Leeds Health and Wellbeing Board: Board to Board

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Date:	09 July 2020
Subject:	Impact of COVID-19 on Health Inequalities

1. Purpose

The purpose of this report is to:

- Provide an overview of the key headlines of the health and wellbeing inequalities facing Leeds and how they have grown during COVID-19.
- Describe the key headlines of the challenges going forward around the inequalities gap growing now and ongoing impact.
- Give an overview some of the work of the Tackling Health Inequalities Oversight Group, People's Voices Group and Communities of Interest Network to support / better understand the above work.

2. Background

Case study – carers, mental health, and financial impacts

Healthwatch Leeds has heard from a number of carers that their ability to cope with lockdown has been undermined by the "desultory" financial support they receive.

One example was "Michelle" (not her real name). Michelle cares for her husband, "John", who has early-onset dementia. Before the pandemic, John attended a day centre five days a week. When the day centre closed due to lockdown, John took to his bed and would ask Michelle to take him to the toilet up to 15 times an hour. He would get up dozens of times every night. His mood became angrier and he was less able to attend to his personal care.

John's mobility also declined, and he had a number of falls which meant that he now needed several carers to support him. Eventually, John's mobility deteriorated to the extent that he had to move into emergency temporary care.

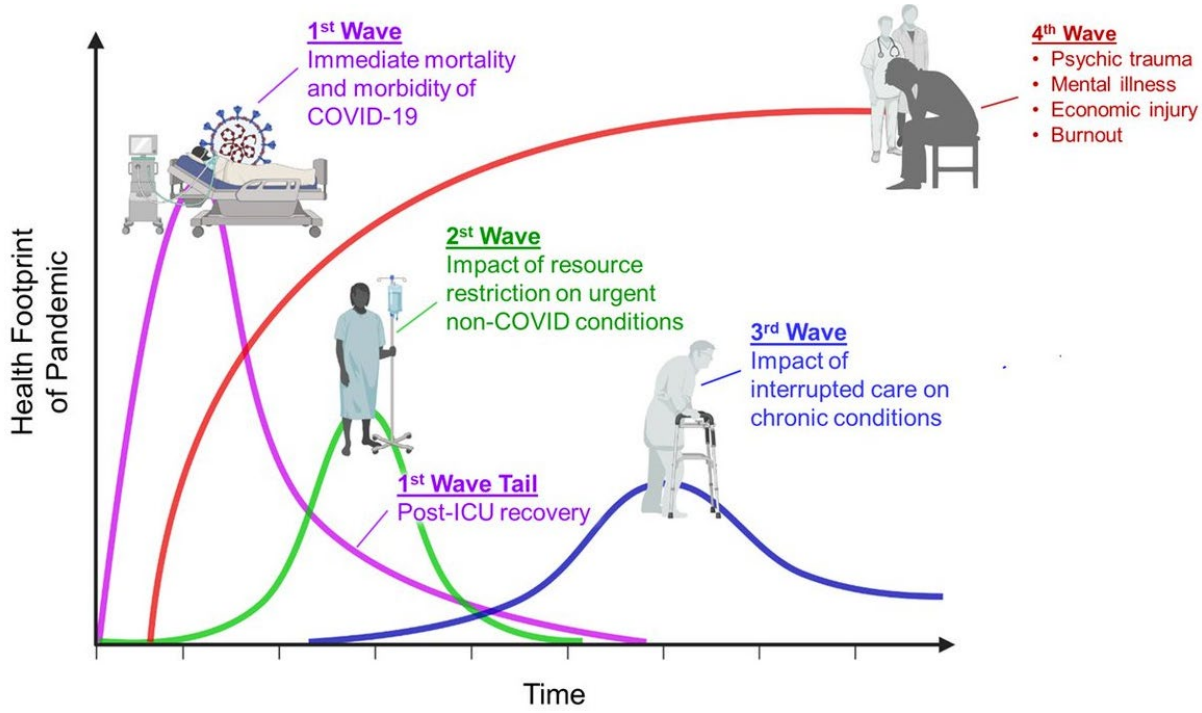
As a result, Michelle was left in an "impossible" financial situation. She left her job a few years ago to look after John, but she is below state pension age. The couple had lived on her Carer's Allowance and his PIP and ESA, but because John has moved into temporary care, both the PIP and Carer's Allowance have ceased, leaving Michelle to live on £114 per week as she applies for Income-Related ESA. Assuming her application is successful, her ESA will be withdrawn once John moves out of temporary care and Michelle will be obliged to apply for Universal Credit as a single person. Given current economic circumstances, she feels her chances of finding employment are low.

