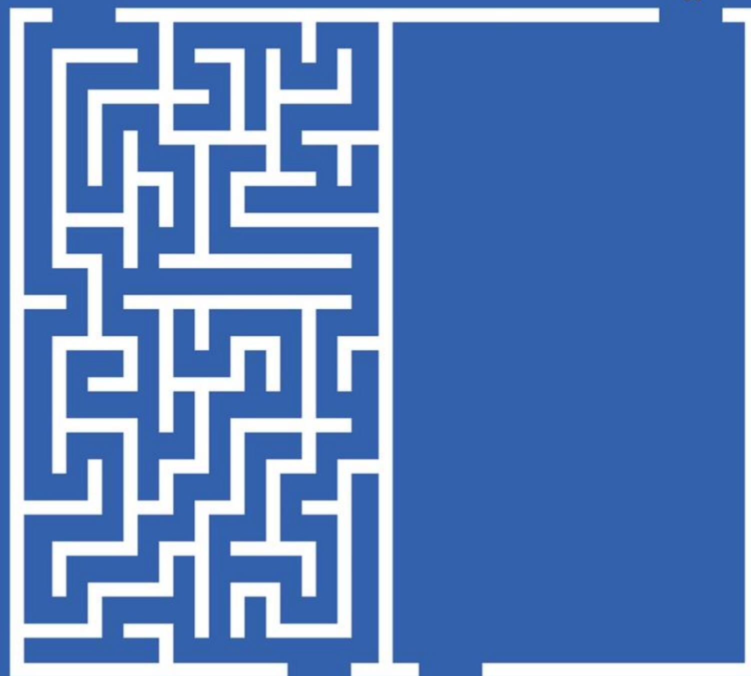
Your healthwatch Leeds

Health Inequalities:

What Can Health and Care providers do to play their part in addressing health inequalities?



Conversations with communities in Leeds facing the greatest health inequalities

March 2021

"There are no hard-to-reach communities, just hard to reach services"

Victor Adebowale,

WYH Inequalities conference, February 2021

Forum Central

A collective voice for the health and care third sector

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Introduction

What is this document about?

In Leeds, we have a shared ambition from our Health and Wellbeing Strategy to improve the health of the poorest the fastest. Despite being considered one of the leading cities in the UK, a fifth of our population lives in poverty and significant inequalities exist and continue to increase. We know that tackling inequalities is multi-faceted and that health outcomes are influenced by where you live, your income, your social connections, your education and more. But we also know that there are things that health and care can do to play their role in improving health inequalities through the way that they deliver and design services.

This report is about communities' observations as to what health and care services can do differently to meet the needs of people in Leeds facing significant health inequalities.

We would like to say a big thank you to those community organisations who have shared their insight for this report. We clearly heard the call to action on this, and the ask not to keep repeatedly ask the same questions of communities but to act on what they have told us.

Over the next few pages, you will be able to read about the specific ways that health and care services can better meet the needs of individual communities. We have also identified some of the themes that impact on multiple communities and provided some ideas and reflections around this.

Who is this document about?

From December 2020 to February 2021, we spoke to a number of organisations to find out their ideas and insight from previous engagement around what services can do to improve their offer for the people they work with.

For a list of the organisations we spoke to, please refer to the Contents on page 2.

Why did we choose these organisations?

These organisations represent just a portion of the many different communities we have in Leeds and, as such, it is important to note that this document is just the start of ongoing work around inequalities and putting the voice of communities at the centre of what we do. There are also many different groups and populations who need to be asked about the health inequalities they are facing and, while some of these will be reflected in this report, there are others that will be unique and just as important as the examples you read here.

All member organisations of the Communities of Interest network were approached for this project. While there were some organisations (such as the Culturally Diverse Communities Hub) which weren't able to find a time to contribute at this very busy period of the year, we hope to connect with them at a later date as our focus on health inequalities continues. Our aim is to do a focused piece of work that understands the experiences of the many culturally diverse communities in Leeds.

What did we ask community organisations?

We asked:

1. What could health and care services do better or differently for your community?
2. What might work even better?
3. Have you seen any examples of good practice?
4. What would amazing look like?

How did we gather this information?

The following community testimonies were gathered between December 2020 and March 2021. Sometimes, we interviewed organisations over the phone; other times, they shared their thoughts and observations with us via email.
Because of the different ways in which organisations were able to take part, their testimonies are varying in length and style and written in their own unique voice (hence why much of what follows is in quotation marks). We hope this makes for an enjoyable and engaging read.

Top 10 actions for the Leeds health and care system to address health inequalities

As well as hearing the specifics from each of the different communities in terms of how health and care services could better meet their needs, we also wanted to identify the cross-cutting themes. There are 10 in total and they are detailed below, along with some questions and reflections.

1. The key role that GP practices play in a person's health and care

As we heard at the Big Leeds Chat in 2018, one of the key themes that communities talked to us about was the importance of GP practices' role. Many communities' responses focused on GP services not because they are felt to have more to improve than elsewhere in the health service, but because they are a hugely important part of people's wider relationship with health and care. 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. Therefore, it is vital that GP practices are designed for this role.

Do we need to re-imagine the GP practice experience focusing on the user journey and experiences of different communities facing health inequalities?

People often talked about the following points when speaking about GP practices, but they can equally be applied to all health and care settings and services.

2. Front-of-house experience

What does the front-of-house experience feel like? Are there quiet areas? Is the receptionist welcoming? Are front-of-house staff fully trained in inclusive working and the rights of specific communities such as refugees & asylum seekers? Does the front-of-house take a person-centred approach?

3. Accessible health and care services

We heard from many communities about key barriers that prevented people from gaining initial access to health and care services.
Is there a focus on how people can initially access services? Are appropriate translation services offered? Do practices have up-to-date records adhering to the legal requirement of the Accessible Information Standard, so that people are communicated with in a way

that meets their needs? Is there a programme to increase the number of carers who are identified as such? Are paper resources available as well as online resources? Do we need to focus on accessible language that all can understand and use and move away from clinical language?

