaining doesn't help – too many report hearing 'it's not their fault, they have issues' when they report an abusive male which they describe leaves them feeling worthless as though the man's issues are more important than theirs

Role of men and boys in making women feel safer

- ALL agree that men in leadership roles/in authority need to be visible in speaking out about violence against women and girls – specifically mentions of councillors/sports teams/teachers/senior leaders across sectors.
- A real need to stop hearing ‘not all men’ from men and instead hear ‘what do we need to do to help?’
- Educate boys that they also need to report if they see a girl being targeted/abused, not be a bystander

Feeling safe after dark

- Feeling safe in the local area (during the day, and after dark) has significantly decreased in Kirklees since 2016. Females were significantly more likely to feel unsafe in their local area after dark compared to males, and this gap has widened since 2016
- Younger residents and those living in the most deprived areas were also more likely to reporting feeling unsafe in their local area after dark

‘Staying Safe’ from a young person’s perspective

- When out and about, they are scared to report crime and when they do, reporting crime to the police isn’t always easy
- Young people feel they know more about staying safe on social media than adults and believe they should be given the opportunity to peer educate each other
- There are a range of people, professionals, places that they feel should keep them safe but don’t

Criminal justice system

- Victims wanted to see the criminal justice system prioritise their needs ahead of perpetrators, as well as see improved victim services for women and girls
- Victims were more likely to record lower levels of confidence in the criminal justice system and in police effectiveness than non-victim respondents
- People want the police to focus on crime that causes the most harm and impact, such as child sexual abuse and adult sex offences
- People also want there to be a focus on neighbourhood crime, road safety, and serious violence
- It was common to receive feedback that people did not want to see ‘low level’ neighbourhood crime neglected by the police

- People understand that addressing poor mental health and child vulnerability can help reduce crime and should be an area of focus

r) Sexual abuse

Misogyny as a hate crime

- Women are removing themselves from social media as abuse of them is normalised and nothing happens if they report it – includes open misogyny – threats of violence and rape and graphic images sent unsolicited.
- Abuse of lesbians/those in same sex relationships has become normalised, no women only spaces allowed any more either in person or online further exposing them to this
- Abuse of women by media normalised – accusations of being feminazis/bigots/hateful if women speak out for women's rights – there is rightly a backlash against racism on social media, but abuse of women is met with silence and no support
- Everyday sexism also normal in every part of society – even women in leadership roles talk of being dismissed when they speak up, told it's just banter/a joke/they're obviously hormonal etc. or being told they only got the job because they're a woman, not because they deserve it
- All women feel it's become too normalised for the police to consider this as a hate crime – they don't pursue domestic and sexual violence so why would they pursue things that are hateful towards women – especially when women speaking out are deemed hateful themselves
- There needs to be understandable descriptions of what misogyny looks like – examples from disrespect to harassment to abuse, many believe that this is why men seem to believe it's okay to treat women in ways that they would never do to another man
- Essential that this work is multi agency and high profile with women given the chance to speak while men listen but also for men to stand up and speak out that it's not okay
- Women are made to feel it's their problem, if they try to speak out their concerns are minimised, if they stay silent it's deemed that they must 'like it'

Support services – multi agency trauma informed service delivery

- From many – no knowledge of what support services are available that are purely for women and girls. The Black African and Caribbean participants highlighted this as a distinct issue and also that they find no/limited support from their churches and faith groups

- All ages believe that reporting to the police would see them being questioned more aggressively than the perpetrator both by the police and the courts so many feel that ‘it’s not worth being re-traumatised’
- A perceived lack of response from the police when a crime has been logged leaving victims having to chase officers for updates only to find it has been classified as No Further Action (NFA) and they haven’t been informed
- Lack of support for those who do go through the criminal justice system – leaves them feeling even more alone – also length of time it takes to get to court means that many women re-live trauma

Women felt that the health system labels abuse victims as having a ‘disorder’ that needs medicating rather than depression/anxiety/anger etc. as a response to trauma – there is a lack of trauma informed services for women and girls –at times women being referred to male counsellors when they have asked for a female means they don’t engage with counselling which is then used as further proof that they are the ‘problem’.

s) Domestic abuse

Who do people talk to about domestic abuse and/or sexual violence?

- Community organisations and groups say that people presenting with low level mental health issues or other problems will frequently access support, attend groups etc and only after a length of time will they feel safe to talk about what is happening within their relationship
- Friends/family can often prompt women to come forward and seek help – noticing and pointing out abusive behaviour in a relationship that the victim/survivor themselves have normalised
- Organisations working specifically with men who experience domestic abuse or sexual violence told us that men usually have not spoken to anyone before seeking help from their service
- The feeling of shame about the situation is a major barrier for victims/survivors of any gender or background to discuss their abuse
- Often women may lack the freedom to talk, having no unmonitored communication outside family – so the only place they might be able to disclose abuse is through contact with health professionals

What are the priorities of people when they seek support?

- The first priorities were practicalities rather than emotional wellbeing – safety from violence, housing, money, children's education etc
- The welfare of children was reported as a crucial factor, and the fear of losing their children was a major barrier to accessing services for support
- The most important factors when accessing support are a non-judgemental approach and a 24-hour service
- Survivors must be treated first and foremost as an individual and require easily accessible, joined up support from the right agencies at the right time. The complexities of domestic abuse and links to other adverse experiences and needs must be understood and treated holistically
- Victim/survivor engagement, access to services and housing were identified as the top three biggest challenges in ensuring survivors and families get the support they need
- Immigration status is reported as a major concern for people and can create a barrier to speaking out about violence

What is missing from the support currently offered?

- Support needed to be ongoing as longer-term intervention with individuals and families could make a bigger difference than time-limited help
- Suitable accommodation was a major concern, with people feeling that the reality of refuges and rehousing options was poor, and that people's perception was that there was nowhere for them to go
- Some organisations had been affected by reductions in funding for advice and support services and felt there was not enough training available for organisations and individuals working with those experiencing domestic abuse or sexual violence
- Need services that are culturally sensitive and support people who don't speak English as their first language
- Targeted approaches need to be created for people who are more vulnerable to domestic abuse and sexual violence
- Support for men who have been subject to domestic abuse or sexual violence was described as 'under reported' and there is a sense that the messages, information and support is targeted at women exclusively
- Some people report poor engagement by the police e.g. police not believing victims/survivors leading to a lack of trust in police. And police inaction, sometimes linked to high threshold of evidence needed

- For children and young people affected by domestic abuse, support is needed for trauma, anger management and healthy relationships. There continues to be gaps in timely counselling and therapeutic support and also early education around the area of domestic abuse and healthy relationships for children and young people. Early intervention is important and a layered approach to supporting children and young people. Independent advocacy and a safe place for children and young people to talk about their experiences is important. Support for children through non council services may be helpful for parents to give consent due to distance of perceptions of statutory services
- A lack of support for parents of children with additional needs such as autism was brought up by multiple victims/survivors
- Feedback from victims/survivors suggests domestic abuse services delivered by Local Authorities can present a barrier for some victims/survivors due to their perception that the service is closely linked to statutory services, such as Social Care. A domestic abuse service that runs independently, for some victims / survivors, would be a preferred choice of support as it offers detachment from any statutory provision. This is particularly important for some male victims/survivors and some Black and Minority Ethnic communities (BAME) who may wish to access support that is not linked to the Local Authority and rather provided via ‘by and for’ services where victims can receive culturally sensitive and informed support
- Access to groups for victims/survivors and there needs to be appropriate perpetrator programmes. Opportunities for joint working between domestic abuse agencies and schools for parents to drop in to seek support, advice and signposting

What could be done earlier to help prevent domestic abuse and/or sexual violence?

- Long term support for families and individuals experiencing domestic abuse; without these deeper interventions and complex work around social and emotional wellbeing, people often return to abusive situations or continue patterns of behaviour which can be passed on through generations
- People felt that work in schools and faith venues would make a difference, creating positive messages about what healthy relationships should be like. People often repeat patterns of behaviour that they see around them, and good relationship role models were crucial
- Work should be done to increase awareness for women moving into UK for marriage – education about what constitutes abuse and how to get help. These messages should

focus not just on the husband but also in-laws who can also be perpetrators, domestic violence is often witnessed and normalised by those around a marriage

- Awareness campaigns and clear messages were needed. These should be focused on specific communities and made accessible in different community languages – created by people/organisations embedded in the community, not just a translation of a standard message. Domestic abuse and sexual violence needed to be talked about in the open, not just posters on the back of toilet doors
- Social isolation experienced by people from emerging communities, newly arrived in the UK is seen as a significant contributing factor. If people have poor social networks and/or don't understand how to seek help they are more vulnerable
- Work around wellbeing should be embedded into community organisations and into education, housing, employment to focus on building up self-esteem, helping current and future generations to be less likely to be either victims or perpetrators of violence

What is going on in our communities that is contributing to domestic abuse and sexual violence?

- Across all ages, every woman has been or has a close contact who has been a victim of domestic/sexual violence – feel it's so prevalent it's become a norm now, but society still puts the burden of blame and shame on the victims/survivors, not the perpetrator
- Women have been told they are complicit in their abuse and will lose their children if they don't leave – little to no recognition that they can't/have nowhere to go/no support/no money – women highlighted that they don't stay in situations because they like the abuse, they stay because there is no other option, or they have a greater fear of what the perpetrator will do if they try to leave
- Cultural norms and expectations, and the role models in communities. Particularly in BME and white working-class communities, people see other women who have been through and 'put up with' abuse and violence becomes normalised. In some communities' women are expected to stay silent and not talk about domestic abuse or sexual violence
- Communication and language barriers are an issue even within families, for example children speaking English but parents don't – this can create dependency on other family members which makes people vulnerable to abuse
- People from the Slovakian community in particular talked about a fear of authorities which prevents people from speaking up and seeking support when experiencing domestic or sexual violence

- Substance misuse, particularly alcohol, was identified as a contributing factor
- Patterns of behaviour in families and communities are a key issue, for example children watching their parents' relationship and viewing this as normal
- People from Muslim communities spoke about challenges which arise from the misinterpretation of Islamic teachings around marriage, for example men's 'right to sex' or the role of women to preserve family honour
- Women who divorce are at risk of being excluded from community life, this makes then more vulnerable to being repeatedly victimised
- Participants from organisations working with refugees and people recently arrived in the UK described the isolation of immigrant women, who don't want to be sent back to home country and risk separation from children so remain unknown to authorities
- Some women who have moved to the UK to marry see abuse as the price they have to pay in order to remain in the UK and have what they perceive as a better life for their children

What's most important to people experiencing domestic abuse and/or sexual violence?

- Difficulties with support, which is too closely connected to local communities, as this created a barrier as women (particularly from South Asian backgrounds) are afraid of being identified
- Confidentiality is crucial, people experiencing domestic or sexual violence need to trust that their disclosure is safe and that they are in control of their information
- People wanted to be listened to and feel that they are believed by those they report their situation to. And for services to have a non-judgemental approach
- Longer-term interventions and support for people who have experienced domestic abuse or sexual violence. Time-limited support or "quick-fix" interventions don't address the complexity of abusive relationships or tackle the cycles of abuse that are well-known
- Some people still have poor experiences of reporting domestic violence to the Police
- There is a lack of awareness of support that is available – with many people not knowing where they could turn to for help and support, particularly in communities who are not confident to approach authorities such as the Police
- There is a need to take a trauma-focused approach, particularly around sexual violence, and the importance of recognising that it can take a long time for people to recover and rebuild their lives

- Need better connections between different agencies and coordinated interventions to support individuals and families

Views on safe accommodation

- Clients needs regarding mental health and substance misuse is a barrier to accessing refuge and is a key reason for denied access to service year on year. This may be due to the shared accommodation set up of the refuge being unsuitable for them and other residents, and also being unable to provide the level of support required for their needs
- All who were accepted into refuge received support regarding accessing GPs, emotional support, practical support such as clothing, food, accessing banks, budgeting etc. In terms of housing support, the majority were offered support and guidance regarding rehousing and accessing housing options
- The majority of those accessing safe accommodation in Calderdale were from out of area and had self-referred via Domestic Helplines. A survivor detailed their experience of having to be housed in a hotel for a period of time with young children which was difficult, not only because of the lack of food and facilities but also the behaviour of other residents including fighting, loud music drinking etc and the impact of this on them and their young children. Another survivor was also placed in temporary accommodation before a refuge space became available
- One survivor stated that their therapy dog was a barrier to accessing safe and/or temporary accommodation which was of huge concern
- Overall, survivors felt well supported within the refuge especially those with children. It was felt that those without children may have been less supported. One victim felt that due to their previous employment, staff believed they should be able to complete forms and applications themselves and therefore received little support when they needed more
- In regard to support for children, whilst play sessions were held and referrals to family support were made, there was little support available. Survivors felt that support for their children and support for them as parents would have been beneficial

Leaving refuge

- Whilst survivors felt well supported in refuge, a clear theme from the conversations was the lack of support when leaving refuge and after they moved
- Survivors informed us that they had to source their own moving vehicles and support with this. This was a challenge due to some of the staff being male and therefore could not access the refuge, the cost of removals was also an issue

- A clear theme was feeling alone once they had left refuge and a lack of continuing support
- In addition, survivors were told that agencies such as housing providers would pick up their support, but this did not happen
- For those who had moved to new accommodation, the sanctuary scheme was offered but was not installed, due to a lack of funding

2.9 Innovation and improvement

In relation to Innovation and Improvement, a significant amount of work has been taking place with regards to digital and technology and this is captured under the digital technology section of this report. With regards to any other initiatives no additional involvement or consultation reports have been produced since the previous mapping exercise. The themes developed for Innovation and Improvement from the previous mapping exercise were:

a) Cardiac & pulmonary rehabilitation

Based on the findings from this engagement, rehabilitation sessions were moved online, using Apps, although patients can also receive phone calls.

b) ‘Bradford B Positive Pathways’ innovation programme: ‘looked after’ children

‘Bradford B Positive Pathways’ (BPP) is funded through the Department for Education Children’s Social Care Innovation Programme.