Michelle explains that ***"I feel like I been helicoptered and dropped into the deepest part of the north Atlantic. Worthless and unappreciated as a carer and left to pick up the pieces of my broken life alone, not even knowing where or when to start the process. I am mentally and physically drained and I haven't seen my husband for over a month. I am***

‘Health equity in England: The Marmot Review 10 years on’ was published in February 2020. The review cast light on the deteriorating health situation in England in the 10 years since the original Marmot report was produced in 2010 highlighting that life expectancy in England has stalled. The more deprived an area, the shorter the life expectancy and the gap between deprived and non-deprived is increasing. The same can be seen for healthy life expectancy with people living in deprived areas spending more time in ill-health. This national situation had been recognised in previous Board to Boards as being mirrored in Leeds.

‘Covid-19 is emphatically not the great leveller. It has shone a light on the great divides in our society. Everyone can catch it, everyone can die from it but the impact of the virus and the necessary measures to control its spread is not shared equally across society’.
https://fairhealth.org.uk/2020/04/fair-health-in-the-time-of-covid-19/

To consider the depth and breadth of the impact of COVID-19 on health inequalities in Leeds the framework of the four waves of the pandemic has been used. This has enabled us as a place to consider both direct impacts due to COVID itself, those due to the changes in service provision and the wider ones due to system level changes such as ‘lock down’ that were put in place to stem the outbreak.



3. Key Points

Analysis has taken place both of quantitative service data, people’s voices and clinical viewpoints through the work of:

- Healthwatch Leeds;
- People’s Voices Group;
- Communities of Interest that have been established;
- And wider networks.

3.1 Wave 1- Immediate mortality and morbidity inequalities relating to COVID-19

What is interesting about the risk of death or hospital admission from the virus is that it almost perfectly tracks your current risk of death. So, if you are already sick, from a BAME background, grew up in poverty or already older you are more likely to develop serious symptoms and/or die.
https://fairhealth.org.uk/2020/04/fair-health-in-the-time-of-covid-19/

A number of national reports (1) have confirmed that the key groups directly affected are:	
Older people	the largest disparity found was by age, of people diagnosed with COVID-19, those who were 80+ were seventy times more likely to die than those under 40
Men	deaths of those diagnosed with COVID-19 are higher in males than females
People from deprived areas	mortality rates from COVID-19 in the most deprived areas were more than double the least deprived areas, for both males and females
People from black and ethnic minority communities	death rates from COVID-19 were highest among people of Black and Asian ethnic groups
People in low-paid or low-skilled occupations	security guards, taxi drivers, chefs, care workers and bus drivers are the occupations with the highest death rates involving coronavirus
People with underlying health conditions	among deaths with COVID-19 mentioned on the death certificate, a higher percentage mentioned diabetes, hypertensive diseases, chronic kidney disease, chronic obstructive pulmonary disease and dementia
People with disabilities	Disabled women with limiting disabilities aged under 65 in particular

In Leeds the data supports this view with 95% of deaths, where COVID-19 is mentioned, occurring in those over 65 years, with 65% occurring in those aged 75 – 89 years, and death rates being higher in more deprived communities (91.8 per 100,000 COVID-19 deaths in 10% most deprived areas of Leeds to 69 per 100,000 in 10% Leeds deprived areas[1]).Excess deaths in care homes were 2.3 times higher compared to previous years, with deaths in care homes accounting for 1 in 3 deaths (hospital is 3 in 5).Research has showed that living with frailty increases risk of mortality, even after accounting for age and other known comorbidities linked to COVID-19 ; and we know in Leeds there is a higher prevalence of people living with frailty in the most deprived areas.

Analysis of LTHT COVID-19 deaths between 21st March and 16th April 2020 also shows a higher number of male deaths but the differential is smaller than national figures - 57% of males versus 44% females. The relatively small numbers of deaths and **the fact that ethnicity data is not always recorded**, make it difficult to draw conclusions about the link between deaths and ethnicity for Leeds. But it does appear that BAME people living in the most deprived areas are experiencing higher rates of deaths than BAME people living in the least deprived areas. This does not show a clear pattern for those of white ethnicity. Limited local data on deaths by occupation and small numbers mean it has not been possible at this time to indicate whether this holds true for Leeds.

[1] Data source: ONS 'Deaths involving COVID-19 by local area and deprivation', published 12 June 2020
Deaths for Leeds residents, where COVID-19 is mentioned on death certificate, March to May 2020
Deaths involving COVID-19 by local area and deprivation - Office for National Statistics

In addition there is evidence that behavioural risk factors have a negative impact on morbidity and mortality from COVID-19.Evidence from China suggest smokers with the virus are 14 times more likely to develop more severe symptoms compared with non-smokers. This is consistent with the UK symptom tracker data. People who have a higher body mass index have a higher number of hospital admissions compared to population based prevalence and an increased risk of death (PHE, 2020). Those who drink more than 14 units per week, can be more at risk from the effects of COVID-19, as alcohol use (especially heavy use) weakens the immune system, which reduces the body's ability to deal with infectious disease. We also recognise that in Leeds the wider impacts of deprivation and poverty lead to a clustering of these risk behaviours in higher in areas of deprivation.