4. Joined up health and care services leading to better health outcomes

How can we further develop health and care IT systems so people's information is shared and they receive joined up health and care, to ensure they don't have to repeat their stories time and time again (especially where communication might be an issue)? How can IT systems highlight if they have additional communication needs or are from a specific community, such as carers?

5. Impact of poverty on accessing health and care

We heard about the disproportionate impact poverty has on people trying to access health and care services. 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. How do we minimise or eradicate unseen additional costs for people with the greatest health inequalities?

6. Digital inclusion

As we have moved to delivering services remotely, how have we ensured that we have not further excluded people with inequalities? How do health and care providers ensure that digital is not an additional barrier? What plans are in place for this? Blended online and in-person offers are potentially a step towards making services more accessible.

7. The importance of having an inclusive workforce trained in person-centred working practices

For many, working in a way that understands different communities does not form part of standard clinical training. How do we develop a health and care workforce that is both inclusive *and* trained in inclusivity?

8. Gaps and improvements in current service offer

A number of gaps have been identified which, if they were filled, would support better health outcomes for communities:

Extended appointment times:
Do we need to offer extended appointment times for any community that may experience health inequalities (particularly in primary care but potentially across health and care services)?

Seeing the same GP:
Could people with inequalities be seen by the same GP to enable co-ordinated and person-centred care?

Mental health services and culturally appropriate language:
Mental health was a strong theme both in terms of gaps of services and support for specific communities, but also in terms of a culturally appropriate approach and language. Does the new mental health strategy need to take a nuanced approach to destigmatising mental health? For some communities this means using language in a way that moves the focus away from being "mentally ill" (for instance by using terms such as "emotional wellbeing" instead). It also means understanding that people express pain and trauma in different ways – and this isn't just about language differences, but about wider communication.
Support with domestic abuse that includes a nuanced understanding of a person's wider needs was also mentioned in communities' testimonies.

Community-specific services:
For full details of where communities are asking for changes to very specific services, please read the testimonies that follow. Here are a few examples:

- Medication reviews for people with learning disabilities
- There is variance in annual health checks for people with learning disabilities in terms of effectiveness and implementation.
- Male-only services (including prostate cancer screening) and the need for gender differences to be designed into plans for how people access health and care services
- A gap in respite for carers was strongly identified

9. Partnership with trusted community organisations
Examples of partnerships with trusted community organisations include 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 means involving community organisations in the earliest stages of service planning. It also means knowing what the third sector can offer in terms of the stepping up and down of a person's care, and the long-term resource needed for this.

10. Do all this with people and communities

Our number-one recommendation would be to coproduce all subsequent work on health inequalities with people from those communities (or community organisations), so that the people for whom the service is designed are at the centre of decisions. It is only by people and communities leading this work that will we really understand how best to meet communities' needs.

Refugees and Asylum Seekers (part 1)

LASSN (Leeds Asylum Seekers Support Network)

LASSN works to meet the unmet needs of refugees and asylum seekers living in Leeds, many of whom have limited English, experience acute isolation, poor mental health, and prolonged uncertainty over their asylum claim.

What could health and care services do better or differently for your community?

- "Make a clear unambiguous statement of when and how interpreting services will be offered at each point of contact, and an explicit minimum standard of help – along with how to complain if this is not offered (GP, LCC helpline)
- Better access to bilingual advocacy services, in acknowledgement that asylum seekers and refugees have some of the worst health in the city
- Stop implementing the NHS Overseas Charging regime for people with no right to work, no right to a bank account, and no income – and tell central government NHS Improvements that this is negatively impacting on the health strategy for Leeds as well as being morally wrong, especially when it comes to survivors of abuse and mistreatment.

- A 3-point plan, adopted by Health and Wellbeing Board and championed by a senior member of the HWB Board, to address the systemic problems encountered by migrants living in Leeds (including refugees and asylum seekers), and progress against these reported every quarter. Nothing fancy. Nothing too hard. But a steady way of improving the lives of the 10% of people who were born outside the UK and living in Leeds."

Refugees & Asylum Seekers (part 2)

Solace

Solace provides psychotherapy to refugees and asylum seekers across the Yorkshire and the Humber region.

What could health and care services do better or differently for your community?

- "Services need interpreters and multi-lingual literature.
- Services should also use a destigmatising approach towards mental health, using positive language about emotional wellbeing as opposed to mental health problems."

What might work even better?

"A lot of clients find it hard to make contact with GP surgeries, so outreach work can help to find those who are in need."

Any examples of good practice?

"Solace has found it helpful to identify a specific need and gear a service directly around that (for example, a wellbeing group for Albanian women). The key is to understand the cultural sensitivities of what the needs of a group might be."

What would amazing look like?

"Train members of staff to be sensitive to what clients are and have been going through. Staff should understand that they often don't have one problem but many problems."

Refugees & Asylum Seekers (part 3)

Health Access for Refugees Programme – Refugee Council

HARP empowers asylum seekers and refugees to access the UK health system in an appropriate way and at the appropriate time.

What could health and care services do better or differently for your community?

Access and entitlements in primary care:

- "It is common that GPs charge for letters. Not everyone can afford to pay.
- GPs should follow government policy by not asking for ID when trying to register. People will not be able to get a COVID vaccine if they are not registered, as they need an NHS number.
- Accessing dentists has been impossible, particularly for asylum seekers.
- There are issues with interpreters not being used. Some practices will not give people an appointment unless they bring their own interpreter, which they must pay for themselves. People without an interpreter often get turned away.
- People should be informed that they can book a double appointment if they do not speak English."

Knowledge and culture:

- "People should be told who does what in a GP surgery and how it operates. (For example, when people see a nurse instead of a doctor, the fact you need to get to an appointment on time or what time is best to call for an appointment). In other countries, people go to hospital to access health care, but we want don't want A&E to be overcrowded. Not everyone knows the UK process of referrals to a specialist."