One of the key messages highlights that operation of the residential component of this service is dependent upon the ease of integration of multi-agency specialists from health, policing and education. Agencies that work alongside BPP homes’ managers and practitioners, to provide enhanced individual support for ‘looked after’ children/young people with multi-faceted needs.

The impact of this innovative, multi-agency service provision – including health – is considered to have been positive, as:

- outreach data demonstrated that most adolescents (just over 90%) considered to be on the edge of care were diverted from a care placement
- there was evidence of increased accommodation stability after placement in a BPP home
- just under two-thirds of the 94 children and young people residing in the 4 BPP homes had improved wellbeing, demonstrated through results from a standardised measure of emotional and behaviour traits

2.10 Maternity care

Ambition

Reduce stillbirths, neonatal deaths, and brain injuries by 50%, and reduce maternal morbidity and mortality, by 2025

In relation to maternity care, **four** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to maternity care. The themes developed for maternity care from the current and previous mapping exercise were:

a) The impact of Covid-19

- They received less contact from maternity services, many maternity and community/voluntary services they could normally access were closed or operating only online. They were unable to meet with friends or their extended family. Many felt more isolated and anxious as a result
- The impact was often greater on women living in poverty or deprivation as they have less access to the internet to access online services. Women who do not speak English were also disadvantaged as they often found communicating online or by phone more difficult
- Disjointed midwife support and a lack of face-to-face appointments leaves the individual feeling a lack of professional support and the inability to build rapport with the professionals
- Partners not being able to be present during the whole of labour, so large parts are spent on their own without support
- Partners not being allowed on the ward to bond with their baby and to help and support the new mum
- Feeling lost in the system and feeling lonely and isolated during their pregnancy journey
- The importance of face-to-face service provision, as opposed to virtual consultation
- Black, Asian and minority ethnic communities were the most dissatisfied with services
- LGBTQ partners voiced concerns that they were not recognised as ‘partners’ in the same way as heterosexual couples

b) Examples of what has worked well

- **Specialist midwifery services** – e.g. Haamla, really understand people’s whole situation including social issues that may impact their journey through maternity services and can help people to get support they need

- **Peer to peer support** – was seen to be really valuable across the maternity journey e.g. Maternity Stream offer a Peer Support Group
- **Doula services** – were seen to be helpful, where they were available or known about
- **Birth centres** – were talked about positively, in terms of the environment, facilities and ethos

c) Experience of care – before pregnancy

Information

- Absence of information surrounding miscarriage and where people can go to access support
- Lack of information on lifestyle factors potentially affecting conception such as smoking and drinking alcohol
- Awareness and understanding the impact of contraception in order to make an informed decision
- Knowing where to go for mental health and wellbeing support at this time
- Information is not distributed in a way that speaks to different communities
- Lack of information around pre-conception for males

Accessibility of services

- More opportunities for people to access information surrounding services particularly for asylum seekers and refugee communities in a language that speaks to them. Information provided should acknowledge differences in culture and values
- Not everyone knows about the services available to them through the maternity journey

Continuity of care - Lack of consistency in support after miscarriages

Equity - Ensuring that asylum seekers and refugee communities understand the care that is on offer to them. Special consideration to be given to their experiences within their home country and how support differs here in the UK

Capacity and resources - Lack of support for males to make proactive steps in increasing the chance of pregnancy

d) Experience of care – during pregnancy

Information

- Not knowing where to go for further information

- How information about risks is communicated and then letting parents make decisions based upon a personal review of the risks
- Explanations during antenatal appointments can be lacking and there is not enough time to talk about other concerns

Accessibility of services

- No access to interpreters for appointments, scans and later during labour and birth, or partners / family members being relied upon for interpreting
- Can be difficult to get a community midwife appointment
- Can be difficult to get in touch with a midwife, or someone else to answer questions, between appointments
- Many women and parents are not aware of places of support e.g. antenatal classes, support in the case of domestic violence or doula services
- Some people are charged for receiving maternity care. This can result in fear about accessing services and not accessing when needed
- Partners were not allowed to attend or access appointments with people during lockdowns

Continuity of care - Lack of continuity of care from same health professional

Equity

- Limited access to interpreter at appointments for scans
- Longer appointments needed for women with twin pregnancies

Capacity and resources - Lack of childcare for antenatal appointments

Environment

Environments people access for antenatal appointments are now always comfortable (e.g. type of seating or lack of seating) or meet basic needs (e.g. no facilities for drinking water or affordable food)

e) Experience of care – labour and birth

Information

- How information is shared, and the language used around ‘risks’
- How consent is articulated and confirmed

Accessibility of services

- Access to interpreters
- Some women may not be able to afford to travel to and from the hospital if they go in too early. This isn't something that is checked before women are sent home

Continuity of care - Lack of continuity of care from same health professional or someone the parent(s) trust

Equity

- Giving birth alone
- Encouraged to have an induction at 37 weeks due to being black. Worried about the rising link between induction and caesarean sections and what this means for choices and outcomes.

Capacity and resources

- Lack of childcare for labour and birth
- Can see staff are made to work more than what would be effective
- Systems and processes can inhibit choice and care

Environment - Environments for labour and birth do not always allow women to have the birth experience they want e.g. the bed in the middle of the room does not encourage an active birth, or the space may not allow for a Doula to be present

Person-centred care - An illusion of choice for some people e.g. birth plans were encouraged but then not read or responded to, people were given choices but then felt they were made to work hard to get the alternatives they wanted

f) Experience of care – after baby is born

Information

- Partners have need for information or answers to questions so they can support the birthing parent
- Neo-natal death and offer of emotional support
- Lack of information for partners on signs to look out for mothers / birthing parents struggling with mental health

Accessibility of services - Partners not allowed to wait with you once baby has arrived (Covid-19)

Continuity of care - Different services offering support once parents and caregivers are out of hospital due to funding locality constraints “postcode lottery”

Equity

- Data collection and ensuring this is accurate to inform new services
- Support when leaving hospital with twins is limited
- Partners may be perceived to have less parental responsibility

Environment

- After birth experiences for women can feel overwhelming and rooms can be crowded with items that seems unnecessary, using up space for family members
- Mums with babies on neonatal unit having to be around mums with their babies on the postnatal wards can be hugely distressing

Person-centred care

- Feeling like care is task focused
- Normal is different for everyone, caesarean is normal for some whilst others it is not

g) What maternity care should look like

All women

- Listen to me and treat me with respect. Don’t judge me. I’m more likely to follow your advice if you do
- I want the midwives to be friendly and professional. I differ in how much I want them to feel like a friend
- Involve me in decisions about my care
- Don’t rush through appointments and give me time to think. Take the time to answer my questions fully
- Even if I need a different approach or specialist services, don’t think of me as a problem
- When appointments are by phone or video, I don’t get the chance to build a good relationship with you
- I may worry that there are long gaps between appointments and I’m not getting checked often enough

- I may be reluctant to disclose any worries about my mental health
- If you refer me to a specialist midwife, you still need to see me holistically and be ready to provide information and support for other areas of my life, e.g. travel costs and vouchers
- I may need more help after the baby than is routinely available
- You sometimes signpost me to community organisations, but these organisations don't always have the time or resources to help me. Make sure you know about the support that might be useful for me
- It can be really difficult if I can't take my children into scans or appointments. I might not have anybody to leave them with
- Try not to discharge me from hospital in the middle of the night as I might struggle to find somebody to collect me
- Don't pressure me to breast feed but make sure I have enough support if I need it
- I may want you to involve my partner more, e.g. you could send information and suggestions to partners
- I tend to focus on the birth and don't anticipate how tired I'll feel afterwards. I need to know about the importance of resting and looking after myself, even though this is difficult when I have other children
- You need to be very compassionate if I have a miscarriage, and make sure I am signposted to organisations that can help. If I've previously had a miscarriage, I'm likely to be anxious about my next pregnancy

Teen Mums

- I might need more explanation and a bit more time in my appointments
- Don't patronise me or treat me like a problem or as if I have done something wrong
- I have things to offer too in terms of sharing my experience with others or becoming a volunteer – don't dismiss me just because I am young
- I may be reluctant to attend group sessions in case I feel judged by the other Mums, or that they are only for rich people. I'd like the option of classes just for young Mums

Refugees and asylum seekers

- I may not speak English
- I don't know about all the services I could be accessing
- I may not understand all the roles or terms, such as the difference between a midwife and a health visitor, or what a birth plan is. I'd benefit from more time during initial appointments so that you can explain how the service works

- I may assume that I need to pay for maternity services, so delay seeking care
- I may not know that women usually give birth in hospitals, and I can assume this is dangerous
- I may not have any social support so could feel very isolated, lonely and afraid
- I may not have anybody to look after my other children, so I need to bring them to appointments
- I may have been subject to violence or trauma
- I may not have any money to pay for bus fares or taxis
- I may not know the city or understand the transport system, making a taxi the only realistic option, even though this is more expensive
- Find out and tell me about all the sources of help available to me
- I might find it difficult to make a post-birth plan if I don't know where I'll be living
- I may be frightened to disclose any information in case you inform the Home Office
- I might not understand the different roles that help me during my pregnancy, e.g. the difference between social worker, midwife, health visitor. The transition between midwife and health visitor at 10 days is hard. Not knowing what services are available makes it hard for me to find information for myself - I don't know what to search for

Poverty and deprivation (including homeless)

- It's really important to tell me about claiming travel costs and to make it easy for me to do so. If I need to go to another office in another building, this is difficult, especially if I have other children with me. Offer this up front rather than waiting for me to ask
- Even if I can claim back my travel costs, I may not have the money to pay for my travel up front, which means that I might have to miss appointments, even though I don't want to. It may have been the choice between putting food on the table and attending the appointment
- Find out about sources of help so you can signpost me to additional support. Don't wait for me to ask I may not know what is available or I might be too embarrassed to ask
- If I don't have any money, it can be difficult for me to follow the advice, you're giving me. I may have more fundamental challenges, such as paying for housing or food

English is not my first language

- Find out about the interpretation service and make it available to me. Don't assume the interpreter understands medical terms, e.g. pre-eclampsia, so explain things in layman's terms

- Provide information in easy read format, using pictures
- I may miss appointments because I can't read the letters
- Even if I speak English, I may not be able to read it
- Covid rules mean I have to attend appointments alone, yet I may need a friend or family member to help me communicate

BAME

- English might not be my first language
- My ethnicity means I may be at higher risk, but don't assume that I'm a problem.
- My culture might see childbirth as less medical than you are used to
- My culture may have less involvement for partners, but they might still want to be involved
- Make it clear that you are listening to me, and I can make decisions about my care
- I might get advice from family that contradicts what you tell me
- I might find it easier to talk to people who look, and talk like me. While this isn't always possible, it's useful if you understand a little bit about my community and culture
- If I'm a traveller, I may not be able to read English even though it's my first language Being on time is less important in my culture, so expect me to be early or late. Going for a scan with my partner is important in my culture, and so I may feel that I should pay for a private scan. Tell me that this isn't necessary for the safety of my pregnancy. I prefer to trust the hospital rather than make my own decisions about my care, so making a birth plan can be difficult
- You may not be aware of some of my cultural practices around giving birth (e.g. Chinese ladies have a confinement period, during which they don't shower)
- I may be reluctant to attend antenatal classes as I'm not familiar with them and I fear I may be very different to the other mums
- Some cultural practices aren't talked about in my community, e.g. female genital mutilation (FGM)

Prison or detention centre

- Don't judge me.
- Tell me what will happen to me and my baby. If social services will be involved, I'd like to know in advance
- I may be reluctant to disclose any problems in case you take my baby away from me

- There is a lot of peer support available in prison but once I am released, I no longer have access to this

Addiction

- This is a hidden problem – you can't tell by looking at me or talking to me that I have an addiction. I may be reluctant to disclose that I have a problem
- I may be facing other challenges, e.g. domestic violence, poverty and deprivation
- Don't assume I don't know how substances can affect my baby
- I may find it difficult to engage with services, so try to make it easier for me, e.g. by offering me telephone appointments
- I may be worried about negative consequences if I haven't engaged with services throughout my pregnancy

h) Mental health

- Talking about mental health in general, most felt that there had been a lot of progress over recent years and especially in 2020 where people opened up more about their mental health and in an attempt to try and normalise how it is perceived and reduce the stigma
- 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

i) 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
- 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
- Parents most commonly received perinatal mental health support from their GP
- While relatively few parents reported getting mental health support from midwives, those who did were the most likely to be satisfied with their care
- 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

- Proactive, open-ended and frank conversations about the subject were felt to be more effective than “tick-box” style questions
- Peer-support groups provided useful support, but information about them was not given out consistently
- 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
- 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
- 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
- number of people being assessed for post-natal depression and receiving perinatal support from mental health services has fallen since 2019. Long waiting lists to access mental health support were highlighted by the local workforce as a concern
- To an extent, fathers also felt side-lined in discussions about emotional wellbeing and sometimes didn’t feel equipped to support partners. During times when fathers/partners have faced restricted access to perinatal appointments, this has sometimes resulted in decreased wellbeing for families

j) Breastfeeding

- A majority of parents agreed that they had been given enough support and information on breastfeeding and infant feeding whilst they were pregnant and postnatally. Parents spoke highly of the support received from local peer support groups, baby cafes and particular health professionals
- Comments from some parents indicate that appropriate support relating to breastfeeding has been lacking during the pandemic. This includes a lack of tongue-tie services, in-person peer support groups, and breastfeeding cafes

k) Sources of information

- Women rely on other mums for information, either their close friends, and also through Facebook groups, WhatsApp groups, online groups such as Netmums and Happy Moments. Instagram was not used much in the women the network talked to
- Family members are also a source of information, and mothers and mothers in law are particularly important in some ethnic minority communities
- Some women also look for information on NHS websites and approach children's centres
- Women who are new to the UK can struggle to understand the different terms used, even if they speak good English. They may not have encountered terms such as "birth plan" and do not understand the roles of the professionals they encounter during their pregnancy. They would benefit from an orientation session to explain how maternity and post-natal services are structured and the choices they will be asked to make. There is variation on preference for communication. For some, written is better as they can Google a translation, others want to talk, and others prefer WhatsApp

l) Materials to support women

Overall the aspects that worked well were:

- Where the tone is positive and gives hope – this is considered so important as when someone is in a dark place, they need to be able to see light at the end of the tunnel to encourage them to talk. This is the hook that draws them in
- Getting better and Recovering – Building on the hope, women need to hear that they 'will recover and get better' as it's the incentive they need to encourage them to seek help
- Talks about the condition being a real medical condition – a message that women stated to being an important component. People need to hear that it is real to help break down the stigma associated with mental health. Encouraging women to seek help isn't just about shaping what the individual thinks and knows, it is also about changing the perception of how mental health is viewed in general
- References to the commonality of the condition – ensuring that women can take comfort in the fact that it is more common than people think and that anyone can suffer from perinatal mental health concerns
- Without judgement and not reflecting on you – Knowing that people will not cast judgement on them seeking help is important and that it is not that they have done anything wrong to feel this way

The aspects that didn't work as well:

- An authoritarian tone – propositions which sounded 'bossy' or too official were instantly disregarded with women stating how important it is that the communication sounds like someone genuinely cares
- Words that can drive 'guilt' or underplay how hard it is to ask for help – the importance around word choice is apparent with women stating how words such as 'admit' and 'just' should be avoided
- Words which downplay or appear to contradict the message – 'feel real' and 'relatively common' were also sticking points as it was felt that these were less impactful as they dilute down the core message

m) 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
- 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
- Most women gave birth in the place that they had planned to
- The presence of consultants and doctors as opposed to midwife-led care can impact on women's choices around where to give birth

n) 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
- 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

o) 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

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. More staff and greater stability around staffing cover were cited as the most significant ways of improving staff members’ experience of their role. Professionals also felt that staffing levels should be a key consideration during service planning.

2.11 Mental health, learning disability and autism

Ambitions

- reduce suicide by 10% overall by 2020/21 and achieve a 75% reduction in targeted areas by 2022.
- reduce the gap in life expectancy for people with mental health, learning disabilities and autism by 10% by 2024.

In relation to mental health, learning disabilities and autism, **nineteen** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to mental health, learning disabilities or autism. Themes relating specifically to children, young people and their families and maternity care can be found under those sections. The themes developed for mental health, learning disabilities or autism from the current and previous mapping exercise were:

a) Impact of Covid-19

- Mental health issues, particularly anxiety and stress, were exacerbated by Covid-19
- Some people with learning disabilities struggled with lockdowns, shielding, masks, and exemption cards
- Most people went to their GP as their first port of call regarding mental health. However, people had a mixed experience of seeing their GP
- Whilst some have found the support offered useful once they manage to access it there are a number of barriers that are preventing people from accessing help including long waiting times, staff attitudes, the stigma around mental health and impersonal care
- A supportive network of family/friends, exercise/being in nature, a positive home/ work environment and routine all help contribute towards positive mental health and well-being. The impact external factors, such as the news and increasing financial constraints, have on mental health and well-being also needs to be recognised

b) Promoting positive mental health

- Health promotion on how to look after mental health in a range of locations (i.e. workplaces, schools, community venues) and accessible formats
- Providing accessible, varied, and affordable ways to support mental health
- Funding and mental health resources for new and existing community groups, sports teams and social exercise, activity groups, nature projects, youth projects

- More opportunities for promoting mental health need to be not only available, but visible and accessible within all communities

c) Preventing mental ill-health

- Health promotion on prevention and early signs of mental illnesses and where to seek help, in a range of locations and accessible formats
- Improve availability of lower level mental health services and offer different types of support services (i.e. use existing support networks in the community for when people first show signs of struggling)
- Work with other services to tackle factors that contribute to mental ill-health

d) Early intervention

- It should be the dual responsibility of everyday people (friends, family, colleagues) as well as institutions (healthcare, schools, police, employers), to look out for signs and offer/signpost support. This way, fewer people ‘fall through the cracks’ and some situations would not escalate
- Early intervention services need to be truly early – waiting lists must fall and capacity must increase otherwise situations will naturally escalate

e) Mental health: accessing care and support

- Long waiting times and time-limited support are potentially compounding people’s problems with their mental wellbeing
- 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
- About half of people were offered ongoing support for their mental health condition, but this support was generally considered hard to access and ineffective
- Differences between local authorities 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
- Different services (i.e. services looking after physical health and those looking after mental health) do not always join up
- There is a preference for locally accessible services. Public transport can be a barrier when it is limited and costly

- 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

f) 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
- 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
- People would like to see all health care staff given training in how to identify mental health issues in patients and refer them appropriately
- 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

g) 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
- Communications about mental health care were not generally found to be consistent

h) Community mental health provision

People highlighted the following as important when delivering community mental health services:

- The service should be available for and accessible to anyone that needs it. This should take account of location of services, language and other access needs and how people contact services and access support
- The service should be able to adapt and be flexible enough to meet the needs of different communities and individuals
- There should be simple and clear information about the service, who can get support (and who cannot) and how it can be accessed
- Services and systems need to work together and talk to each other so people can get support for all their needs

- The role of carers should be an integral part of the service, and they should be fully involved and supported
- There should be a key worker type system in place to ensure people have consistency, both in their care and the staff that support them
- Clear and honest communication about waiting times is needed and regular check-ins should take place with people on waiting lists
- People should be involved in their care and care planning, and wherever possible, have choices about how that support is given; options should include, for example, face-to-face support, group sessions and remote appointments
- The service should ensure that people are always treated with kindness and compassion and feel listened to

i) Mental health: crisis services

- 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. Some people describe being turned away or ‘bounced’ between First Response and A&E over a number of hours, which can be highly distressing and does not give the patient the support they need in that moment
- Almost half of people experiencing or supporting someone in crisis for the first time said they would not know where to go for support. Need to promote what a mental health crisis is and how to get help quickly
- 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
- Having someone to talk to was highlighted as being the most important and helpful thing during a crisis
- People perceived some mainstream services as having a lack of understanding of mental health crisis
- Most people said they had not used a hospital passport, autism alert card or other form of identification, and many said they had not heard of a hospital passport or were not aware of other identification
- Less than half of people were told about post-crisis support.
  - 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
- 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)
- A good Single Point of Access service is described by people as being:
  - Responsive and accessible 24 hours a day
  - Reassuring and empathetic
  - Flexible enough to adapt to the needs of people with autism and learning disabilities
- People told us that longer opening hours, more staff and changing the way crisis services are delivered, including more locations of existing services would help improve capacity of these services
- To improve integration and the pathway of care, people told us they want to see their information being shared with relevant organisations that are working together (such as GPs or care coordinators)
- People told us that getting help when you're unwell can be stressful, upsetting and confusing
- Fewer people from BAME backgrounds accessed SPA (Single Point of Access) or the Crisis service compared to white British people. People from minority ethnic groups were more likely to report the police was more likely to be cited as a barrier to accessing services by people from BAME backgrounds

j) Forensic inpatients

- The assessment process can be daunting – people asked if this could be broken into sections, especially for patients who have Autistic Spectrum Disorder (ASD) / Autism
- A welcome/induction pack shared on admission should be referred back to during the stay as there was too much information to take in when unwell at admission point
- Clear explanation of restrictions that can be put in place is needed
- Clear explanation of different types of leave requests and how they are granted
- The need to understand the range of activities on offer and where service users can influence new activities
- More support to tackle 'bullying' on wards
- Exposure to other mental health conditions and behaviours did have an impact

- Medications side effects and impact on patients could be better explained (e.g. increased appetite, weight gain, sedation, drooling, speech affected)
- Staffing: not enough staff to support physical needs of service users
- Staffing: concern about lack of regular staff for support and relationships
- Staffing: lack of staff has impact on supporting leave entitlements
- When medications were stopped in community, service users reported becoming unwell with behaviour escalated, some led to criminal activity and arrests by the police

k) Employment support for people with mental health difficulties

- Ensure that employment support includes support in the following areas:
  - Ongoing encouragement and support
  - Interview practice
  - General help to find a job or placement
  - Help with CV and application forms
  - Managing condition at work and support to stay in work
  - Help with financial matters
  - Goal setting
  - Help with furthering education
- Focus on support within current employment as well as support into employment
- Work with the person as an individual, including support with any additional needs they may have in addition to their mental health condition
- Provide regular and consistent 1:1 support for people without pressure
- Ensure that there are a variety of options for people to meet with their employment specialist both in person or over the telephone / internet call
- Ensure that the new service is promoted through a variety of means

l) Mental health: migrants

Many migrants describe experiences of poor mental health in themselves or their children including post-traumatic stress disorder, anxiety or depression, which was aggravated by complex asylum processes, unemployment and financial deprivation, lack of family support and moves when relocated or dispersed. However, they also identified issues with accessing mental health care including:

- The impact of stigma which remains attached to mental health issues in some vulnerable migrant communities

- Lack of information about mental health and services for migrants in vulnerable circumstances
- 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
- Failure to refer for support – NHS staff seeing all issues including an individual's mental health problem as rooted in someone's asylum case and not referring for treatment
- Lack of availability of appropriate services and long waiting times
- Lack of interpreting provision
- Available mental health services not being aware of the needs of refugees and asylum seekers
- Difficultly in accessing treatment in NHS services until granted leave to remain
- Insufficient services being available for children, in particular those who have experienced severe trauma

m) Mental health: homelessness

- **Addiction as a barrier to accessing mental health services** - people experiencing drug and alcohol dependency were less likely than others to successfully access mental health services. They felt that GPs and mental health services often misunderstood the relationship between mental health and addiction
- **Untreated mental health conditions affecting trust in health services** - expectations of GPs' role in referring to mental health services were high. When these expectations were not met, it could lead to a loss of faith in the NHS and a consequent disengagement from services. In turn, this led to a worsening of physical health conditions
- **Unmet mental health needs leading to homelessness** - around half of people thought that their homelessness could have been prevented if their health needs had been better met beforehand. Women were twice as likely as men to believe this. The unmet needs discussed in relation to this almost exclusively related to mental health
- **Praise for specialist homeless services and peer support** - dedicated health outreach services, especially in homeless daycentres, were positively regarded. Some support and advocacy, however, exposed power inequalities and feelings of helplessness. Support from people with lived experience of homelessness and addiction was enthusiastically supported as a solution

n) Mental health: hearing impairments

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.

o) Service provision for people with learning disabilities

Improvements to services

- Services working together more to prevent crisis and making services available when they are needed. Joint working between services and services taking responsibility for what is within their roles. Also to make it easier for third sector services to provide support to those who need it
- Support in getting employment or volunteering opportunities was an area for improvement noted by people with a learning disability, carers and professionals. This included having more job availability and courses and opportunities to develop skills that are transferable to the workplace. Better transitions between school/college and work opportunities were also noted
- Planning, support and communication during transition and services working together during this time
- Suitable short breaks and respite care. Lack of respite post age 18
- Better choice of support and activity regardless of the finance arrangements for those who use them or need them. More activities for young people, age appropriate and better signposting to these. Recognition of the funding difficulties for third sector organisations
- Listening to those who use local services and their families. Getting voices heard more and involving people in creating flexible plans
- Support in hospital and when leaving, including the person and their family in planning for leaving the care setting
- Support with finances e.g. when moving to supported living and better explanation of managing budgets
- Recognise the needs of the young people who, although adults, still have the same needs they had when they were children
- Easy to use and understand access to help, advice, support without having to have a referral or lengthy waiting lists. Promotion of services to make access easier
- Giving the people we support more control and choice of who they live with and where. Also support in making choices and decisions

- Those people that had used Shared Decision Making Tools described them as ‘fantastic because it helps the NHS to make things more personalised and keeps us at the centre of our care and support’
- Increased awareness and training for GPs and their teams on learning disabilities, general training on supporting people with learning disabilities and their carers
- To enable people with learning disabilities to be fully involved in their own care they need to learn more about their health conditions
- Support groups are highly valued at providing support to all aspects of learning difficulties and neurodiversity. From social and practical skills, advice on navigating services, respite for carers, independence building, and generally contribute to wellbeing. However, this relies on access (e.g., travel, respite care, referral) and availability (e.g., funding, staff, volunteers, facilities).
- Mainstream services are not as well equipped, and often appear to be unable to meet the needs of patients who have learning difficulties or are neurodiverse. For example, standard procedures such as cervical screening may need adapting, and as a result fewer people with additional needs may receive these tests
- While it is understood that the NHS has strict protocols for a reason, some people shared that a rigid approach to care means services are unable to meet differing needs of patients with learning difficulties, valuing a more flexible ‘common sense’ approach. Provision in mainstream services do not always fit these needs, meaning people either do not attend or become upset
- Getting to appointments is not simple with a disability or learning difficulty. The process of preparing mentally and/or physically to attend, travelling (often to an unfamiliar location), being around new people –all this can be time consuming and challenging for the patient and carers, and may not be the most effective or appropriate way of accessing care
- Diagnosis of one or multiple conditions is usually needed to access support, and this process can be lengthy and hard to navigate, both for children and adults (although adult diagnoses are seen as more difficult to obtain). However, it’s also important to note that sometimes people felt as though they were treated ‘as a diagnosis rather than a person’, and that not all conditions present in the same way. Experiences of ‘person-centred care’ were seen as a better way of approaching things.