> "Among deaths with COVID-19 mentioned on the death certificate, a higher percentage mentioned diabetes, hypertensive diseases, chronic kidney disease, chronic obstructive pulmonary disease and dementia than all cause death certificates. Several studies, although measuring the different outcomes from COVID-19, report an increased risk of adverse outcomes in obese or morbidly obese people." [1]

It should be noted that there is now growing evidence in relation to the long term effect of COVID-19 both in terms of people's physical health and mental health with a focus on post-traumatic stress disorder

3.2 Wave 2 - Impact of resource restrictions on urgent non- COVID-19 conditions

The COVID-19 pandemic led to a dramatic and fast-paced reorganisation of the way in which NHS services are delivered, with much resource being deployed into acute / critical care. We know in Leeds there was a reduction in A&E attendance by 45%; with 33.8% in 'majors' giving particular concern. There was also a reduction in use of urgent treatment centres by between 77% and 80%. Nationally (IFS April 2020) and locally we also know that use of health care (with the exception of acute planned care) is higher in Leeds for those living in the most deprived areas compared to those in the least deprived areas, with the most significant difference shown in usage of these 'same day services'. We also know people living in more deprived areas are more likely to die prematurely due to physical and mental health long term conditions issues.

In April there was a 20% reduction in emergency inpatient admissions in Leeds compared with 2019 for long term conditions, and admissions for heart attacks dropped by 50%, (also showing as late presentations). Further analysis is required, but people in Leeds have told us how they were too frightened to call 999 when they had a fall or an angina attack in case they were taken to hospital. We have also heard from Consultants in LTHT who are now reporting seeing people at a higher acuity of illness than would be expected. Interestingly for children with complex needs and long term conditions, there does not seem to be the impact, as proactively every child known to services (and specifically those with an Education Health Care Plan) was risk assessed and supported if required. Disruptions to non-coronavirus care and emergency care are likely to have most impact on older and less affluent individuals. A survey by Ipsos MORI for the Centre for Ageing Better found that over half those surveyed have had a medical or dental appointment delayed or cancelled, prompting fears that untreated conditions could set back the health of this generation.

There have been significant impact on people with mental health issues. LCC/Adult Social Care report a quadrupling of requests for mental health act assessments in the latter period of lockdown – during June 2020.

Analysis is ongoing on the data that is available. It is possible that perceived resource restriction (of mental health or other support services) has resulted in people not seeking help until they are very unwell. CCG analysis indicates that between February (pre lockdown) and April, referrals to mental health services fell by 78% overall. Crisis referrals however increased. It may also be the case that wider social service/families/carers have requested Mental Health act assessments, rather than attending A & E (see above).

3.3 Wave 3: Impact of interrupted care on chronic conditions

In relation to addressing the inequality gap in premature mortality we know in Leeds the majority of premature mortality in areas of deprivation are due to Cancer, Cardio vascular conditions, and respiratory conditions. We also know there are significantly higher prevalence levels for some groups of people (e.g. people with severe mental illness). The disruption of care therefore will have significant impacts on health inequalities. This has particularly been the case for cardiovascular conditions. The pause of the NHS Health checks will have also meant some people with at high risk of cardiovascular conditions will not have been identified, which will further contribute to future health inequalities . There was a 37% drop in collaborative care and support planning appointment for long term condition reviews in primary care during April. All formal self-management support also stopped. All Cancer screening programmes were paused giving a 60% reduction in 2 week wait referrals for cancer across West Yorkshire and Harrogate (WYH Alliance). As noted above requests for mental health act assessments (LCC) plateaued and then increased x4 towards end of lockdown period, and between February (pre lockdown) and April, referrals to mental health services fell by 78% overall.

The impact on the 'pause' of routine care on health inequalities will take time to be realised but can't be underestimated.