Creating a welcoming environment:

- "It would be nice to see a welcome sign in practices.
- Surgeries need to get Doctors of the World training and become what is known as a "safe sanctuary" so they understand the barriers that people might face. HARP give free training to health professionals on this."

What might work even better?
"Working on building a trusting relationship: doctors need to turn away from their computer screens and talk to the person in front of them, use interpreters, smile and understand what they are going through."

Any examples of good practice?
"Haamla midwives are excellent. They are for women seeking asylum, new refugee arrivals and Gypsy community and. When people access healthcare, they should have an automatic referral to this service. The midwives reach out, visit and write letters for people. Bevan is another good practice. They are kind and welcoming."

Migrants

Migration Team, Leeds City Council

The Migration Team works to help migrants get the support they need in Leeds.

What could health and care services do better or differently for your community?
Digital access:

- ***"When designing services, be aware that migrants' phone credit is often limited and third-party organisations often have to step in to give people private space for contacting services remotely"***

GP services:

- "GPs and receptionists should be fully trained in migrants' and visitors' entitlement to NHS care
- People aren't being made aware that they can book a longer appointment if they don't speak English as a first language
- There should be greater understanding of the entitlements of people who don't have access to public funds.
- GPs should be aware of their powers to speak to women without their husband present where domestic violence is suspected
- Staff should have some cultural awareness of how people might express their pain and trauma in different ways. It's more than translation issue, it's about understanding how people communicate more broadly and how difficult it can be to talk about trauma with staff who may not be able to relate with their life experiences.

- Burmantofts health centre requires refurbishment to make it a bigger, more welcoming surgery.
- Place people on hold when calling surgeries, rather than having a busy tone and making them call again.
- Use videos in GP surgeries to share information messages in different languages."

Families and children:

- "Health visitors don't always signpost women to services that can help them, so they are left unsupported.
- The impact of lockdown on children's mental health will be an issue for a long time to come – we need to prepare for this now."

Autism

Autism AIM

Leeds Autism AIM is a free service for autistic adults in the Leeds area who receive little or no funded support. It was founded in late 2014 by The Advonet Group.

What could services do better?

Improve access to GPs

"People with autism have a high rate of co-occurring conditions and differing communication and sensory needs which means that accessing a GP can be more difficult. Here are some of the reasons:

Getting to the GP

- "If they are isolated, people might not have someone to go with them (having no support network can in itself be a barrier). They might not be eligible for or able to afford a support worker.
- If a person has the same doctor so they don't have to explain themselves each time, they will form a better relationship and the doctor will have a better understanding of the person. Could priority access to the same GP be given to people with Autism?"

At the GP

- "This is where having someone with them would really help autistic people, as retaining information given by a practitioner can be difficult, and this means they might not understand what to do next. Could it be standard practice for GPs to put advice in

writing so that people with autism can take it away (i.e.: information discussed and follow up appointment details)
- Not all people with autism are flagged or asked about autism when talking about reasonable adjustments – so autistic people might not know whether to tell someone about it. Could this be standard practice when asking about reasonable adjustments?
- As processing time can be slower for autistic people, could their appointment times be extended as a matter of practice, instead of leaving it up to the patient to book extended sessions?
- Receptionists are a real mixed bag – some have no autism awareness at all.
- Waiting room: a quiet waiting room would be preferable for autistic people due to sensory sensitivities. Something as simple as receptionists' phones being turned down could be beneficial. Could there also be some specialist autism practices in Leeds? There are practices that specialise in other areas.
- Doctors' understanding of autism varies widely (with some people experiencing doctors that "don't believe" in autism). Autism awareness training (including information on how some people respond to questions) would be beneficial. A good example of this is being asked about pain levels. Sometimes people are asked on a scale of 1-10 or judged by their body language and facial expressions. Some autistic people could be in severe pain and not show it or could verbalise using words that make sense to them but not necessarily the doctor. This can lead to the doctor dismissing or misjudging the level of pain the person is in. A person could also get sensory overload and again be dismissed as being hysterical or panicking."

Other things to consider:

- "Whilst E Consult can be useful, as people don't need to speak to the receptionist, there is a downside. A lot of the questions don't always make sense. For example, it might ask what the problem is, then ask what the symptoms are. It can get very confusing and a lot of people with autism would give up. It would help if there was some guidance for each question.
- GPs in York have a badge/award to say that they are autism friendly. Advonet are doing some work with the diagnostic service to get something similar in Leeds.
- There is a higher occurrence of LGBT+ in people with autism, in particular trans and identifying as non-binary. The language

people use to express themselves and communication issues can make accessing things like gender clinics especially difficult."

Single Parents

Home-Start

Home-Start's work with children and families is based on a recognition that often the best way to help children is to support their parents, so that they can give their children the best possible start in life.

What could health and care services do better or differently for your community?

A more flexible, understanding approach:

- "Services should offer parents appropriate appointment times, taking into account their childcare needs and offering support where possible.
- People's personal circumstances can represent barriers to attending. When people don't attend their appointments, they shouldn't be "written off". Workforce development offers a way to do this, so that staff will be trained to think about what is going on in people's lives.
- Having an offer that includes a variety of approaches can help to include people."

Joint, community-based working:

- "While there have been moves to make services more local, barriers still remain. For example, there have been initiatives to find out if third-sector organisations have rooms they could open to services, the idea being that these would be more welcoming and familiar to some people. However, these haven't come to fruition because organisations can't afford to upgrade their facilities; they also can't be confident that investment from services would be long term.
- Third-sector organisers can be part of a more comprehensive system that takes a holistic approach to individuals' circumstances (which might include, for example, domestic violence, mental health, special educational needs and disability). However, it should be borne in mind that smaller support groups seem to have disappeared in recent times, and capacity is a problem for many organisations."