Support for parents / carers

- Little specialist support appears to be available for new parents of children born with learning disabilities

- Carers of those who are leaving school to have access to the options open to them for further meaningful activities and development, relevant to each person's particular disability and wishes. Support during transition
- Ability for carer to contact GP on behalf of their loved one
- Health professionals are the experts on health issues but treat Support workers and family carers and the individual themselves as the experts on the individual
- Budgets for carers who provide 24 / 7 care

Digital

People with learning disabilities were more likely than not to be willing to have medical appointments over the phone or by video call. For some people with learning disabilities 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.

Many people with a learning disability and autism are still not aware that they are able to have their doctor’s appointment via video call. And due to the lack of accessible information some people are hesitant and think it will be more difficult.

p) Service provision for people who are autistic

- Most people said the initial support they received when they approached health care services about their autism was not sufficient
- People reported that waits for initial support and assessments were often long (with most people waiting one or two years), which sometimes provoked distress
- There was perceived to be a lack of knowledge among GPs about autism. There is a need for more awareness of autism in women
- 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
- The support that already exists in the community needs a higher profile
- Most young people were referred to autism services by their school
- Nearly half the families of young people contacted more than one organisation to get a referral to autism services
- People who reported a good experience of getting a referral for autism services cited speed as a key factor

- Around half of parents of children with autism received their child’s diagnosis at the assessment stage. The most common way in which parents found out about their child’s diagnosis was face-to-face
- Just over half of parents whose child had been diagnosed with autism felt they had a good understanding of their child’s condition
- Parents highlighted that if their child is home educated would the ASD referral be rejected as no school information would be available
- Parents highlighted some schools and academies need more SEND (special education needs) support from the Local Authority and SEND, ASD EWB training
- Parents reported that they felt their child had to be in crisis before services accepted that they needed support
- Support needs to continue after school, with assistance to make the transition

Communication

- Communications during and after diagnosis of ASD, ADHD (attention deficit hyperactivity disorder) also known as ADD (attention deficit disorder) were frequently felt to be inconsistent or lacking and not always tailored to people’s individual needs and circumstances
- Some parents of people with autism and learning disabilities felt that they were not included in communications when this would have been helpful
- One in two people were not informed how long their child could expect to wait to get care and support for their learning disability

Support for parents - Delays in their child receiving support and assessments can have significant negative effects on parents’ employment, finances, health and relationships.

Autism hub - Attending the Autism Hub has had positive outcomes for all in terms of increased social skills, confidence and making friends; the majority also have improved mood and feel less isolated; and half also have increased independence, improved relationship with family and reduced anxiety.

Autism employment hub - Attending the Autism Employment Hub has had positive outcomes for all in terms of increased confidence; the majority also have improved social skills, mood, feel less isolated and have made friends; and half also have increased independence, improved relationship with family, reduced anxiety and are accessing another service/group/course or voluntary work.

q) Service provision for people who are neurodiverse

- People said they wanted to be known and flagged on the record as neurodiverse so that all staff (reception team and doctors) know when they telephone or walk in that they may need some additional help
- Some young people found it helpful for their parent to make the phone call to arrange the appointment on their behalf although this was sometimes discouraged by the practice, creating more anxiety
- Face to face appointments were preferred to telephone appointments by many
- Many young people expressed fear that the reception staff might not know that they may need some additional help from staff or from a parent/ supporter, even though they have filled in the forms which explain that they may require some additional help, and some wore the hidden disability lanyard
- A very frequently expressed worry was whether the receptionist would be friendly and understanding. The need for eye contact and patience came up frequently
- Strong agreement for the need for consistency in service and a request for things not to change so much. It would be helpful if receptionists said the same things each time by way of introduction
- Being told by the receptionist who they are going to see, and photographs of the staff is helpful
- Many prefer automated check-in, but not all patients will; some like the human interaction
- Telling patients that they have the time they need, reduces interaction anxiety
- Ask about their communication preferences
- Shared decision-making works well (power sharing)
- Capturing what needs to happen afterwards in a way that

Neurodevelopmental assessment pathway

- Families reported that they liked having feedback in person. They found the level of explanations useful and not overwhelming. The people in the team were reported to be friendly and made the families feel listened to. Some reported that the process of assessment had been quick, but that they did not feel rushed
- Families reported that the waiting times to get to the point of assessment were too long and felt it was not acceptable. Some families reported that they feel more funding should be allocated to the service, in order to support children and families quicker. One family reported that they felt the time assigned to completing the Neurodevelopmental Parental

History Interview needed to be extended in order to have sufficient time to provide all of their viewpoints

- Families reported they wished the waiting time from referral to assessment was quicker. They were happy with being provided with a face-to-face assessment and felt this was much more personable

r) Dementia pathway in Wakefield

People in Wakefield want a clearer process and named point of contact to follow throughout the dementia journey. They told us peer support in groups is very important to them and acknowledged there are a lot of great organisations and services available. However, many people are unaware of them, some are dependent on location and many people cannot access these services due to transport issues. There was support for the standardised implementation of the annual review, and better at home services for people living with dementia.

- **Dementia knowledge and a timely supported diagnosis** - two key challenges, the first around a lack of knowledge of dementia symptoms and where to get help. This caused a hesitancy to seek support. The second challenge was in the diagnosis process. This was described as slow. At times the individuals affected needed to chase health and social care professionals to receive the support that they needed
- **Access to a pathway of support -** There were two key challenges identified around the access to support services. Firstly, people wanted a clearer understanding of what services were available and a clear pathway supported by a single point of contact to direct them to the help they needed. Secondly, for particular groups such as those living alone or those with difficulty accessing public transportation, additional support was needed to ensure equal access to services
- **Collaborative working** - Key challenges in the current service provision existed because professionals were not always aware of available services across different areas across the region
- **Transition to care, hospitals and end of life** - Key challenges in the provision of residential and domiciliary care services. Care homes were struggling to accommodate people with dementia or higher needs which was placing additional pressure on carers and hospitals

Overall themes

- Despite some positive accounts of memory services, some respondents report lengthy waits for diagnosis and a lack of compassion and understanding from GPs
- Many report happening upon support by chance and the vital role that local groups play in connecting them to wider service provision
- A clearer, more systematic pathway is needed. People want to access this through a single named contact. There is confusion over who to contact six months or a year down the line when things change, and some people feel forgotten and abandoned
- There is a strong will to work better together to achieve better outcomes for people affected by dementia, and there are many great services. More needs to be done to connect these by creating space and time for professionals to collaborate
- People are losing their care packages whilst in hospital and staff shortages in the domiciliary care sector have led to longer unnecessary stays in hospital. These are distressing for the person and family, make things more difficult for staff, and are more expensive for local service providers

2.12 Other

This category was included in the mapping report for May 2022 as there had been a few pieces of involvement activity that focused on restructuring and governance arrangements. These were the merger of NHS North Kirklees and Greater Huddersfield CCGs to become Kirklees CCG, the transition to West Yorkshire Integrated Care Board, and the West Yorkshire ICB draft constitution. During 2022/23 we consulted people on the development of our joint forward plan. The key themes raised from these activities were:

a) Merger of clinical commissioning groups (CCGs)

- The majority of people were supportive of the change and felt that it was a natural progression which would give the CCG a stronger voice; provide consistency in commissioning decisions; improve partnership working and would be a better use of resources
- The main concerns expressed were that it could lead to a Huddersfield centric organisation that is unable to meet the needs of all of its communities, particularly those in more deprived areas. This was a particular concern expressed by those that live in or represent North Kirklees, and people from a black ethnic group were more likely to express concerns about the impact on people from communities with higher levels of deprivation
- That this was a cost cutting exercise and to achieve equitable provision across Kirklees, rather than levelling up, service provision would be levelled down to save money. Leading to services no longer being provided or to people having to travel further to access services
- A bigger overall footprint could lead to a loss of local knowledge and an inability to understand the needs of local communities
- That the CCG would have a ‘one size fits all’ approach and would not be able to meet the needs of its diverse population and address health inequalities, specifically those in communities with higher levels of deprivation
- That it could lead to a reduction in staff which in turn could mean an inability to commission services effectively, and a loss of local knowledge
- Any changes being made now would support the direction of travel being proposed in the NHS England / Improvement consultation on Integrated Care: next steps to build strong and effective integrated care systems across England

- The challenges of working with two acute trust providers that provide services across other areas. And whether this could lead to neighbouring CCGs taking funding provided to Kirklees to support patients in Wakefield / Calderdale / Leeds / Bradford

Suggestions for how to provide assurance were to:

- Work and invest in deprived communities to tackle health inequalities
- Make sure that we don't have a one size fits all approach and invest where investment is needed. And to recognise that across Kirklees different communities have different needs
- Ensure that patients aren't expected to travel to Huddersfield for services that they currently access in North Kirklees
- Hold meetings in locations across Kirklees to show that the CCG represents all of Kirklees
- Ensure that Governing Body and CCG committees include representatives from across Kirklees

b) Transition to NHS West Yorkshire Integrated Care Board (ICB) and Kirklees Place-based Partnership

- People were interested in how the voice of Kirklees would be heard when it is part of the West Yorkshire Integrated Care System. There was a real concern that funding could be directed towards the larger areas and places such as Kirklees would be overlooked, leading to a lack of consistency across West Yorkshire in what is delivered and how it is delivered
- Some were also interested in how the new structures would link with social care.
- The needs of people with learning disabilities and a hope that their needs would be a priority both locally and regionally
- Keen to understand how the public would be represented in decision making committees, and what opportunities would be available to enable the public to be involved in the new structures
- There was concern that a reliance on using the existing GP Practice Patient Reference Groups (PRGs) to engage with the public would not be sufficient as not all practices have one and the quality of PRGs varies considerably
- Interest in who would be members of the Integrated Care Board, specific interest was the role of private providers and whether this could lead to any potential conflicts of interest
- Whether there was going to be a shared digital platform for the organisation to share data within the Partnership

c) Development of the NHS West Yorkshire ICB constitution

The issues that received most responses were:

- the size and composition of the ICB Board
- the arrangements for delegating the ICBs functions to our places and
- public and patient involvement in our ICS

Issues raised in relation to public and patient involvement were:

- How does Integrated Care System (ICS) plan to involve patients in the work of its ICB and ICP? Is any patient assurance planned at WYH level?
- There should be mechanisms in place for people across joined up care to feedback and understand how this has been used to shape services
- Will the disabled community have representation in the ICB? Will there be representation and understanding of the needs of staff who have a disability or long-term condition in the ICB – not all disabilities are visible
- Arrangements for public participation in meetings of the IC Board (and any other bodies that it delegates its functions to) should beno less than current arrangements for public participation in the non-statutory ICS Board meetings and CCG meetings
- There need to be easy read minutes of ICB meetings as well as recordings of meetings which are publicly accessible. In addition, consideration should be given to BSL signed meetings and the availability of translation services. There needs to be greater clarity as to how the ICB will receive information about patient experience
- The constitution should specify that the ICB Annual (rolling) 5YearPlan should be an accurate, current, readily accessible and understandable source of public information. There should be meaningful public consultation on the plan

d) Development of NHS West Yorkshire ICB Joint forward plan

Main themes raised were:

- **Access -** people’s need for better access to services and how they could be accessed
- **Inequalities** - feedback highlighted various concerns about equality and health inequalities for example children, older people and those with disabilities. People asked us to look at the different mixes of people who live in the area. We have people of different ages, ethnicities and disabilities for example
- **Co-ordination -** need to ensure that organisations and services are joined up

- **Workforce** - people have concerns about capacity, especially of front-line staff, noting that we need to improve retention and recruitment
- **Get the basics right -** people commented that getting the basics rights seems obvious but is extremely important. Those basics include things like health provision and patient safety
- **Money -** people expressed concern that more funding was need for health and social care to thrive but also highlighted that such funding comes from taxpayers
- **Listening** - respondents said they were pleased to be asked for their views and hoped we would continue to listen. They reminded us that people should be at the centre of all of our work

2.13 Our work with the voluntary, community and social enterprise sector

In relation to our work with the voluntary, community and social enterprise sector (VCSE), **two** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to working with the VCSE. The themes developed for working with the VCSE from the current and previous mapping exercise were:

a) Impact of Covid-19

Positives highlighted were:

- resilience and adaptability of the third sector, this was shown in the way it adapted services, innovated and supported communities through very challenging times
- the fast tracking and flexibility of service commissioning and delivery between health, local authorities and the VCS, meaning services can respond quickly and everyone works together to make things happen at greater pace

Finance

Many VCSE organisations had experienced a loss of income and were concerned that they would not be financially stable. However, over time there was more confidence about financial resilience, continued flexibility from funders and newly developed partnerships that remain.

Digital technology

- Demand for services to move online. Some services had been able to move to this, using platforms like ‘Zoom’, but others had faced difficulties in reproducing the same service online
- Digital exclusion had presented significant challenges and had an impact on the ability of people to access VCSE organisations during the pandemic
- Digital working had reduced the need for travel
- Organisations came together online and worked jointly, where they would not have otherwise had the chance to do so
- Opportunities to interact with others they would not usually encounter

Solutions

- WY HCP should work with VCSE organisations, to put in a place a workforce offer enabling further development of VCSE workforce capacity – including aspects such as: health and wellbeing; finance and business adaptation; governance and planning

- The NHS, local authorities plus other funders and commissioners should commit to putting in place a strategy for the longer-term, ‘joined up’ investment in VCSE organisations
- All partners should ensure that the VCSE community voice is listened to and reflected in service design and delivery from the outset
- Partners should commit to taking practical action to reduce digital exclusion, with a focus on the most socially isolated groups
- Increase collaborative working between VCSE and public sector organisations, in order to support and encourage local people to live healthier lives
- Develop talent within the VCSE organisations
- Influence policy development and the co-design of services
- Identify gaps in health and care provision and communicate this to partners
- Ensure that the most ‘hard to reach’ people within communities are heard

b) Voluntary, community and social enterprise sector (VCSE) and primary care

- Pathways improved the physical and mental wellbeing of patients. There were also signs that increased self-confidence, adoption of self-help techniques and some reduction in the use of GP time would help to reduce pressure on clinicians. It also demonstrated the benefits of integrated care, with the confidence that comes from a GP referral improving uptake of alternative provision that created opportunities to invest time in building relationships with potential participants, that in turn led to better reach into the target populations
- The factors that improved the likelihood of success included co-production of the pathway, simple pathway design with bespoke selection criteria, GP engagement, clinicians’ recognition of VCSE potential, mature working relationships, and VCSE experienced in working with Health. An integrated Place-level social prescribing service also helped

c) Partnership with trusted community organisations

Examples of partnerships with trusted community organisations included a call for GP practices to work closely with community partners to take a whole team approach to meeting a person’s needs. The need to forge stronger links between the third sector and health and care services was identified, sometimes because people might experience distrust in statutory NHS partners. This meant involving community organisations in the earliest stages of service planning. It also meant knowing what the third sector could offer in terms of the stepping up and down of a person’s care, and the long-term resource needed for this.

d) Structure, dynamics, and impact of the VCSE

Impact in 4 key areas

- **Personal health** – direct support on disability and mental health and physical health issues
- **Personal wellbeing** – training, education and life skills that create resilience, and add to social capital
- **Financial security** – better access to benefits, basic services, paid work and other routes out of poverty
- **Community wellbeing** – cohesion, ownership, pride and inclusion. Good physical and cultural environment and facilities

It’s organic rather than a designed, unified system.