3.4 Wave 4: Wider Impacts

The economic impacts will be most acutely felt by those with the fewest resources: people in low paid jobs, people who have chronic mental or physical illness or disability, people on temporary or "zero hours" contracts and those who are living from pay day to pay day. It is also likely that those in low paid manual jobs (e.g. supermarket, social care, construction workers etc) will be less able to socially distance by working from home and, hence, less able to minimise the risk of Covid-19 infection. Those who are now confined to home in poor quality or cramped housing will have the most miserable experience and those living in the least affluent, vibrant and green surroundings will suffer the biggest fall in wellbeing. These individuals are all part of the same group: the poorest in society.
https://fairhealth.org.uk/2020/04/fair-health-in-the-time-of-covid-19/

It is well recognised that wider issues have a significant impact on people's health and wellbeing. The economy is now on the downtown with people losing jobs. Centre for Economic Policy Research that estimates that a 1% fall in employment could lead to around a 2% increase in the prevalence of chronic illness. There is also the issue that people who have had COVID-19 are now experiencing long term symptoms and will not be able to return to work for some time. The Centre for Ageing Betters findings highlight that older and younger workers are more likely to be made redundant or furloughed. For older people this will mean entering retirement without enough money to support themselves in retirement. Throughout this time Healthwatch Leeds have co-ordinated a weekly check-in listening programme with key groups affected by the pandemic – e.g.

carers; people who are shielding. The Communities of Interest network have also ensured we have been hearing the voices of people with the greatest health inequalities. The challenge is to cross reference this insight with the quantitative and service data we are receiving.

Children
We know that pre-COVID-19 20% of children in Leeds were living in low income households (Public Health England, 2016). With many individuals left unemployed or on reduced hours as a result of this crisis this will likely increase, along with the associated impacts on health and wellbeing. Children living in areas of deprivation are likely to have lower levels of access to the technologies and resources required to support effective home learning and parents may not have the confidence or skills to be able to support with home schooling. Children living in deprived areas are also more likely to be living in poorer, higher occupancy housing which is not conducive to effective learning. Add to this, BAME groups also living in areas of deprivation who may also have language barriers which make home schooling increasingly challenging.

Food poverty
It is estimated that over 43,000 food bags have been distributed by the Emergency Food Service in Leeds which have been made up into over 27,000 food parcels (and culturally appropriate food now included in the food box provision) over the whole 13 weeks. Gipton and Harehills, Burmantofts and Richmond Hill and Hunslet and Riverside are the top 3 wards where service requests are delivered. However, there are lower percentages of people from some BAME backgrounds, particularly Asian who are shielding that have signed up for this type of support. In addition to this service, Leeds City Council have also been delivering breakfast and lunch to 230 homeless people every day that are currently being rehoused in hotels and B&Bs . This has equated to 1,610 breakfasts a week and 1,610 lunches a week. A significant number of faith groups and Third sector organisations including Leeds Black Health Initiative and St Vincent's have also responded at huge scale to local need on a huge scale.

Mental wellbeing/illness
COVID-19 has had significant and far-reaching impacts on people's mental health in different ways according to what stage of the life course they are at but also in relation to their cultural, ethnic, religious background, socio-economic position, where they live, jobs family/caring. Increased levels of anxiety and stress of current situation (exacerbation of fears of leaving safety of own home and conversely being trapped in temporary, unsuitable accommodation); issues of social isolation (especially for those who were asked to shield); the stress on carers; and the impact of bereavement and grief, particularly in light of not being able to come together for support and to mourn the loss of loved ones have all been highlighted.

There are national surveys which very clearly highlight who to target re suicide prevention: those that are anxious/isolated/lonely, under mental health care, economically vulnerable, children and young people experiencing domestic violence, traumatised people including health and care staff, and those who have been bereaved. Also evidence from previous disasters (e.g. SARS in Hong Kong) shows women >65 at risk of suicide; and the previous recession showed it took 4 years for the suicide rate to peak.

Housing
Housing / living arrangements in areas of deprivation increase COVID-19 risk with people more likely to be living in more densely populated areas including high rise flats, back to back terraces and multi-occupancy accommodation and multi-generational family households.. This makes social distancing much harder. Data released by the ONS (May 2020) clearly evidences the

disparity in COVID-19 deaths between densely populated urban areas and more sparsely populated rural areas with significantly higher age standardised mortality rates in urban areas. Children and young adults living in a flat or house with no access to a garden or private outdoor areas also face greater challenges to maintaining their physical health and enjoying space to play.

Domestic violence
Leeds has seen a rise in domestic violence and parental disputes impacting negatively on children. A related concern is the rise in total alcohol sales during the period of the epidemic. Retail sales grew by 21% in value since the beginning of the lockdown (Nielsen off-trade retail sales YTD to 30th May 2020). Although pubs etc. have been closed this does not necessarily mean an increase in alcohol consumption. However a survey by Alcohol Change UK found that whilst some had decreased their alcohol intake, the 18% of daily drinkers had increased the amount they drank.