Getting the language right:

- "Services should be more mindful of their use of terminology (for example, ideally they would use "adult", "child", "young person" instead of "patient").
- Language should be shared across services
- The third-sector has a lot to offer in terms of building trust with people through conversations"

Prevention:

- "Services are starting to think more and more about children and families (including Local Care Partnerships), but there is more room for preventative work. For example, prevention around perinatal mental health could help prevent problems from taking root early in life.
- Mental health is a huge issue at the moment, the consequences of which won't become fully clear for several years."

Coproduction:

- ***"Ask people's views about services before putting things in place. There is still a tendency to ask people too late, when a project's parameters are already very much in place. Third-sector organisations can be a good conduit for this. If we get this right, we can support people the way they want to be supported."***

What might work even better?

Collaborative partnership work:

- "The connections Home-Start has made at the Communities of Interest network have been really useful
- As things start to get tougher in the sector over the coming months, there is a worry that people will start to retreat back into their own organisations (although it's been clear that collaboration makes us all stronger!)
- It's important too that small organisations (such as Home-Start) don't get forgotten. Those which are reliant on grants have to worry all the time about sustainability, making it much harder to plan long-term. You can't build any foundations if your funding is at risk year-on-year, and it also makes organisations more reluctant to offer long-term engagement to people, as they don't want to have to disappoint them when the funding runs out."

Flexible service offers:

- "Especially at times of lockdown, flexibility is an important part of any service. While services are starting to offer out-of-hours appointments, this could be rolled out more widely.
- Remote services have been fantastic for those individuals who can access them. It would be great to see a blended offer being available over the long term."

Any examples of good practice?

- "Home-Start has a great relationship with Early Help Teams, Children's Centres and Leeds Mental Wellbeing Service, which enables them to offer "wraparound" support for families. This works because it reflects the fact that "one size doesn't fit all" (i.e.: some people are more likely to engage with one service than another).
- Home-Start Leeds is part of the Leeds Mental Wellbeing Service (LMWS). While the service at the Mount isn't perfect yet, the partnership has developed and the whole service and pathways are still being looked at. It is important that small voluntary organisations are not forgotten.
- While there is still progress to be made around culture and language, it's good that honest conversations about them are happening."

What would amazing look like?

- "Whoever the service user is, whatever their age, they get the right support from the right team.
- Services are restorative and are based on the person's strengths, rather than what they can't do (for instance, there is recognition that we all react to life events in different ways, so we have to accept this into our expectations about how people should behave)."

People with Learning Disabilities

People in Action

People in Action works with people with learning disabilities and autism to support happy, healthy and independent lives.

What could health and care services do better or differently for your community?

Mental health

- "Appropriate mental health services for people with a learning disability are really difficult to find. Some people access IAPT but support is limited to a certain number of sessions. This increases people's anxiety before even getting access, as there is a fear of missing an appointment and being 'dropped' from the service.
- Lots of people with a LD also have a mental health diagnosis and tend to fall between services. They often end up with LD support organisations such as People in Action which don't have the mental health expertise to fully support them. People in Action has seen an increase in people experiencing mental health crisis, particularly men who are isolated because of COVID."

Domestic abuse/violence

- ***"There are some good links with services, but there is no tailored support available or understanding of what people with a LD require or the barriers they face to getting help."***

Medication reviews

- "Some people have been on the same medication for years and, in a lot of cases, reviews are not happening as they should with the GP. Sometimes it can take a lot of phone calls to get the GP. Staff working with people with LD are not medically trained so, if the GP says there is no need to review, should staff accept that decision?
- People in Action are looking at some training around medical conditions for people with a LD."

Annual Health Checks

- "Everyone with a LD should be called for an Annual Health Check, but some aren't. There is also an issue with parents saying that their son or daughter doesn't need an annual check-up.

- Where people are in supported living or residential settings then support organisations tend to know more about medical records and the person's health. If the person is living in a family home, the support organisation often has more difficulties. Families can be quite protective, so there are more barriers in place.
- If health services could work with support organisations and family carer, that would help join things up more and organisations like People in Action could work more closely with the family to help allay any potential fears."

Sexual health and gender identity

- *"Quite often there are barriers with parents not wanting to accept their child. It would really help if support organisations could be more involved (for example by being signed up to Leeds Care Record)."*

Accessible Information

- *"Easy Read is helpful but always seems to be an afterthought. While there has been improvement (especially in relation to COVID), Easy Read isn't a "one size fits all" solution. Finding out people's accessible information needs is key."*

What would amazing look like?

- "More joined up services: attending the Local Care Partnership (LCP) has made a real difference for People in Action in getting information quickly and being involved in discussions early relating to LD. For example, at the York Road LCP, some work was being done around employment training that wasn't accessible, but People in Action are now involved to make sure this is rectified.
- Thinking about how services work for people with LD (especially in the planning stages) would make a lot more things amazing. Use the skills, knowledge and experience of staff (at organisations such as People in Action) to help plan new or changing services."

Carers

Carers Leeds

Carers Leeds gives specialist and tailored support, advice and information to unpaid carers aged over 16.

What could health and care services do better or differently for your community?

The importance of respite:

- "Ensure carers can take breaks, so there are more respite opportunities. This would include scheduled weeks where home-based care is provided. It would help if there was a more holistic (rather than task-oriented) view of caring."
- There should be a priority on reopening essential services (in a safe and managed way), and unpaid carers should be prioritised for vaccinations."

Financial support:

- "Offer a one-off payment to help carers through the winter months and as recognition for what they have done over the last nine months keeping the cared for person safe and well and ultimately away from mainstream services.
- Ensure carers can continue to remain in work if they wish. Continue our work with the Working Carers Business forum, as well as Leeds Anchors Healthy Work. Nationally, Carers Allowance should be increased so it is at least the same as unemployment benefit. Develop a Carers Card."