- The sector addressed a wide range of issues, many of which are unrecognised or ignored
- Proudly independent from the state, it focuses on creating social, cultural or environmental value rather than profit
- Often working in complementary ways, the sector uses its skills, experience, ideas, beliefs, resources and ambitions to create a valuable energy

Added value

- Public sector savings
- Economic multipliers (the ripple effect)
- Benefits of using the sector’s services (personal recovery, employment, independence etc)
- Stronger communities
- Better quality of life
- Latent capacty e.g. sector’s response to Covid-19

e) Support for volunteers

There is a need to provide ongoing support for volunteers this could include regular online group sessions, training and support to access these and other online sessions, as well as bespoke support sessions for individuals. This can lead to:

- Volunteers feeling less isolated
- Volunteers having a purpose
- Volunteers having access to accurate information to support them in their role

f) Awareness of VCSE

- Public are not always aware of the wide-ranging services provided by the VCSE and how to access these services.
- Some people who have received services from the VCSE are not aware that it was a VCSE organisation that provided the service to them
- Highlighted a need to raise awareness of the role the VCSE plays in providing services in West Yorkshire

2.14 Personalised care

In relation to personalised care, **ten** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to personalised care. The themes developed for personalised care from the current and previous mapping exercise were:

a) Views on what personalised care is

- It is 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
- Some people also described personalisation as relating to choice and control over care being shared between patients and professionals
- People from BAME backgrounds and young people under the age of 15 were particularly unlikely to be able to define the term “personalisation”.
- Additional needs are often met when people attend specialist services, however they do not cease to have additional needs when in other ‘services, which are less equipped to meet these needs. If the system was getting it right, the patient would be viewed more holistically, as a ‘person not a diagnosis’. Allowing a space (e g in SystmOne for patients to give context about themselves, may help services offer practical support and understanding

b) Accessible information

People who need information in an accessible format do not get it regularly or consistently from health and care organisations, who are legally obliged to do so. This means someone else has to tell them what it says and someone else may find out private information about them.

Many organisations send information in a standard letter format and only offer a phone number for queries, to change appointments or to book follow up appointments. However, some people with sight loss, learning difficulties or other conditions cannot access or understand a standard print letter and rely on others to read it out to them. Similarly, some people who are D/deaf, people who are neurodiverse, or have speech issues cannot always use the phone. With no other option to contact services, they have to rely on someone else to have conversations on their behalf.

Unfortunately, on many occasions, the responsibility is still on the person to ask for information in their preferred format. However, even when it is raised many times, respondents said their needs are often still not taken into account.

Some respondents said they know their medical notes include information about not phoning them up, but still the default is for them to get a phone call or to be told to phone up. Others said that they cannot read or access text messages, but appointment updates are still sent by text, meaning they can miss appointments or turn up to appointments that have been cancelled.

Some respondents expressed particular frustrations they have with receiving inaccessible information from eye clinics and hearing clinics. Information should be accessible in any healthcare setting, but it should be the default for certain settings such as eye and hearing clinics.

It is also important to note that the same format does not work for everyone. Respondents were clear that assumptions only lead to problems and not every person with a particular condition wants information in the same way; choice is key. Similarly, whilst some people are keen on using technology for information and communication, for others, digital is not the most appropriate or accessible option meaning it should not be the default.

c) Access to services

- People want the choice of a range of locations, appointment times and different providers. A major priority for many was the shortest possible wait time and many patients would be prepared to travel further/take time off work for a one-off appointment able to provide the speediest diagnosis.
- It is clear that there is no ‘one size fits all’ method of both making appointments or attending services. Face to face, telephone, online, post, home visits all can be seen as excellent or terrible depending on the person, their needs and their circumstances

d) Reasonable adjustments to enable people to attend outpatient appointments

In person hospital appointments - Key adjustments people wanted were longer appointments and quiet places to wait. Other things that people wanted were being able to have someone with them to support them at their appointment, and user-friendly directions so they could find their way around.

Virtual hospital appointments - A key requirement people asked for were specific appointment times, also mentioned was the need for support during the appointment, more time to understand what is being said and to ask questions, and also for services to understand that virtual appointments don't suit everyone.

A symbol for all disabilities? There was some negative feedback about the sunflower lanyard for invisible disabilities possibly putting people at risk of abuse or being stigmatised. Some people felt that a discreet credit card sized information card could be useful to show that they might need support.

e) Making decisions

- Involve patients, carers and families in care planning - they want to be involved in decisions about their care. And that they and their families are kept informed and involved throughout, so they know what to expect, are aware of what support is available and how to access it. Where appropriate they would also like to have a named person who is responsible for co-ordinating their care and who can provide them with support and advice
- Patients want their healthcare records to be shared by organisations, to enable health and social care professionals to be able to make a more informed decision about their care and so they don't have to repeat their story
- People with multiple conditions or complex health problems faced additional barriers when making decisions about their health and care
- The role of families and carers was important
- A significant cohort of patients are not comfortable exercising choice - feeling that they are ill equipped to make such choices and would prefer the choice to be made for them by the referring GP or other qualified clinician
- Many patients were unaware they had a right to choose, were unsure of how they should request choice and unsure as to what information was available to support them in making this choice
- 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
- Homeless people reported that feeling listened to and involved in treatment were highly valued. Many homeless people felt uninformed about treatment, test results and diagnoses, resulting in feelings of disconnection and disempowerment

f) Materials to support people

- Provide patients with information to enable them to make informed choices - people want to receive clear and good quality information to help them to make informed choices about their treatment, and to be able to have the choice to access a wide range of services / treatment options
- Materials should be available in a range of accessible formats, for example leaflets in plain English with pictures or videos in simple English with subtitles. It should also be made available in the most commonly used community languages
- Participants proposed materials be placed in a wide variety of health settings e.g. GP, pharmacy, clinics and outpatient departments. They also suggested voluntary and community organisations provide support in promoting the materials to their groups
- Provide a contact number on the letter to clarify content of communication
- Provide easy read information that is simple to understand, with pictures

g) Personalised care 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
- There is a reliance on friends and family to make the initial booking of the GP appointment
- Systems should be in place that identify a patient as needing an interpreter on booking of the appointment, gender preference of interpreter and confirmation should be received that an interpreter has been booked
- Feedback about the availability of interpreters when these were booked by the practice, adding to appointment waiting times
- Length of time interpreters are allocated can lead to lateness or missed appointments
- There is a need to raise awareness amongst both staff at GP practices but also increase publicity within practices to make patients aware that they can request an interpreter
- Responsiveness of the service to make sure that a patient can still be supported during same day and urgent appointments

- Patients suggested more provider quality checks on qualifications, to ensure accurate interpreting of medical information and language ability such as the correct dialect being used
- People being asked or choosing to use family members as unofficial interpreters and the risks of poor translation and confidentiality
- Need for Deaf awareness training for GP’s and primary care staff
- Support for greater use of digital technology, but patients should be offered a choice

h) Palliative and end of life care

Awareness of hospice services

- There are many areas of support that people aren’t aware of, particularly outreach, support for families and carers, Lymphoedema clinic, and complementary therapy. Most people are aware of in-patient and bereavement services
- People are interested in being able to access a wide range of support, in particular support for family and friends, advice on nutrition and exercise, exercise sessions, and advice on planning for the future
- open days and more information about services on offer would encourage people to go and have a look around a Hospice
- Social media, leaflets, promotion through newsletters, and more information given out by other professionals, such as GPs, were thought to be the best ways to promote the Hospice
- Those that had visited the Hospice, as a patient or, for example, attended an open day, were full of praise for the atmosphere, physical environment and support that they had received

Experiences of palliative and end of life care

- People raised concerns that it took a long time for services to remove end of life equipment after the relative had died. It was acknowledged by professionals that this was a common experience and had an impact on the wellbeing of family and friends
- People raised concerns that services sometimes struggled to meet the needs of people from certain religious communities
- People told us that carers, friends and family sometimes struggled to access practical support around things like funerals and wills
- People told us that sometimes people can change their mind about the place they want to die. If this happens in the last stages of life options can often be limited

- People told us that sometimes people can change their mind about ‘do not resuscitate’. If this happens in the last stages of life options can often be limited
- Some people reported that it was painful to see others passing away at the same time as their loved one was while at the hospice

Suggestions for how palliative and end of life care could be improved

- Discuss options earlier about end of life care and arrangements
- Importance of checking that requests for end-of-life care are followed up
- Information about after death and funeral arrangements and buying a leaf in memory for the tree should be given at admission as difficult to deal with when grieving
- More thought about removing loved one’s belongings from the hospice

2.15 Preventing ill health

Ambition

increase the years of life that people live in good health, and reduce the gap in life expectancy by 5% in our most deprived communities by 2024

In relation to preventing ill health, **four** additional involvement reports have been produced since the previous mapping exercise that either focus on or include reference to preventing ill health. The themes developed for preventing ill health from the current and previous mapping exercise were:

a) 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
- 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

b) Self-care

- Exercise was the most common thing people did to stay healthy, followed by eating a healthy diet
- 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
- Those people that had been given a ‘fake away’ recipe pack felt that the pack provided them with a healthy, filling and tasty meal that saved them money and encouraged them to cook from scratch. 90% of people found the campaign information pack and resources easy to understand and would use the recipes again

c) Developing cardiac and pulmonary rehabilitation programmes

- People’s experiences of the rehabilitation programmes had been mostly positive
- The programmes had helped improve people’s confidence and well-being
- The regular meetings provided space to socialise and offer/receive valuable peer support

- Waiting times, accessing, and getting transport to the venues for scheduled sessions could be difficult and be a barrier to people wanting to benefit from rehabilitation programmes

d) Social prescribing

- Social prescribing should be made more widely available
- Greater focus on prevention/a more proactive approach to preventing ill health was needed
- Accessing social prescribers was challenging and there was a need to review how organisations could be added to the social prescribing list
- It was felt third sector organisations could be used more to tackle physical health problems, not just mental health

e) Communication

- People like positive, simple messages containing images and limited text
- People like videos and messages that are animated, with voice overs and subtitles
- Messages delivered continuously and across a wide range of media get high community recognition
- People with literacy problems or limited English struggle to be able to understand text-only communications
- Direct messages from GPs reach communities, but are usually text-heavy and only in English
- Messages communicated verbally are vital to some people
- Some messages fail because they are not delivered often enough/through enough channels

f) 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

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.

2.16 Primary and community care

In relation to primary and community care, **sixteen** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to primary or community care. Themes relating to digital technology can be found in the digital technology section of this report. The other themes developed for primary and community care from the current and previous mapping exercise were:

a) GP Practices

GP access

People see GPs as the front door to the wider health and care service, and many feel let down when they can't access their GP in a way that works for them. There have been significant changes made to the way people can access GPs as a result of the covid 19 pandemic. People have reported that there has been a lack of communication and confusion around the changes

Some comments also reflect a view that people's perception is that while other services have returned to normal after the pandemic, they feel the same has not happened with GP services.

For some, the result of a lack of access to their GP has had a detrimental impact on their health and wellbeing.

Booking appointments

Many people are frustrated around the challenge of booking an appointment, whether online or on the phone. The issue of having to call on the same day, is a long-standing concern. People have also told us about challenges with call systems where they are having to wait in long queues or sometimes being cut off without the option of waiting in a queue.

This is resulting in long waits, not being able to get an appointment on the same day or when they feel they need it, or people just giving up and not booking an appointment at all. The result of this is potentially minor issues are being left untreated and escalate into major concerns that require more interventions. People told us about having to keep calling back to try and get an appointment. Having English as a second language acts as a barrier at some surgeries.

In terms of booking an appointment online, people have talked about not understanding how to do this, there being multiple options for booking causing confusion and online systems not being consistently available to people.

Some patients are unsure what constitutes a ‘routine’ and ‘urgent’ issue, and how routine appointments are supposed to be booked. Respondents requested future booking systems offer appointments given days or weeks ahead.

Appointments

Regarding the different modes of appointment available (face-to-face, telephone, video, and online), respondents showed an overwhelming preference for face-to-face, but many have reported difficulties in making appointments to see GPs face-to-face.

The issue of face-to-face contact is especially highlighted by people with different communication needs and those who may not be able to get online and are digitally excluded.

Telephone was seen as appropriate in some instances but not for everyone and are better suited to certain types of appointments and issues but not to others. There were mixed views towards online and video consultations. Digital exclusion and confidence remain an important issue to consider when offering online services. However, younger generations tended to be happier with video and online consultation compared to older residents, and some even preferred it due to its convenience. However, some respondents remain sceptical over how effective non-face-to-face consultation can be and face-to-face is seen as the gold standard and default option.