Financial hardship
Third sector organisations working with specific communities and more marginalised groups have come together with other partners to gather intelligence, share information and respond to critical challenges for these communities of shared interest. A key theme emerging from this network relates to financial inclusion, including stigma of asking for help; access to advice services, for example Chapeltown Citizens advice (where 85% of pre-covid advice was face to face) seeing fall in Demographics for BAME communities; access to money (mistrust of online banking) and difficulties in applying for universal credit.

Digital inclusion
Digital inclusion has been raised across all sectors many people and communities. Older people remain less likely than younger generations to use the internet and social media. The reliance on technology continues to bring the "digital divide" to light as many will continue to rely heavily on technology resulting in unequal access to support and services during this time. People who don't have access to the internet, or the skills and confidence to use it, are becoming increasingly disadvantaged and isolated. They're more likely to be older, managing a long-term health condition or living with a learning difficulty or disability. They're more likely to be living in poverty or on a low income. Their first language may not be English, they may be refugees starting a new life in the city, or they may be trying to overcome issues such as substance misuse, domestic abuse and mental health issues. Loss of access to data through drop in services and public spaces e.g. libraries, cafes has exacerbated exclusion of refugees and asylum seekers and the Gypsy and Traveller community where, compared to 90% of the general population only 37% had Wi-Fi and a numbers of young people were found to be sharing one mobile phone. The 100% digital team has provided brilliant support but due to the challenges faced this needs expanding.

To note there has there has been a citywide response to many of the issues raised above with the third sector work closely with partners to respond rapidly and flexibly to support people and communities through the Community Care Volunteering programme with public sector and local third sector organisations to deliver critical new welfare services across 33 ward hubs, which is now being reviewed.

3.5 Inequalities Oversight Group
The Leeds Health and Wellbeing Strategy has had its ambition for 'Leeds will be the best city for health and well-being, where people who are poorest improve their health the fastest' since 2016. However we must recognise that health inequalities have been increasing over the recent years.

As referenced above COVID-19 has shone a light on this in Leeds as much as in other areas, giving us a context of renewed focus and momentum for change.

The Health and Wellbeing Board have therefore asked that our health and care system re-energises its efforts on working together, and with communities and people, to collectively reduce health inequalities. This requires the agreement that tackling health inequalities is a strategic priority for all partners; we will consider it in every decision and action we take. Our principles of starting with people, working as team Leeds and ensuring we deliver is central to this work. A small group, representing organisations across all system partners, has been set up to develop a framework for the city with a set of standards and tools we can all use. The group will not 'do' all the actions – that is for us all – but it will inform, connect and challenge our partnership to move further and faster on our ambition. We will need to agree how we measure our outcomes and take action to: move resources to areas of need; re-prioritise prevention and the role of communities; ensure services really are accessible and equitable to all; improve experience and outcomes; and create the conditions for the impacts of the determinant of health to flourish.

4. Conclusions

The future will be different. Let's make sure it will also be more compassionate, and more equal, with people's rights at its centre. The many people who died, who lost loved ones or whose lives have been made immeasurably more difficult deserve nothing less
(National Voices June 2020)

Leeds has long recognised the overall importance of tackling health inequalities with its ambition that the poorest improve their health the fastest. Now more than ever this is an imperative, because the impact on health inequalities of COVID-19 can be seen throughout all the four waves of the pandemic. The greatest impact of this pandemic will be felt by those communities already living in poverty; by older people; by people from Black, Asian and Ethnic Minority Communities; by people in low-paid or low-skilled occupations; and with underlying health conditions and disabilities. Across all these communities the impacts on mental health a far ranging.

It is now our collective challenge to build on the work done by all partners throughout this period to ensure that we make an impact as people, in communities, as system leaders, in our work and together. To ensure that we can measure a movement in resources to areas of need; that we can demonstrate how we have prioritise prevention and the role of communities; that people tell us our services are really person centred, accessible and equitable to all and that we have ensured the conditions for the impacts of the determinants of health to flourish.

5. Recommendations

5.1 All partners to ensure their representative on the Tackling Health Inequalities Oversight Group is supported and represents their organisations efforts.
5.2 All partners to ensure future actions and conversations in relation to health inequalities are rooted in community participatory conversations with those most affected.
5.3 To ensure action on this issue within each organisation, including engagement with communities; resource realignment; strategic commissioning (where relevant); service provision (where relevant).
5.4 For each organisation to jointly commit to collective actions across the system
5.5 For all partners to use a Health Inequalities Impact tool for all reset work and future planning
5.6 For all partners to ensure that ethnicity data is collected and recorded comprehensively.