Make carers visible:

- ***"Ratchet up the carer ID scheme and support across all health services (GP, hospitals, community). It is happening, but there is much more to do."***

Service access:

- "Make sure digital access to services is good, but provide hardcopy information about them too. Give people the choice of how they want to access support, and find out how carers want to be communicated with. Make sure every carer has a digital kit to access Carers Leeds' services (and other support).

- Offer carers support across Leeds, based in communities, rather than just in the city centre and take support out to people (for example by taking a bus to supermarket and community centre car parks).
- There should be continued support for bereaved carers in the wake of the pandemic."

Men

Men's Health Unlocked

Men's Health Unlocked is a project and network which seeks to connect and liaise; involve and develop; and promote and celebrate the health and wellbeing needs and activities of men in Leeds, from all backgrounds and at all levels.

What could health and care services do better or differently for your community?

- "They should recognise that making an appointment is very tricky and that men can struggle more with communication.
- They should also have an understanding of men's lives. A lot of policies are put in place without an understanding of what it is like to be in poverty. For example, advising that one should try meet others more is of no use if that is not facilitated at the same time - it will just create a barrier and make "healthy" an inaccessible notion, when in reality there may be other ways in which one can be healthier."

What would amazing look like?

- "Consider men in policy.
- Reinstate male-only services and offer healthcare designed with men in mind, for example by reinstating prostate cancer screening.
- Create domestic abuse support services that are more cross-gender, or target men specifically, given that around a third of victims are male and that they are less likely to report."

Any examples of good practice?

- “Examples include peer-led groups where men help to lead, for example Men in Sheds, Andy's Man Club, BEA Saturday Men’s Group and the Zest Impact Group.
- The Manbassador Project uses apparently unhealthy settings (such as a chip shop) to promote good health, because the proprietors provide high quality peer support to their customers.”

Older People

Leeds Older People’s Forum

The aim of the Forum is to promote the well-being of all older people in the city of Leeds, and to give a more powerful voice to older people in shaping their city for the benefit of all its citizens.

What could health and care services do better or differently for your community?

“Where possible, health and care services could be mindful, adapt and respond accordingly to the ongoing and emerging issues reported by older people and organisations supporting older people. These include:

- The third sector is reporting a marked rise in referrals around mental health - including reports of mental health issues in people who have not previously been reported with mental ill health. There are increased levels of anxiety and panic attacks. Reasons reported include:
  - trauma from previous lockdowns and the impact of being seen as one of the 'vulnerable' groups during the pandemic
  - low self-esteem due to a combination of factors, including growing impact of isolation, lack of face-to-face contact;
- Older people with sensory impairments are experiencing extremely high levels of isolation
- Older people who live alone and older men have been identified as particularly affected by isolation; older men are more reluctant to engage in support services and online groups
- Digital exclusion is an issue, especially as online services become more prevalent and prioritised
- Increase in concern regarding domestic violence and substance misuse has been reported by Age UK Leeds”

Mental Health

Volition

Volition is the voice of the mental health third sector in Leeds.

What could health and care services do better or differently for your community?

Service delivery:

- ***"Keep having an online offer as well as a face to face offer, and being able to change between the two depending on what's most convenient."***

Coproduction and community working:

- "Put co-production at the heart of service improvement - make sure it sets the agenda, rather than responding to an agenda that is already fixed. Make sure broad segments of the population are involved and represented, whilst acknowledging that people can't represent their entire community/demographic - it is far more complex and nuanced than that, there are no easy answers
- Organisations should foster a community – services should feel more like a community than a service, moving away from medicalised models where appropriate.
- Continue learning from the "I statements" (National Voices Network): people want to be treated compassionately, feel listened to and have agency. They want to be helped by an identified person with a name, and have access to culturally appropriate services that are relevant to them."

Interacting in a person-centred way:

- "Trauma-informed practice embedded into all health and care services, to lift barriers to services for many of the hardest to reach people.
- Combine exercise and social connection in different contexts to typical exercise classes, for people who wouldn't ordinarily join - as physical activity and social connection are a mood-boosting combination in terms of early intervention/prevention work.
- Try to ensure people don't have to keep repeating their story to different staff members, as it can be retraumatising.
- Ensuring, when supporting people who can be harder to reach within medicalised mental health models (e.g. older people,

men, some people of colour), that mental health language is more softened and relationship-focused, so it's more accessible for those who still strongly associate mental health with stigma or shame.

Where provision isn't enough or isn't right at the moment:

- "More mental health support for people in care homes.
- Eating disorder clinics need to not tell their patients that they are 'not thin enough' to access treatment - it is life-threatening language and has huge power.
- Work to try to reduce stigma around sex workers accessing mental health services, as they are often met by judgement, or told that the sex work is the root of their issues and they should stop doing it to solve their mental health issues - this is a very exclusionary approach and we know it isn't working.
- Have more services that allow people to engage even though they are still using drugs and alcohol - balanced of course with the safety of the staff. It becomes a chicken and egg situation where people can't get off drugs and alcohol without that support, but they can't access it - new online models could be key to this work."

Stepping support up and down:

- "More stepping up and stepping down of care - less of a cliff edge when you are discharged - using third sector peer/social groups and early intervention provision to keep people connected, and ensuring that this translates to more intensive support as and when people need it.
- Keep striving to improve communication between services to ensure a better service-user experience and pathways to and from support - continuing to strengthen links between mental health services and services that support the wider determinants of health."

Any examples of good practice?

- "In Mafwa Theatre, a staff member from Leeds Mental Wellbeing Service (Nasia from Touchstone) comes into the group to be a familiar face and build relationships, so that they feel they can come to her for support if needed - this is such a brilliant model and they have said it's really working.
- Leeds Irish Health & Homes is a really strong example of building a community rather than a service - the result is high

engagement and trust from their members, and a really accessible atmosphere.