Variation

One of the key themes that has emerged is the lack of consistency and variation between different practices. While surgeries are seeing people face to face this does seem to be easier to do in some practices than others. We have heard of variation in terms of communication, access, booking appointments and access to additional support through the GP.

Triage

People have told us about their confusion and discomfort around the triage questions that they are asked by reception staff and online booking systems. People either do not understand the reason for these questions or feel uncomfortable about sharing personal information with the reception staff – whether that be health information or other private matters.

There was also dissatisfaction about the outcomes people had following the triage questions. Some people felt they did not get what they needed, and the questions asked had been an unnecessary obstruction to getting an appointment with the GP.

Staff Attitudes

The issue of staff attitudes was another theme that we have heard about. Much of this related to reception staff and linked in with the triage questions. However, there were also concerns that reception staff were not always kind, compassionate and flexible in their approach and in many cases acted as gatekeepers.

Routine checks

We have also heard about regular reviews and check-ups moving to phone appointments or not happening at all. Some people told us about the deterioration in their conditions due to not being seen for routine checks.

Accessible Information Standard (AIS)

We have consistently heard that people with sensory and other impairments sometimes find it difficult to access GP surgeries. There is evidence that the AIS is not being applied routinely across all surgeries, with people not always being asked about their communication preferences, and those preferences not always being acted upon. People with sensory impairments and other disabilities have told us it would be helpful if information about their needs was flagged within and across services.

Some GP practices use an electronic banner display to notify patients in the waiting area when they can go in to see their medical practitioner, but it was pointed out that some people cannot see this display and others are unable to read it.

We heard from people with learning disabilities and their carers about medical forms not being properly understood. The issue of staff not always taking the time to ensure things were explained and people understood what was happening was also highlighted. Medical staff may not see that people with a learning disability need to be treated any differently, but reasonable adjustments still need to be made when appropriate.

Quality of the service provided at GP practices

- One of the key themes that communities talked about was the importance of GP practices' role. People saw them as their central point of information, their key access point to healthcare, the co-ordinator of their care, as a trusted partner in their health and care, of the central part of someone's health and care journey
- Some people felt that there is a difference in service provision across GP practices leading to a lack of consistency and quality of care for patients
- 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

b) Extended hours

The majority of respondents would certainly consider using an out of hours service for both routine and urgent appointments. However, people did express concern that more appointments would only increase workload for already overstretched doctors, and this may impact quality of service. For that reason, involvement of other healthcare professionals, such as ANPs and pharmacists, was generally positively received. However, patients expressed a need for reassurance that quality of service would not suffer as a result of extended hours, and that appointments with other health professionals would be triaged properly and only offered when appropriate.

Patients would be willing to access the new service in a variety of ways and there are significant differences between demographic and social groups (e.g., age group) as well as different life circumstances (e.g., transport or employment). This suggests primary care should seek to offer a range of ways to access out of hours GP services in order to cater to the different needs of the population.

Most respondents would prefer for GPs to be open in the evenings (6.30-8pm), which was by far the most popular time, especially among employed people so they can attend appointments after work. Some, however, would prefer early mornings and Saturday mornings. Sundays and bank holidays were the least preferable times.

When asked to travel to a face-to-face appointment, car drivers are rather happy to cover some distance especially in urgent cases, but others would struggle to attend anywhere other than their local GP due to transport limitations. Additionally, continuity of care is important for some respondents, who would rather attend their local GP for this reason.

c) Experience of using GP practices – mental health

- People seeking support for a mental health crisis said they most commonly contacted their GP
- Over a third report a positive experience, just under a third report a negative experience, and the remaining third have had a mixed experience. Those who have had a positive experience mentioned quick referrals as well as understanding, and patient GPs
- Along with Accident and Emergency, GP surgeries are particularly likely to be described as not taking mental ill health seriously or not understanding it
- 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

d) Experience of using GP practices – LGBTQ

- Some felt that there needed to be training for clinicians, particularly GPs, in relation to the clinical and other needs of LGBTQ patients
- Training for reception staff in customer care, and equality, particularly around the needs of LGBTQ people
- GP practices need to become more “LGBTQ friendly”

e) Experience of using GP practices – migrants

Migrants in vulnerable circumstances highlighted that it was important to develop trusting relationship with practitioners and services and that they prefer continuity of care. They also identified that peer mentors could support them to access and navigate the healthcare system

Numerous barriers to accessing healthcare were identified, some of these were personal factors and some were related healthcare providers and healthcare systems:

Personal factors

- Lack of awareness among migrants in vulnerable circumstances about their entitlement to healthcare
- Poor health literacy and unaware of how to navigate the UK healthcare system
- Fear of being apprehended by immigration authorities if they accessed care
- Fear of or previous experiences of being charged if accessing health services
- Lack of English language skills

Health systems and providers

- Lack of cultural awareness among staff, or not considering cultural differences can lead to people who are new to the UK mistrusting advice or services, unnecessarily worrying about their health or feeling unnerved in a service setting
- Lack of awareness among some providers about the immigration system, and rights and entitlements of refugees and asylum seekers
- GP practices demanding full ID or proof of address for registration, or asking about immigration status, none of which are necessary for registering a patient
- Being denied GP registration and subsequently lacking an NHS number which is required to access other services
- Waiting time to get through to a GP surgery – some participants have waited so long on the phone that their credit runs out
- Appointments being insufficiently long to address needs
- Language barriers - this relates to both availability, quality and appropriateness of interpreting services (e.g. female patients requiring female interpreters) and reluctance among some staff to use an interpreter
- Limited provision of NHS dental services
- Charging for some secondary health services which leads to avoidance of healthcare.
- Difficulties securing an HC2 certificate (to get full help with health costs) and the complexity of filling out an HC1 form (16 pages long and in English)
- Failure to transfer patient records and ensure ongoing care when transferring between services within the NHS in different geographical areas

f) Experience of using GP practices – homeless

- **The effects of the pandemic on relationships with GPs -** the frequent need to change GPs when insecurely housed, coupled with restrictions on face-to-face appointments, exacerbated existing difficulties with establishing trusting relationships with GPs. Those who had maintained long-term relationships with an individual doctor reported the most positive experiences

- **Patient-led treatment** - feeling listened to and involved in treatment were highly valued. Many participants felt uninformed about treatment, test results and diagnoses, resulting in feelings of disconnection and disempowerment
- **Positive relationships with pharmacies** - consistent relationships with pharmacy staff were sustained throughout the pandemic and these staff were highly praised, particularly for their non-judgemental attitudes and personalised advice
- **Stigma of drug and alcohol dependencies -** Accident and Emergency units and GPs were often identified as exhibiting discriminatory behaviour towards those with addiction issues
- **Addiction as a barrier to accessing mental health services** - participants experiencing drug and alcohol dependency were less likely than others to successfully access mental health services. They felt that GPs and mental health services often misunderstood the relationship between mental health and addiction
- **Untreated mental health conditions affecting trust in health services** - expectations of GPs' role in referring to mental health services were high. When these expectations were not met, it could lead to a loss of faith in the NHS and a consequent disengagement from services. In turn, this led to a worsening of physical health conditions
- **Unmet mental health needs leading to homelessness** - around half of participants thought that their homelessness could have been prevented if their health needs had been better met beforehand. Women were twice as likely as men to believe this. The unmet needs discussed in relation to this almost exclusively related to mental health.
- **Praise for specialist homeless services and peer support** - dedicated health outreach services, especially in homeless daycentres, were positively regarded. Some support and advocacy, however, exposed power inequalities and feelings of helplessness. Support from people with lived experience of homelessness and addiction was enthusiastically supported as a solution
- **Prioritising health** - financial barriers and the stresses of homelessness often prevented health needs from being met. A lack of access to nutritious food worsened existing health conditions
- **Access to dentistry** - a lack of information about access, and the challenge of remaining registered while homeless, meant that few participants had seen a dentist in the previous year, despite a clear need to do so

g) Experience of using GP practices - 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
- Most under-18s reported relying on parents to interpret for them
- It was sometimes felt that GPs and their receptionists talked to the carer or interpreter, rather than the patient
- Deaf people suggest that staff in GP surgeries would benefit from having greater deaf awareness

h) Experience of using GP practices - visual impairment

- 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
- 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. Some visually impaired people struggled with the digital displays used in some GP surgeries or hospital waiting areas to notify them about their appointments

i) Experience of using GP practices – young people

- **Health concerns -** children/young people concerned about their health behaved differently, depending on age. Those 16 and under were more likely to discuss issues with a family member, whilst those 17-25 much preferred going online, using an App or calling NHS 111
- **Booking appointments -** although most appointments were made by phone, again age range was a factor, with those 16 and under having an appointment booked for them in part, due to not wanting to have to discuss the reason for their appointment with a receptionist
- **Availability of appointments -** most young people did not find it difficult to access appointments, although some would prefer a more flexible, easy to use booking system with shorter waits to be seen. Both same day and advance appointments were considered important
- **Communication -** most respondents felt that they had been able to understand what they’d been told and that the doctor/health professional had used simple terms

- **Treatment -** many respondents felt that they had been listened to and provided with the care/support that they needed but some felt that their doctor/health professional didn’t understand their condition/take the time to listen to their concerns or answer their questions
- **Respondents identifying as LGBTQ -** expressed a much higher preference for seeking digital information, via Google and other online websites and Apps. Felt that GPs / health professionals did not have an adequate understanding of LGBTQ issues especially those around gender
- **Young carers -** indicated a strong preference for using NHS 111 or discussing concerns with a friend

j) GP practice websites

- There are a good number of examples of best practice, which could be shared with other practices across Primary Care Networks (PCNs)
- There is a good deal of variation across practices, in terms of the provision and accessibility of information available to patients, with some practice IT systems appearing to be much more “user friendly” than others
- Key aspects identified as needing improvement included: insufficient support and information provided in respect of interpreting and translation; a lack of up-to-date information about practice Patient Participation Groups (PPGs); difficulties in relation to how to make an appointment or how to make a complaint

k) Primary care abuse towards staff – campaign development

- Patients did not understand why Primary Care had been affected by the pandemic so badly, and further to this felt that it was just an excuse to cover up years of underfunding and inefficiency
- There was no dialogue between patients and Primary Care explaining the situation, so that patients could understand and empathise
- Frustration built in the number of places from
  - ➢ Trying to get through to their surgery to book an appointment
  - ➢ Trying to actually get an appointment
  - ➢ Trying to get a face-to-face appointment
  - ➢ Trying to get a referral to investigate or resolve the health complaint

- Patients would have liked more information about what was happening and why, and further to this when could they expect services to return to some normality as covid is here to stay so some risk is always going to be there

l) Pharmacies

Many people complemented staff who they recognise are often struggling due to staffing shortages. However, in some cases people said they have changed pharmacies as a result of issues with staff. There were a number of comments about the time taken to get prescriptions being quite long, that some pharmacies have poor stock, don't always have what is needed and there can be long queues. Also, some people noted the poor communication that can exist between the GP and pharmacy and a few people mentioned getting the wrong medication. People seem to appreciate the text service that tells them when their prescription is ready, however there were some reports that this service does not always work.

m) Accessing medication during the Covid-19 pandemic

- Due to the reduction in face-to-face appointments with healthcare staff, some found it more difficult to obtain medication in a timely way
- Some were happy to have a medication review on the phone, whereas others would have preferred a face-to-face appointment and there was some frustration around the limited amount of communication regarding medication reviews
- People were generally impressed with the way pharmacies adapted their services in response to challenges presented by the pandemic with some starting to offer home deliveries for the first time. Some people now find it easier to order medication online and have medication delivered
- Periods of shielding and self-isolation meant that people who were previously managing their own medications suddenly had to start requesting and relying on support from other sources such as family, friends, neighbours and volunteers. South Asian people were twice as likely to rely on family and friends to collect medication, which they hadn't done previously. The pandemic often brought out the very best in people; a great deal of compassion and good will was extended towards others who might be struggling but some people, understandably, did not like being dependent on others for things like medication ordering and collection
- Some people faced additional barriers relating to access, communication and digital technology and these are areas which could be improved in future to ensure good quality,

equitable access for people who need medication during the continuing challenges presented by the Covid-19 pandemic and beyond

n) Care homes

COVID-19 - Impact on residents

- Deterioration in physical and mental wellbeing of care home residents as a result of prolonged severely restricted contact during the pandemic
- Impact on emotional wellbeing of family carers who had little or no contact with loved ones for long periods of time
- Concerns raised about quality of care and safeguarding when family members weren’t able to play informal ‘monitoring role’ through visiting regularly
- Fear of repercussions on resident care or even eviction if concerns raised or complaints submitted
- 14-day isolation rule after admission to care home detrimental to wellbeing of residents

Visiting care homes

- Huge variation throughout the pandemic in terms of how different care homes enabled contact and meaningful visiting
- Lack of involvement of family carers in making visiting arrangements and doing person-centred individual risk assessments to consider residents’ wishes and needs regarding visiting
- Huge variation in terms of how regular contact/communication with family members was maintained when face to face visiting was restricted
- Variation over what care homes were ‘allowing’ in terms of visiting at the end of life despite guidance saying that end of life is the last months of someone’s life not the last days and visiting should be permitted as much as possible
- Lack of awareness amongst care homes and families and/or reluctance amongst care homes to enable ‘essential care giver’ role as outlined in the current guidance on care home visiting. Blanket visiting policies e.g. half an hour once a week for everyone in a designated room, irrelevant of individual needs
- No visiting allowed on evenings or weekends

Mandatory vaccinations

Many care homes did indicate a positive sentiment towards fully vaccinating staff. However, the majority of feedback highlighted the uncertainty, difficulty, and perceived unfairness of the legislation's application.

o) Care staff crisis

The challenges that the sector is facing in recruiting and retaining staff is:

- Having a detrimental impact on the physical and mental health of the people who need care
- Placing significant pressure on unpaid carers, mentally, physically, and financially
- Increasing the stress and pressure placed on care home and domiciliary care staff
- Perpetuating capacity issues in hospitals due to delayed discharge

The main issue individuals raised is that there is not enough care available to support themselves or their family member at home. Other issues included long delays in being able to access support or care at home, no day care services being available and no respite places available in a care home close to home.