Appendix 1

The Communities of Interest Network (partnership with LCC, Healthwatch, VA-L and Forum Central) brings together a network of twenty organisations around inequality themes including homelessness; Black, Asian and other minority ethnic communities; Carers; Older people, LGBTQ+, men and women. Working with Comms and Public Health we this network to communicate COVID messages into communities and are exploring using existing structures should outbreak happen again to have communication channels and messages ready to use. Communities of Interest information can be found here: https://forumcentral.org.uk/communities-of-i hthttps://forumcentral.org.uk/communities-of-i https://forumcentral.org.uk/communities-of-interest/terest/tps://forumcentral.org.uk/communities-of-interest/terest/

Connecting Communities of Interest During COV-19

#TogetherLeeds #PositivePartnerships

1. Introduction

Forum Central and Healthwatch Leeds, with support from a broad range of partner organisations (see appendix 1 for full list), have been working on a project to ensure that the needs of communities of interest in Leeds are being addressed during the Covid-19 pandemic.

We have defined communities of interest (CoI) as groups of people who share an identity, for example, people with a learning disability, or those who share an experience, for example, the homeless community. The aim of this project is to better understand any disproportionate or differential impact of Covid-19 across Leeds' communities of interest.

The report provides a 'snapshot' of how inequalities are amplified in a time of crisis, and it can be used as a resource to support change within the city around inequalities.

2. How the Information Has Been Collected

We gathered information in the following ways:

- 'Link' organisations (see Diagram 1)
- Weekly check-ins via an online survey and telephone and social media contact
- Routine outreach to and engagement with members and key contacts
- Community of Interest Virtual Q&A engagement events held every two weeks
- Feedback from Local Care Partnership meetings
- Queries offered by ward hub staff
- Expert knowledge from the Forum Central and Healthwatch teams and partner organisations.

This report brings together all of the information and learning collected between April and June 2020. See diagram 1 below for a visual representation.

This work is supported by Healthwatch Leeds' People's Voice Group which aims to make ***ensure that people are at the heart of decisions made about their health and care.***