- Armley Helping Hands have bought 4 ebikes and are planning to do cycling trips with small groups of members - rather than always taking a van, where they can, they want to trial these trips, so that members can exercise as well as go on a day out. Is a great way to minimise COVID risk whilst still being able to do day trips (post lockdown), and combined exercise with social connection.
- Victim Support have developed an online resource called My Support Space which they use in addition to support - it includes guides on topics like trauma, recovery diaries and the ability to 'request support' - very interesting model for low level support.
- Citizens Advice Leeds & Chapeltown are an incredible access point, both to crisis services and the wider determinants of health.
- Leeds BME Hub is an excellent example of coproduction - the members set the agenda and the facilitators are there to support them, not to lead them."

What would amazing look like?

- "I would love to see people able to have an online hub for their care, full of guides to help with low level mental health issues, e.g. a toolbox of coping mechanisms to try, rate and embed using principles of habit formation, with an easy, really accessible way to self-refer if they need more intensive support. There are so many apps on NHS digital that could be embedded within this model and it would be a great way for clinicians to be able to build a holistic picture of the individual and what keeps them healthy.
- Calm Harm is a good example of a resource (app) with embedded toolkit of coping mechanisms."

Poverty and Mental Health

Chapeltown Citizens Advice

We provide free, confidential and impartial advice and campaign on big issues affecting people's lives.

What could health and care services do differently for their community?

1. “Have a real understanding of the systemic racism that pervades the institution and act upon that.
2. Adopt a paradigm shift towards patient centred services that shift some resources away from the clinical powerhouse.
3. Truly understand the link between poverty, social justice and health and wellbeing and act upon that understanding”

Context:

- “Moneyandmentalhealth.org states that in any given year, one in four people will experience a mental health problem, and over a lifetime this rises to nearly half the population.
- People with mental health problems are more likely to be living on low incomes or in insecure work and can experience a range of difficulties accessing the benefits system. Common symptoms of mental health problems, like low motivation, unreliable memory, limited concentration and reduced planning and problem-solving abilities, can make managing money significantly harder. As a result, it is estimated that people with mental health problems pay up to £1,550 more per year for essential services than people without mental health problems.
- Chapeltown Citizens Advice is very aware of the impact on mental health of COVID-19 and the necessity of living within lockdown and all that entails. In August Cit A estimated nationally 6 million people have fallen into debt since the pandemic began - more so in the North of England. Nationally it is estimated that 350,000 face eviction because of rent arrears.
- Inevitably this will impact further on the mental health of this city and, given the link between poverty and COVID-19, Black communities and COVID-19 and Black communities and mental health, we can easily identify which communities are going to be the hardest hit and where interventions are best placed to prevent poor mental health developing into a chronic condition requiring clinical interventions and resultant higher expenditure.

- We also know that these same communities are going to be impacted more by the recession and any following austerity measures, so their health and wellbeing is under ever-increased threat. The city's long-standing aim of reducing health inequalities and inclusive growth will require a well-coordinated approach that needs to be built now."

Neurological conditions

Epilepsy Action

Epilepsy Action is a community of people committed to a better life for everyone affected by epilepsy.

What could health and care services do better or differently for your community?

Diagnostics

- ***"To get a diagnosis for some neuro conditions, you are dependent on being able to access a number of areas of clinical pathways before getting to your diagnosis appointment. If one part falls down (for instance, if you have had one test but are waiting months to get a result), then the time to get a diagnosis gets longer, meaning treatment can't start."***

Getting a response

- ***"People have been without an appointment for a long time as they have not been able to contact their service. Lots of people haven't been getting a response when they ring their specialist nurse. They either get a voicemail saying there is no one to contact or they are being referred to their GP - but the GP is not an expert in neuro conditions. If they were called back, it might just be a question of adjusting medication. It also gets complicated if GPs have to start referring people back into the system."***

Rehab services

- "People that would have normally been doing important exercises, have not been having hands on support and their conditions have deteriorated.
- There were beds for neuro rehab and day centres, but it is now difficult to get patients transferred after acute treatment to

recovery – this is probably as much a workforce issue as anything. Are areas of rehab being de-prioritised?"

What might work even better?

A more person-centred approach

- "Some people have been scared to go into hospital, so more things being done at home is potentially good. However, while some virtual appointments have been positive, others have not – for example, a phone appointment where an exercise is explained is not as good as having this done via video.
- There are model systems in other countries where practitioners come to your home with the relevant equipment, for example a skull cap where EEG are sent to hospital to help with diagnosis. In Leeds you need to sit in a bed in a unit where someone would be watching you for a week so they can spot if you have seizure activity. If a camera could be set up at home that would be better than a week in hospital."

What would amazing look like?

- "Joined up records between services: a lot of people with multiple long-term conditions are seen by a lot of different services and are on multiple medications. They have to re-tell their story everywhere they go, and it's also difficult call for paramedics to make decisions if they don't have access to the records.
- Shared records are especially important when a person has had a stroke, for instance, and can't tell practitioners about their condition.
- When long-term conditions are discussed, there is often a focus on diabetes or heart conditions. If you have a neuro condition, you are not as often brought to the table."

Dementia

Memory Lane Day Centre

Memory Lane Activity and Day Centre is a specialist service providing day care in the community for older people who have a form of dementia.

What could health and care services do better or differently for your community?

Post-diagnosis support:

- "There has been concern from carers of people with dementia around **support following a diagnosis**. People get a diagnosis of dementia and there is no support or regular check – how does anyone know how the condition is progressing? It seems to be left until the next annual review.
- If people's care is privately funded, they don't get a social worker so don't know where to turn. Sometimes support might be offered to the partner of the person diagnosed but not to the rest of the family who often offer the main bulk of care.
- There needs to be a regular assessment – people won't often reach out unless prompted or they are in crisis. The Admiral Nurses do a great job but, in Leeds, people have to have some affiliation with the armed forces to access them."

Dementia and other mental health conditions:

- ***"There is not enough recognition about low mood and depression in patients and their carers after a dementia diagnosis. This ties in with the lack of support - there is no offer of counselling. Patients and carers need to be told that it's not all doom and gloom."***

Communication:

- *"There is often not much understanding about why people are taking certain medication, so more clarity around that would be beneficial."*

What might work even better?