Some care home managers said the issue is not that they don't have beds available, the problem is that they cannot accept any more people if they don't have enough staff. This means beds are left empty.

What does the staff shortage mean for them?

The care staff shortage is having a detrimental impact on the people who need care, with responses revealing that people's health and well-being is deteriorating as a result. People are also facing financial strain due to having to pay for private services and many are having to ask their family or friends for more help too.

Some people commented on the difficulties of attending hospital appointments without a personal assistant. The issue of having different carers who do not understand the patients' complex needs was also raised. These constant changes to routine and staff result in stress and confusion for people who need care, especially those with dementia. One respondent said the individuals they support are unable to verbally communicate, so heavily rely on staff to spot changes in their 'normal' behaviour which relies on them having staff that know them well. Due to the staffing challenges and increased use of agency staff this may well mean that staff miss signs of illness.

There are also fewer activities taking place in care homes due to staff shortages. As the basic care and safety of residents comes first, this often means activities and trips out are limited which in turn has a negative effect on both the physical and mental health of the residents.

p) Dentistry

Good practice

- Staff attitude have been described as: “friendly”, “helpful”, “welcoming”, “brilliant”, “great” and “lovely”
- Some dentists have kept patients up to date with information during the pandemic
- For patients who have been able to access a dental appointment they have felt safe in the environment during the pandemic

Waiting lists

- People have told us that they simply cannot find an NHS dentist taking on patients
- People have told us about the difficulties of registering with and seeing an NHS dentist, or even getting on to a waiting list. When people have managed to get on to a waiting list many have reported not knowing how long they will need to wait before being seen or being told the wait will be years
- We have heard reports of people being taken off lists without being aware of why, or how, that happened, or thinking they were on a waiting list to only be told that this is not the case
- We have also heard about the challenges people are facing to find up to date information online about which dentists are taking on patients and how they can register. People have also told us that individual dental practice websites can be confusing about what they offer (e.g., saying treatment is available but when contact is made this is only for private patients.)
- The only way to get the information is having to make many phone calls to dentists across the region

Emergency Dental Care

- Access to urgent dental treatment and care has also been highlighted as an issue. People are contacting NHS 111 for support when they need emergency care and are finding the service to be busy and not as responsive as they would expect
- We have also heard about people contacting local dental practices for urgent treatment as per NHS England guidance but in reality, not being able to access this support due to not being registered with the practice
- People have told us about the impact that not getting dental treatment has had on them. This has led to obvious oral health issues and people having to live with extreme pain and broken teeth. This in turn has had an impact on people’s mental health and wellbeing and is leading to greater health inequalities as those unable to pay for private treatment are suffering the most

Impact on Patients

- Difficulties getting support has led to many people living in pain and unable to eat properly
- Being unable to access an NHS dentist is having a detrimental impact on people’s mental health. Many respondents expressed the anxiety and frustration they have suffered due to not being able to register with an NHS dentist and the worry they feel about whether they will be able to access local NHS dental services in an emergency
- The dentistry crisis has not only resulted in new mental health issues, but has also exacerbated existing mental health conditions, with some respondents saying the difficulties they have faced when trying to access an NHS dentist have worsened existing conditions, such as depression
- A number of respondents also said their self-esteem and confidence has diminished due to unresolved problems with their teeth, meaning they feel embarrassed about going out in public and smiling in photos
- Respondents also raised concerns about the potential long-term health impact for their child/children. The impact of not being able to access NHS dental services on children’s mental health was also mentioned
- Over half of respondents said they have taken over the counter pain medication or used self-help remedies they found online, such as DIY kits to fill broken teeth. A few respondents said they have even resorted to pulling out their own tooth/teeth

- Some patients have been advised that private dentists are registering new patients and they could register privately but some individuals cannot afford to pay for private dental care and treatment. Patients feel that this is “unfair” (inequalities)

Children’s Orthodontics

One of the key issues people have been telling us about is around a lack of communication of changes with existing patients and those on the waiting list. People have told us that despite from being told their current provider was going to cease providing treatment at the end of March 2022, there has been no further communication about who will be providing future treatment or what to do/who to contact in the interim if treatment and advice is needed.

q) Leeds Community Neurological Rehabilitation Service

Staying overnight

- Patients should have the option to visit the hospital and meet staff before their overnight stay, to familiarise them with their environment
- Community Hospitals such as Chapel Allerton should be prioritised for patients using the Neuro Rehab services, with free Wi-Fi, radio, TV, books and other materials provided for patients
- Many from South Asian communities’ fear staying overnight and therefore need more reassurance from the hospital as well as culturally sensitive or religious materials available to them
- Visiting times should be more flexible for patients, with either broader times available or freedom for patients to pick a preferred time
- Due to differing preferences between single and shared rooms, patients should be able to choose the type of room they get placed in, with shared rooms being single sex

Location

- Community venues such as religious buildings, charities or community centres should be utilised for patients who need to receive therapy away from home. These should also be close to the participants’ home
- Each therapy session should be run in the same location to avoid patients having to travel to multiple venues away from their locality

Staff

- It is vital that patients' therapists are not switched as this has a negative impact on patients both physically and mentally
- While thoughts on staff are overall positive, complaints from patients about individual staff members need to be followed up and addressed more effectively
- Offer patients independent advocacy services such as Advonet to help address any complaints
- Language barriers could be addressed by allowing family members/carers to interpret for patients. If this is not possible, then patients should be assigned befrienders or doctors who are from the same background and / or speak the patient's language. Any materials given to the patient should also be translated

Discharge

- Patients were disappointed that there was no follow-up from the final review and wanted to stay in touch with the services in case their condition worsened
- An updated written record of the patient's condition should be provided to avoid the "frustrating" prospect of the patient having to describe their condition to every new doctor / therapist they meet

Current day service

- More contact should be kept with patients following their discharge so that they can continue to improve once out of the hospital
- Waiting lists are often years long for patients despite them being recorded as 'would benefit from neuro rehab', therefore, funding should be put in place to make sure waiting times are cut down or that patients can stay informed whilst they are waiting
- Patients were positive about the level of staffing received in St Mary's, implying that the above aspects were a bigger contributor to the day service not meeting patients' needs

Managing their own condition

- Family members/carers should be regularly informed about the patient's condition and treatment, particularly due to the patient being unlikely to take everything in due to their condition
- Patients need to be provided information by the hospital about peer groups available rather than having to look themselves

- Due to technological barriers for neuro patients, an advice line would be easier for those looking to gain professional support while managing their condition

Self-referral

- If the waiting lists are long, then patients need to be informed on why the wait is long and what processes still need to be completed
- Patients would like to be able to use their local GP to be referred to services
- There should be a range of methods in place which patients can use to accommodate personal preferences and the different senses that are affected by different neuro conditions

r) Social care

- Most people who were receiving care in the home were very appreciative of it, with several people calling this contact from their carers a ‘life saver’ particularly at the moment. There were many positive comments about the care in the home that people were receiving and how much it meant to them
- Where there were some negative comments about care in the home, these tended to be more around the organisation of the care. Carers not turning up at the expected time can have a big impact on mental health
- Where telephone appointments had been accessed there was very positive feedback about them. Most people would still prefer to have a face-to-face appointment and worried about things being missed, but on the whole, people understood the need for different ways of doing things
- Most people reported that they had additional support from family and friends or neighbours. This was often in the form of a family member providing care or help with shopping
- Many people were very lonely
- Some people were not managing very well, and the isolation was having a grave impact on them. A few people mentioned suicidal thoughts. Even for these people, one phone call and the knowledge that someone cared seemed to make a big difference to them

2.17 Stroke

In relation to stroke, **one** additional involvement report has been produced since the previous mapping exercise that focuses on stroke. The themes developed for stroke from the current and previous mapping exercise were:

a) 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
- Any awareness-raising campaign should have a co-ordinated approach across all organisations, including the voluntary and community sector

b) What would be different… in hospital?

Survivors play a role

- Stroke Ambassadors (survivors) talk to people who've just experienced stroke
- Survivors give feedback
- Survivors make choices about their own care and set SMART goals
- Survivors take home an individualised care pack which gets updated annually through ongoing conversations

Everything is joined up

- Multidisciplinary teams communicate with families and set goals together
- There's a key contact / family liaison who signposts to support throughout the journey
- There's a central plan that shows what is available to survivors locally

Care is flexible and ongoing

- Someone you've seen as an inpatient sees you in the community as well (e.g. like midwives)
- Survivors meet their surgeon and get information before surgery, written down in a doc to read

Support networks kick in

- There is support and education for those who will be providing future care (e.g. families).
- Survivors have a tailored rehab resource file for info and resources

- Peer support starts with patients talking to each other on the ward
- Local support group attached to the ward

c) What would be different… at home?

Survivors play a role

- Not overwhelmed by number of people coming to see patients at home
- Focus on need rather than timeframe (this is in the new guidelines)
- Write your stroke recovery plan
- Getting back to work - long- and short-term goals
- Care pack - what is available and what is planned - range of information - GP can access?

Everything is joined up

- Community matron / point of contact (single point of access for social care referrals)
- Localised information about what support, peer networks and knowledge are available.
- Care is flexible and ongoing
- An additional nurse visit at 3 months to prevent big gap between 2 week and 6-month visit
- Ability to self-refer back into the services that you need

Support networks kick in

- Map of what is available for different stages of journey - you can look around at what suits you - you don't know what you don't know.
- Up to date online directory of services - everything available in region.
- Networking event for all support services
- Groups for families and survivors e.g. Choir (giving voice) - run by speech and language team.
- Weekly art / cycling groups for survivors

d) What would be different… 1+ years later?

Everything is joined up

- There is a way of keeping track of survivors without them still being on our caseload.
- Referral back to NHS after a year (in and out of NHS into support services)
- Education for GPs & practice nurses to understand it's a long-term condition (at the start of your medical career not just afterwards)

Care is flexible and ongoing

- Annual review / 'SOS Appointments' (ring in) /with a stroke specialist who knows you
- Joint clinics 1 year later / ‘MOT’
- Allay concerns/anxieties that appear and see whoever you need to see in one place.
- Continuity of care - have knowledge of patient if they do come back onto your caseload.
- Communication around what happens after the 6-month nurse appointment.
- Ongoing self-referral to relevant services (rather than GP) - access the support you need when you need it.
- "10 year plan with a scan" - easy to re-engage with Stroke services even a long time afterwards.

e) Experience of 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.
- People wanted rehabilitation services to be quickly accessible
- 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
- Support and activity groups were appreciated (including those run by volunteers and targeted at specific groups, such as younger people)

f) Accessing digital healthcare services

People living with the effects of stroke faced the following barriers to accessing digital healthcare services - Memory loss issues, and communication (listening, speaking and following a conversation in detail)

g) Staff feedback

- Identified the need for single assessment and the need to improve clinical pathways
- A “quick win” identified for stroke patients related to the fact that telehealth (vital signs monitoring technology) could be rolled out to people in their own homes, to facilitate early, supported discharge from hospital. It was felt that this should be feasible, as the stroke team had capacity to monitor alerts and could intervene early – supporting prevention and readmission to hospital

2.18 Supporting unpaid carers

In relation to supporting unpaid carers, **six** additional involvement reports have been produced since the previous mapping exercise that either focus on or include reference to supporting carers. The themes developed for supporting carers from the current and previous mapping exercise were:

a) All 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
- Carers reported that they sometimes find it difficult to access digital healthcare services because of restrictions around data privacy
- It was important to carers that they were involved in decisions about their loved one's care
- Carers did not always feel their concerns about their loved one were taken seriously by SPA services in the Calderdale region
- Carers of adults and children with mental health conditions frequently reported not receiving the support they needed
- Emergency care planning could be improved, with stronger links between services and families and quicker response times
- 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
- There is a need for increased options for support for carers who work 9-5 such as more virtual and evening/weekend support
- Some carers have described being advised (incorrectly) that having an unpaid carer can be a barrier to accessing support

b) Carers from different ethnic backgrounds

- Carers from different ethnic backgrounds are less likely to identify as carers than white British carers which may mean they access less support leading to negative impacts on their health, wellbeing and financial situation
- Cultural expectations and stigma can have a significant negative impact on carers, particularly in the South Asian community. Support for carers can improve only when these things are better understood

- Carers from different communities’ experience barriers faced by many other unpaid carers but they have additional barriers which negatively impact on their lives and caring role
- People identified many ways in which they would feel better supported and more able to cope with the demands which caring puts on their lives. They are looking for better ways to access support for their health and wellbeing, so they don’t end up at breaking point and needing care themselves
- Local health and social care organisations could be more flexible and creative in their approach to reaching out into the local community to send a clear message to carers that organisations are available to offer support and that obtaining and asking for help may be difficult but there are often many benefits to getting the right support in place. Services could do more to make their offer culturally appropriate, fully inclusive, accessible and supportive of carers by listening to and understanding their needs, considering barriers which can be created by different cultures, religions, ethnicities and having English as a second language

c) Young carers

- Young carers benefit from a varied approach, such as one to one conversation, social media, mobile apps, forums and groups to access information, advice and support. Engagement and support from professionals need to be flexible to consider young adult carer commitments such as studies and employment
- Awareness raising is important in educational and employment settings to ensure messages reach young people in schools, colleges, universities and workplaces

d) Feedback on direct payments

All who receive them said that, when it works well, it makes a massive positive difference to the lives of the person receiving the payments.