https://healthwatchleeds.co.uk/our-work/pvg/

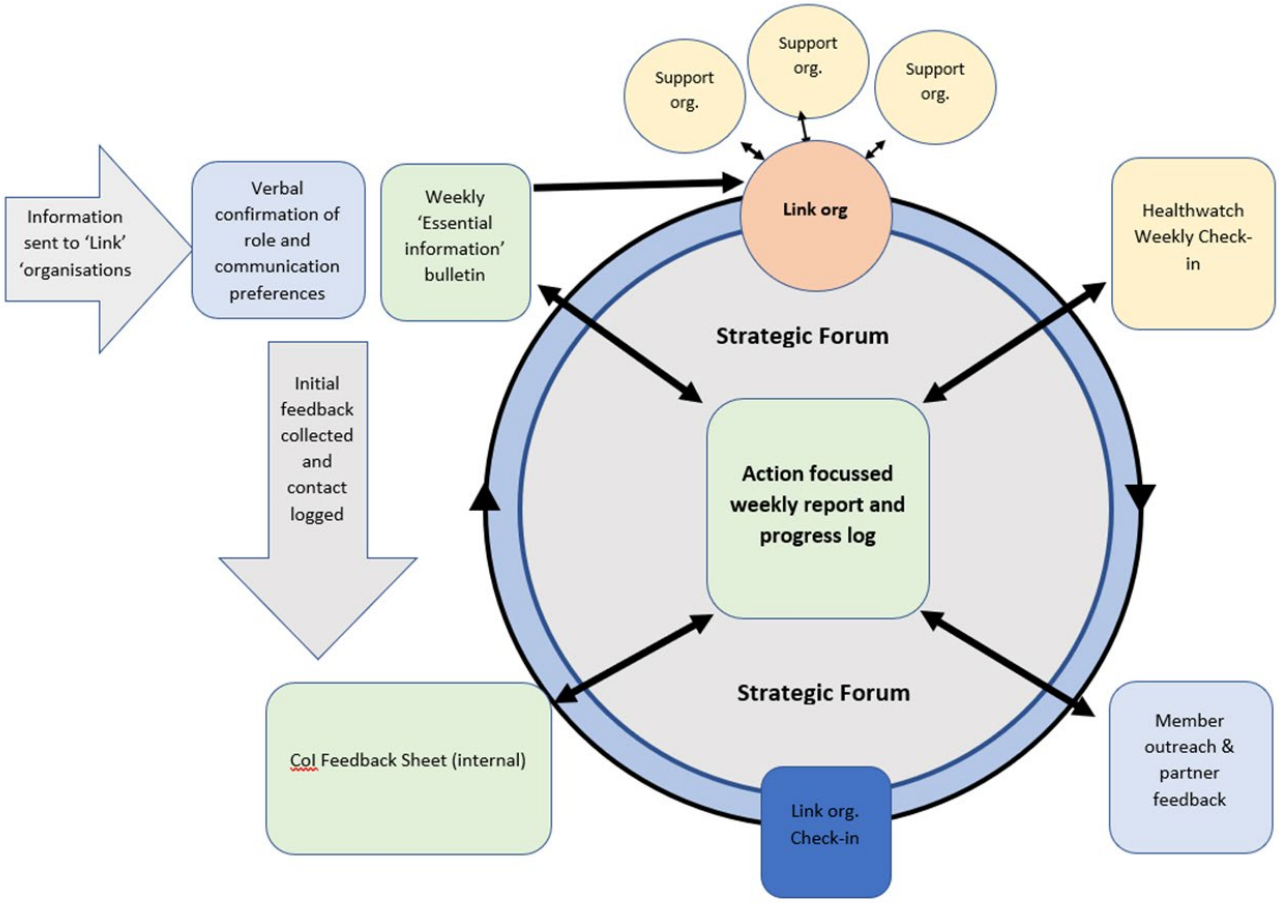


Diagram 1 – Communities of Interest Information Collection Process

2.1. Points of Note

The foundation of this report is the relationships which partner organisations have cultivated with people across Leeds. The report may be referenced to contribute to wider ongoing research.

The labels used for communities of interest are widely referenced but also points of challenge and debate. This is recognised and we would value feedback on any terms used in the report.

Experiences of Covid-19 are highly nuanced, and any one person will likely be a part of multiple communities of interest. Furthermore, the issues raised in this report crosscut a number of identities and in many cases the wider population. These issues will be picked up in subsequent conversations and actions from this piece of work.

Further sources of information providing insight into the experiences of communities of interest in Leeds during COV-19 can be found on Forum Central's website here.

3. Summary of Key Issues

This section provides a broad overview of the key points requiring action. The issues are split into those reported from people and communities, followed by issues more pertinent to organisations supporting CoIs.

A comprehensive summary of feedback is provided in Appendix 3.

3.1. Key Challenges Faced by People and Communities

The following section summarises the key challenges faced by people and communities, reported by organisational leads. Table 1 provides a summary of the challenges for each CoI.

Issues pertinent to all communities of interest include:

- ***Navigating information and guidance***: Challenges around accessing accurate, appropriate and accessible information in a rapidly changing scene, littered with mis/dis-information and complex communications.

- ***Access to essential provisions and services:*** Challenges in gaining/maintaining access to food, essential personal and household items; and accessing support necessary to protect health, care and wellbeing.

- ***Social isolation and boredom:*** Challenges around the loss of social bonds, relationships and contact; the loss of physical and intellectual stimulation.

- ***Mental health – low level anxiety to crisis***: Challenges around management of pre-existing mental health issues and the emergence of new concerns.

- ***Abuse, domestic violence and safeguarding issues***: Challenges around imposed segregation of perpetrators and victims from the wider community, and of accessing support whilst experiencing violence and abuse.

- ***Concerns about restrictions being lifted:*** Challenges around managing change, uncertainty and the concerns and anxieties which this brings.

Additional issue pertinent to Lockdown:

- ***Digital Exclusion:*** Communities and individuals having limited/no access to equipment and/or data thus exacerbated barriers to accessing information, support and social connection.

Table 1 – Summary of Key Issues and Suggested Actions

Community of Interest	Key issues reported	Actions Required
People with mobility issues	• Navigating information and guidance • Impact of legislation and guidance • Social isolation and boredom • Mental health – low level anxiety and individuals in crisis	• Clear and consistent information in a range of accessible formats covering: - what shielding is and who should shield - support available during lockdown, particularly around mental health and social isolation - accessing medication - management of routine and pre-planned treatment and care - potential changes in post-COV-19 world • Advice and support for services on risk assessing activities in the post lockdown world • Joined up support, using structures such as the Local Care Partnerships to promote appropriate referrals across the system
People with mental health issues	• Access to essential provisions and services • Sustaining contact with services • Access to health, care and financial support • Social isolation & boredom • Mental Health – low level anxiety and individuals in crisis • Stigma and hate crime	• Clear and consistent information in a range of accessible formats covering: - managing lockdown (including those who are shielding) - what shielding is and who should shield - service availability (including self-harm and crisis services) - access to food and essentials - mental health for people with additional needs/other CoIs - confidentiality for Children and Young People - Potential changes in Post-Covid-19 world • Support across the system for tackling stigma