- "If there was a 'one stop shop' for dementia.
- More Memory Support workers would be great. It's not always clear how people get access to a Memory Nurse – some come

from Primary Care and some from mental health, but it doesn't seem like it's always offered.
- Promote (and provide more funding for) Memory Cafes – they offer lots of respite, support and activities that are fun, bring people out of themselves and get people living again.
- There aren't enough Day Centres anymore (and they are not promoted – possibly because they are fully subscribed already)."

What would amazing look like?

- ***"Having a directory of dementia services and support available on diagnosis. This could include links to dementia awareness training. Often people don't fully understand dementia and how to deal with it. Having access to this information from the start would be helpful, especially for the family."***

Gypsy & Traveller Communities

Leeds GATE

Leeds Gypsy & Traveller Exchange is a grassroots organisation led by Gypsy and Traveller people in partnership with others in and across West Yorkshire.

What could health and care services do better or differently for your community?

- "Be more inclusive for people who are digitally excluded or have low literacy levels.
- Offer longer appointments and follow up appointments.
- Be more aware and proactive in supporting community members in wider health needs may be missed.
- Being aware that there is more anxiety within the community around health due to lived experience of deaths and higher poor health outcomes."

What might work even better?

- "More partnership working with more experienced organisations such as Leeds GATE and Traveller Outreach Health Workers.
- Be more aware of cultural needs and issues within the community which impact health.
- Deliver more outreach."

Women

Women's Lives Leeds

What could health and care services do better or differently for your community?

Acknowledge the impact of COVID

- "Recognise that women have been juggling multiple roles at the same time and that this has had an inevitable effect on their mental health and wellbeing, both in terms of new issues emerging and pre-existing ones getting worse.
- As long COVID appears to be affecting more women than men, there should be a focus on potential links between long COVID and menstrual or other female health issues. There also needs to be mental health support around long COVID.
- The pandemic has had an impact on women's incomes and employment, as they are more likely to do roles that have been furloughed. Services should always consider how accessible they are to people and families with very low budgets."

Frame services around women's lives and experiences

- "Remember that, when women are prioritising others' emotional needs (if they are caring for children or other loved ones, for example), they might "deprioritise" their own
- Not all women will relate to strongly mental health-oriented terminology and may be more likely to see their issues in terms of "feeling stressed", for example. Services should consider how their frame mental health in their communications.
- Women's health services should be more flexible. For example, could screening services be set up in trusted locations other than GP surgeries?
- There should be greater understanding that cervical screening can be traumatic (or retrigger past trauma) for some women. Ideally, services would provide an opportunity for women to get information about and discuss cervical screening tests, without necessarily committing to getting one."

Continuity of care

- There should be greater continuity of care in maternity services. If women have to see a different midwife at every appointment, for example, this can impact on their wellbeing."

What would amazing look like?

- "There have recently been a lot of headlines about "home kits" for cervical screening, but these have been misleading. They actually refer to kits for testing for HPV. It would be fantastic for women to be able to access screening more flexibly.
- In an amazing system, women's health and wellbeing would be tied into every other aspect of their lives. For example, women's health issues such as maternity or menopause would be included in employment contracts as standard.
- Health appointments would be linked into a much more holistic set of options, so that women can access support with their wider lives as they access healthcare, and vice versa.
- To support women's wellbeing, it would be helpful if they were offered more opportunities for making connections with others who have had similar experiences to their own. By bringing women together in a way than is meaningful to them, we can potentially stave off issues with mental health, isolation and so on before they take root."

Any examples of good practice?

- "Previously, Basis have organised a cervical screening clinic aimed at women sex workers and women who are sexually exploited who ordinarily would have been very unlikely to attend the GP. The women were able to get a "wraparound" service that included informal conversations with a specialist nurse. As a result, they got the reassurance they needed to get tested.
- The Home Births Team in Leeds have remained operational throughout the pandemic (which hasn't been the case in other locations). All the feedback Women's Lives Leeds has received has indicated that the Team has provided a very positive, reassuring service."

Women's Lives Leeds is currently launching a campaign with four key messages called *Shining a Light on Women's Inequalities: This is our Normal*.

Sex Workers and Sexually Exploited Young People and Adults

Basis Yorkshire

What could health and care services do better or differently for your community?

- *"Restrictive exclusion criteria often serve to exclude individuals with the greatest need for the service. Trauma responses can often manifest as exclusion criteria. Addressing the need is more effective the focusing on criteria and specific behaviours. For example, if a mental health service that won't work with anyone who has a substance dependency, that excludes many people who have a high need for mental health support and currently use substances as a coping tool. This puts people at an impasse: they might need mental health support in order to overcome addiction or stop drug use, but they are excluded from accessing mental health support because of their drug use."*
- *"Stigma is a significant barrier to accessing health and care services for many sex workers. Previous experiences of stigma, discrimination, and poor treatment in many services makes many sex workers understandably reluctant to access these services unless absolutely necessary, at the crisis point. Additionally as a result of stigma, health professionals sometimes fail to look past the sex work (or drug use) and see the holistic health needs of the individual, incorrectly over-focusing on sex work as the problem and cause of health needs."*
- *"Since front of house staff, such as GP receptionists, are often the first point of contact in any health service, it is very important that they be non-judgemental and sensitive to a range of complex needs. A discrete reception area that is safe and inviting and allows for privacy while speaking to staff about health issues would also be very valuable."*
- *"Complex phone systems (multiple calls, callbacks, need to speak to many people/middlemen, need to call at an exact time in the morning) can be a major barrier to accessing healthcare and appointments, particularly for people with*

complex mental health needs or chaotic/destabilized circumstances. People without stable housing face a barrier in registering for GP and other services that require an address or rely on post to relay appointments. Early morning calls or appointments are difficult for women who work overnight. Provision of transportation would be beneficial, as many women have cited lack of taxi/bus fare as a barrier to attending appointments. These are a few of the specific, practical barriers that could be relatively easy to tackle yet make a big difference in accessibility."