But it feels like managing a small business; with a lack of clarity on process, spending guidelines and a lack of support for the family who support the management of it.

e) Leaving hospital

- Family members need to be recognised as an integral part of the discharge journey and should, where appropriate, be involved in discharge conversations from admission until the person gets home. Many families provide vital support with everything from transport home, hands-on care and emotional support, as well as taking on a co-ordination role

- Routinely ask people receiving hospital treatment or care and their family members whether they have any communication needs and act on these in line with duties outlined in the Accessible Information Standard. Communication needs aren't always visible
- Improve identification of family carers and refer to Carers Leeds for information and support as required. Work from the assumption that all family members might have a caring role. Carers should be clearly identified and flagged on the patient's record, with permissions actively sought prior to or during admission
- Ensure that everyone leaving hospital is given appropriate follow-up contact details for further support and advice. This information should also be given to any family or unpaid carers who are supporting the person leaving hospital
- All partners involved in hospital discharge should review their discharge information, policies and procedures to check that they involve both people staying in hospital and their family carers, where appropriate, at key points

f) Palliative care

The majority of carers were satisfied with the overall care provided at the end of life however some potential areas for improvement were highlighted.

Provision of information about:

- Who to contact for care and support
- Support available to carers

Communication with families about

- their loved one's wishes
- how these can be supported
- family involvement in their loved one's care.

g) Carer lanyard pilot

Feedback from carers has been overwhelmingly positive; from people who care for people with hidden disabilities, young carers and from carers who feel they are often overlooked, and their role misunderstood, the lanyard has helped people to feel recognised, supported and for the importance of their role to be appreciated.

Feedback from professionals has been just as positive as from carers.

h) Impact of care staff crisis on unpaid carers

Growing numbers of people needing care and the increasing complexity of their needs, coupled with the current recruitment and retention crisis, means that demand is far outstripping capacity. The impact on carers is:

- Family and friends have had to help more due to the lack of access to paid care. This means many more people are becoming unpaid carers
- They have faced additional stress and pressure due to their caring role
- Many also said they often have no break or respite from their caring duties which is resulting in both physical and mental health issues
- Carers commented on the burnout and well-being issues they have faced because of their caring duties. The issue with the lack of practical help, support or respite for unpaid carers was also mentioned
- The cost of care was also raised as a significant issue. Some people told us they had to reduce their work hours so they could provide more unpaid care
- Some feel that that professionals and society do not understand the responsibilities and stresses that unpaid carers face daily

i) Improving involvement of unpaid carers

The main key theme is that carers do not feel that they are listened to. Carers felt this was due to:

- Some health and care professionals not being able to identify carers
- Some health and care professionals not valuing carers as experts by experience
- Carers not being asked for their views, or consulted about the care of the person they are supporting
- Carers not being aware of ways they can share their views, e.g. Patient Participation Groups
- Health and care professionals not communicating changes that have been made as a result of engagement with carers

2.19 Urgent and emergency care

In relation to urgent and emergency care, **two** additional involvement reports have been produced since the previous mapping exercise that either focus or include reference to urgent and emergency care. The themes developed for urgent and emergency care from the current and previous mapping exercise were:

a) Awareness of services available

The main theme raised was a lack of knowledge about the options for ‘out of hours’ care, especially during evenings and weekends, along with some confusion about the different options for urgent care and what the differences were between minor injuries units; walk-in centres; and urgent treatment centres.

To ensure that people access the right service, first time it was suggested that there is a need to raise awareness of the most appropriate service to access, where and how to access these services. However, it was acknowledged that without improvements to access to GP appointments and other services, people will still access A&E (Accident and Emergency).

b) Who people contact prior to attending an urgent/emergency care service

- Most people report that they contact either NHS 111 or their GP practice prior to attending A&E. Some people don’t seek advice prior to attending A&E as they feel that A&E is the right place for their condition
- People that accessed a walk-in centre were less likely to have contacted anywhere else prior to attending, and often chose the walk-in centre due to ease of access and ability to be seen that day
- Many seek advice from their pharmacy and those that do report high levels of satisfaction
- Some accessed GP out of hours. Of all the services accessed for urgent care this service received the lowest levels of satisfaction

c) Why people attend urgent / emergency care services

- Many people report that if they had been able to access a GP appointment at a time that was convenient to them, they may have not attended A&E. People talked about their frustrations at the changes made during the pandemic in accessing GP services and expressed their concerns that services will not return to how they were before the pandemic

- If they are unable to be seen quickly, they feel they have no choice but to access urgent and emergency care services to ensure that their condition is treated. Suggestions were made to be able to access GP appointments early morning, evenings and weekends but they want to be able to access these appointments the same day
- People often report that they have sought advice from a health professional prior to attending A&E, and that they have been advised to attend A&E. Either because they have a health condition that needs to be dealt with urgently; that A&E is the best place to receive the care that they require; or they have been advised to attend if their condition doesn't improve. A common complaint was that many people were still referred to A&E despite trying to avoid going there in the first place
- Many had a health condition that they felt needed to be dealt with urgently, and that urgent and emergency care services was the best place to receive the care that they required, such as X-rays, scans, blood tests, stitches and other treatment. People have suggested if GP practices were able to undertake diagnostic testing this would reduce the need for people to attend A&E
- GP services and community-based health care are also often closed when patients need to access them, forcing them to go elsewhere, despite their preferences to use these services
- Some attended as it was the most convenient place for them to attend, in that it was easy to access as no appointments are required or it was close to home
- People want to be seen by the most appropriate person, quickly and in a setting that is close to home. They didn't want to be travelling long distances when they needed urgent or emergency care

d) Why people aged 20-29 attend urgent / emergency care services

- Most people suggested they had seen information about alternatives to EDs and most had tried to access or were aware of some of these services
- Most people stated that they would like to be able to access medical care and advice via a range of different methods, such as face to face and mobile apps. In general people would prefer in person or telephone appointments
- Long waiting times would deter people from using ED in the future

Majority of people who had attended fell into three groups

- Those who had been referred to the service via a health professional, website or service
- Those who felt assured that they had chosen the correct service for their urgent and emergency needs
- Those who used the service to obtain a quick and efficient service and reassurance of their concerns

e) Communications in Accident and Emergency (A&E)

- 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
- 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

f) 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
- Waiting times were felt to be lengthy in Accident and Emergency departments
- 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
- People said they would appreciate being given an indication of how long they could expect to wait and having more comfortable seating. Food provision was widely felt to be lacking
- 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
- Patient comments about staff attitudes in Accident and Emergency were overwhelmingly positive
- Accident and Emergency units were often identified as exhibiting discriminatory behaviour towards those with addiction issues

g) Alternatives to Accident and Emergency (A&E)

- A one-stop shop for urgent care needs was seen by many as a good idea. As patients don’t always know if their condition is urgent or an emergency, by having it all in one place this would take the responsibility away from patients to have to decide which service they should access
- Ideally, they would want urgent care services to be located with A&E. They felt that it made sense to have all services located in one area, so should their condition deteriorate, and they require emergency care they are already in the right place and do not need to be transferred to another location. They also didn’t want to be arriving at A&E to then be told their condition was not an emergency and that they should travel to another location to receive urgent care
- Urgent care / treatment centres should provide blood tests, X-ray, scans, minor surgical procedures, burns treatment and treatment for factures or broken bones. It was also suggested that the centre should also include urgent dental treatment
- A significant proportion of people that had used a walk-in centre state that they would have attended A&E if the walk-in centre had not been available. Many patients valued the provision of treatment outside of A&E departments, in minor injury units or walk-in centres. These were often popular because they were seen to avoid long waits, although sometimes led to frustration if the service was unable to deal with the presenting condition
- There was some concern that people would choose to attend an urgent treatment centre rather than trying to obtain a GP appointment, and how would this impact on GP services locally
- When asked their views about the idea for paramedics to have a much wider range of care and treatment options available to them, rather than just taking the patient to A&E. They would have the help of a team of doctors and nurses available by phone. Overall, the majority of respondents were supportive of the proposed one stop-shop model, as they felt that it would ensure that only those patients that needed to attend A&E would do so. It was thought that this would lead to a reduction in the inappropriate use of ambulance services, reduction in A&E admissions and as such people would be seen quicker which would result in an improvement in patient outcomes
- When asked their views on a ‘call centre’ approach some were concerned that a diagnosis made over the phone wouldn’t be accurate and felt that this was best done face to face. They also queried the quality of the communication and clinical skills of the call centre staff. They needed reassurance that the staff would have had communications

training and that there would be an appropriate skill mix. It was suggested that staffing in the call centre should include pharmacists

- Many people talked about how they see the walk-in centres as a vital part of the health care services offered in their area and that they would like them to continue to be provided. Many talked about the excellent service that they had received and valued the convenience of being able to access services without booking an appointment. And many felt that having walk-in centres helped to reduce pressure on A&E
- Some suggested that walk-in centres should be located on the same site as A&E to help alleviate the pressure on A&E and should people require emergency treatment they can be easily transferred
- Some people suggested that walk-in centres needed to be in central locations, accessible by public transport, and have parking

h) NHS 111 and NHS 111 First

- Most people are aware that they could call NHS 111 for urgent medical help, and most would choose this option rather than go to an emergency department
- Most people who had used NHS 111 and got through to an advisor were satisfied with the service
- People most likely to say they had a good experience were those who either had their questions answered directly or a timeslot booked at an emergency department
- When calling NHS 111, people were frustrated with having to answer a long list of questions - often multiple times - and felt that they were not listened to about their health condition. However, explanation of the reasons for questions asked did reduce their frustration
- Awareness of the new NHS 111 First service was low; people were not aware that NHS 111 could reserve timeslots at GPs and A&E. People said that knowing this information would make them more likely to call NHS 111 next time they had an urgent medical problem
- People who had used NHS 111 First and had a timeslot booked at A&E were highly likely to rate their experience as very good, suggesting that that the new system can work well

i) Urgent care: mental 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

- 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

j) Views of staff that work in, or with urgent and emergency care (UEC) services

- Some staff talked positively about a system whereby patients are triaged over the phone and then provided with an appointment. They felt that this system worked well and ensured that patients were sent to the most appropriate place for their condition and removed the need for patients to sit in a waiting room for hours. Those that commented felt that it had worked well for both staff and patients and were disappointed that this model was not going to continue
- Although some staff mentioned that patients that had been telephone triaged and had an appointment booked often arrive under the assumption that they will be seen at the time they have been given. Due to the nature of the service this is not always possible which can result in patients being unhappy at having to wait
- Many talked about the need for educating the public in what services are available, how and when to access them. Staff felt that many patients are either not aware of what is available, or they are aware and try to access multiple services. It was suggested that a simpler system should be implemented that doesn’t encourage patients to try each service before they get the answer they want. ‘Talk before you walk’ was felt by some as a way to better manage patient expectations
- Staff felt that the opening times of all the UEC services worked well and that patients were able to access services 24 hours a day if needed. Staff didn’t feel there was a need to increase the opening hours of any of the services. But there was a suggestion that the opening hours of the walk-in centre could be reduced to 8pm as very few patients attended after this time
- Some staff suggested that staff needed to be kept up to date on what services are available and what they offer so that patients can be signposted to the most relevant service for their problem. Some staff commented that there had been so many changes that it was difficult to keep up with what is provided where
- Many felt that the walk-in centres, urgent treatment centre and A&E are dealing with patients that should have been seen in primary care but due to patients not being able to access an appointment they are either being told by their GP practice or NHS 111 to

attend one of the urgent care services, or patients are choosing to attend rather than wait for a GP appointment

- Staff talked about the challenges of referring patients into mental health services, and speciality services and the strict criteria in place. Often meaning that patients were not able to be seen by the most appropriate service for their needs
- Some felt that the referral processes were too bureaucratic with an example being given whereby referrals from a nurse led service had been declined as they needed to be made by a GP. And some felt that services were reluctant to accept new referrals as they were too busy to take on any new patients
- Handovers between different service providers needed to be improved. It was suggested that a standardised handover document that is used by all services to ensure consistency in the type and level of information provided could be implemented. And a shared care record that all providers can access, ensuring all staff have the correct level of access to enable them to carry out their role is needed
- Many described services that were understaffed and the difficulties in recruiting staff, meaning a reliance on locums. A few mentioned the need for more health care assistants, example given was to provide wound care in the walk-in centre that would free up the time of the advanced nurse practitioners
- Some described how extra support is added during busier periods and that staff are offered the opportunity to work extra time but don’t feel pressured to. Many felt that troughs were rare, and peaks were now becoming the norm
- Need to improve communication with staff and value their ideas

2.20 Workforce

Ambition

Have a more diverse leadership that better reflects the broad range of talent in our area

In relation to workforce, a significant amount of work has been taking place with this priority with the development of:

- Check-in – staff suicide prevention campaign
- Health Equity Fellowship
- Health inequalities academy
- Leaving a gap campaign
- Let's talk menopause
- Mental Health, Learning Disability and Autism Workforce Strategy
- People plan 2021-2025
- Race Equality Network
- Racial inequalities training
- Root out racism
- Staff mental health and wellbeing hub
- System and Leadership Development
- The Fellowship Programme

No additional involvement or consultation reports have been produced since the previous mapping exercises.

However, through other involvement exercises the views of staff have been captured and these can be found in this report on the following pages:

- Tackling health inequalities for ethnic minority colleagues and communities
- Anti-racism movement – campaign development
- Planning future maternity services
- Care staff crisis
- Stroke – staff feedback
- Urgent and emergency care – staff feedback

Appendix A – List of documents reviewed

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17. Calderdale Council (2022) Autism Hub survey summary. [Accessed at: Word copy]

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19. Cherry, L. & Froustis, E, (2022) Trauma Informed Education Settings In West Yorkshire. West Yorkshire Health and Care Partnership and Violence Reduction Unit. West Yorkshire: England. [Accessed at: https://www.wypartnership.co.uk/application/files/6516/5934/6537/Trauma_education_report_WEB_READY_NEW.pdf]

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