Examples of good practice?

- *"Basis has found that using a rights-based, client-centred, strength-based approach can be the most effective and empowering support."*
- *"Leeds Sexual Health is a health service that exemplifies a lot of good practice. They have a strong outreach programme linked in with third sector organizations to reach particular communities, such as sex workers, who face barriers in health care but have a need to access sexual health services. This includes (during 'normal' times) outreach and service delivery in non-clinical environments, such as at Basis or via the outreach van. They also offer specialist appointments for sex workers, which entails a fast-tracked, more tailored service to that group's particular sexual health needs."*

What would amazing look like?

- *"Fit the service to the people and the needs - not the other way around"*
- *"Unconditional support - people can receive the support they need without conditionality (such as 'exit sex work' or 'stop drug use')"*
- *"All health professionals trained in trauma-informed and gender-informed care, cultural competency, sensitivity to the community's needs. This involves tackling stigma related to sex work on every level, throughout the service."*
- *"Trauma-informed practice - understanding the trauma is experienced differently by everybody, avoiding retraumatization, creating an environment that fosters trust and safety, strength-based practice that promotes agency*

and choice, transparency and confidentiality, addressing the underlying needs rather than the behaviours."

- *"In visioning sessions regarding health provision and what 'amazing' health care would look like, many service users envisioned a women's health hub that incorporates a range of services - sex work service, sexual health, primary care, mental health, drug services, housing, DV services, alternative and holistic health practice, etc - in a one stop shop. They imagined a welcoming and safe space, free from stigma, judgement, and discrimination, with opportunities for community-building and various classes, workshops, and support groups. This centre would be developed with sex working women at the core - commissioning for the most marginalized communities in order to be inclusive to all women. Key principles and values are: intersectionality, confidentiality and transparency, preventative care rather than treatment, and consistency and follow-through. Compassionate, diverse, well-trained, friendly, relatable professionals with lived experience would also be highly valued."*

Other Work in the City

How Does It Feel for Me?

Following a Care Quality Commission visit to Leeds in autumn 2018 which looked at older people's experiences of moving in and out of health and care settings, as a city we wanted to really understand what people's experiences were, and be assured that they were good. Supported by Age UK Leeds, Forum Central, Leeds Community Healthcare NHS Trust, Advonet, Carers Leeds, Leeds City Council, Leeds Teaching Hospital NHS Trust and St Gemma's Hospice, Healthwatch Leeds and Leeds CCG has been following the experiences of several people in Leeds who have complex health needs and access multiple health and care services.

Inequalities to have emerged so far from these testimonies include:

- Coordination of care: For different elements of a person's care to function in tandem, that person often has to coordinate them themselves.

- Communications: Good communications are central to the quality of a person's experience. This includes communications between private providers (such as home care businesses) and public health and care organisations.
- Carers: A person's caring duties should be taken into consideration during their interactions with health and care services. By the same token, carers should be included in decisions about their loved one's medical and other treatments.

Digital Inclusion

Since the lockdown came into force, the People's Voices Group has produced two reports focussing on the risks and rewards of digitising health and care services, and how these might impact upon existing inequalities.

The first report focussed on how eight factors can make people in Leeds more likely to be digitally excluded. These were poverty, age, literacy and communications preferences, skills and motivation, precarious lifestyles, privacy, disability and specific conditions, and trust in IT.

The second report looked at how digital exclusion affects a range of communities in the city. Here are a few examples of what community organisations told us:

- Carers Leeds: Many carers are with the person they care for 24/7. In some cases, it would endanger the carer if they were to speak openly about their circumstances. For example, carers of people with drug and alcohol problems would not necessarily be safe to speak on the phone. Further to this, Carers Leeds has found it relatively easy to find finance for devices. By far the greater problem is getting carers affordable data over the long term.
- Young Lives Leeds: During the various lockdowns, young people have experienced fatigue with online support, with some choosing to wait until face-to-face services become available (creating an inevitable backlog).
- Basis (an organisation that supports sexually exploited women and young people): Previously Basis would have accompanied women to GP appointments, but this is no longer as straightforward, particularly in full lockdown. Women are not always (made) aware that they can ask for someone to support them on their call, as GPs may not routinely ask if they would like this.

- Women's Lives Leeds: Not all women feel confident speaking to a healthcare professional when they cannot read their expressions to gauge if they understand the issue and are sympathetic.

Inclusion for All

Inclusion for All is a multi-organisation action hub. Its purpose is to coordinate the work being done in the city's health and care organisations to ensure services are accessible for everyone, whatever their communications needs. Some of the recurrent inequalities to have emerged from this initiative are as follows:

- When a person has a sensory impairment, their communications preferences are not always being recorded. As a result, people still receive communications in inappropriate formats (for instance a blind person might receive a letter in the post).
- There remains confusion about the process for booking interpreters for GP and other appointments, which can leave people without vital support.
- During the COVID-19 pandemic, accessible communications were sometimes an "afterthought", nationally and locally. For instance, addresses by key members of government were not routinely signed by a BSL interpreter, which meant community organisations had to act quickly to spread essential messages.

Next steps

This report is hopefully a good start to identify how the health and care system can meet the needs of different communities facing the greatest health inequalities.

The intention is that this report will inform citywide thinking on inequalities and will link directly to the citywide Health Inequalities group who are leading on rolling out health inequality thinking in Leeds. It will also go to the Leeds Health and Care Partnership Executive Group meeting in March, to feed into and drive the live discussions currently happening in Leeds around inequalities and the key actions to address health inequalities from a health and care system perspective.

Again, we would like to stress that the key part of the next steps is co-leadership with communities, and community organisations working with clinical teams to assess how we become a city where the health of the poorest improves the fastest.