		• Enhanced support for those with the greatest needs/challenges such as people with serious mental illness, street homeless, AS,R & migrant communities and sex workers • Joined up support, using structures such as the Local Care Partnerships to promote appropriate referrals across the system • Access to technologies which would promote continuation of services • Greater provision within the city centre • Preparation for anticipated a lag in impact and increased strain on sector
People with long term conditions	• Navigating information & guidance • Access to health, care & financial support • Access to essential provisions and services • Impact of legislation and guidance • Social isolation & boredom • Mental Health – low level anxiety and individuals in crisis	• Clear and consistent information in a range of accessible formats covering: - LTHTCs and shielding - what shielding is and who should shield - Managing long term conditions during lockdown - Medications and their availability - Scheduled and routine appointments - Accessing services when on lockdown - Service availability (including mental health support) - Guidance around visitation in hospital settings - Potential changes in post-Covid-19 world • Inclusive discussions around hospital discharges for people with LTHC • Inclusive discussions around bereavement, grief
Young People and Care Leavers	• Navigating information & guidance • Continuation/initiation of risky behaviours • Social isolation & boredom • Digital exclusion – accessing key messages, core services	• Clear and consistent information in a range of accessible formats covering: - Identification of reliable information - managing social isolation – e.g. safe, online social activities - accessing key services including mental health, abuse and domestic violence - accessing specialist support

	• Access to essential provisions and services • Mental Health – low level anxiety and individuals in crisis • Abuse, domestic violence and safeguarding issues • Sustaining contact with services	- support for parents and carers, particularly for carers of people with additional needs - mental health for people with additional needs/other CoIs and their families - Potential changes in post-Covid-19 world • Alternative PPE that is less frightening for children • Coordinated support across the system, to ensure continued engagement with young people and care leavers • A more joined up approach to care of young people with complex needs across the system, including the third sector organisations • Support for organisations in sustaining services with uncertainty around funding and transitioning to post lock down world - coping with potential post lockdown surge in referrals
People with Physical and Sensory Impairments	• Navigating information & guidance • Access to essential provisions and services • Digital exclusion – accessing key messages, core services • Impact of legislation and guidance	• Reminders to core services to accurately collect information around communication needs • Clear and consistent information in a range of accessible formats covering: - Physical & Sensory Impairments and shielding - what shielding is and who should shield - Social distancing with a sensory impairment – with a particular focus on people with a visual impairment - Access to virtual interpreters and adaptive technology - Management of finances • Ensure all briefings are translated into BSL • Inclusive discussions about the impact of PPE on communication with lip readers • Consideration and support for Third Sector organisations providing communication services to statutory care, in managing surge in requests

Prison leavers/ Ex offenders	• Navigating information & guidance • Continuation of risky behaviours (including breach of lockdown)	• Clear and consistent information in a range of accessible formats covering: - Key guidance around social distancing - Accessing medication (including prescriptions) • Inclusive discussion with authorities on how to manage people who do not self-isolate without criminalising them
BAME communities	• Appropriate access and ability to navigate information and guidance • Digital exclusion – accessing key messages, core services • Impact of legislation and guidance • Access to essential provisions and services • Abuse, domestic violence and safeguarding issues • Continuation of risky behaviours • Stigma and hate crime	• Clear and consistent information in a range of accessible formats covering: - Identification of reliable information - Shielding - what shielding is and who should shield - Registration of shielding status - Social distancing - Accessing essential provisions including culturally appropriate foods - Availability of core services including housing, mental health and provisions within communities - Defining abuse and domestic violence and support available - Accessible information and support around home-schooling - Hate crime reporting - Preparation for coming out of lockdown • Inclusive discussions and support around the growing feelings of injustice and inequality linked to the disproportional impact of Covid-19 on BAME communities • Enhanced access to culturally appropriate food parcels • Clear information giving assurances around immigration status and occupancies • Targeted support for the most vulnerable households and those in multiple occupancies • Information for all services around identification and reporting of all forms of abuse

		• Enhanced support with accessing digital technology and resources • Support for organisations in sustaining services with uncertainty around funding and transitioning to post lock down world
Asylum Seekers, Refugees and Migrant Communities	• Sustaining contact with services • Navigating information and guidance • Digital exclusion – accessing key messages, core services • Impact of legislation and guidance • Continuation of risky behaviours • Stigma and hate crime • Mental Health – low level anxiety and individuals in crisis	• Clear and consistent information in a range of accessible formats (including different languages and with particular focus on new migrant communities) covering: - Identification of reliable information - Shielding - what shielding is and who should shield - Registration of shielding status - Social distancing - Accessing essential provisions including culturally appropriate foods - Availability of core services including existing support mechanisms (e.g. MAP, LASSN, PAFRAS) finances, mental health, housing and immigration - Defining abuse and domestic violence and support available - Hate crime reporting • Clear information giving assurances around immigration status and occupancies • Targeted support for the most vulnerable households and those in multiple occupancies • Support with accessing digital technology and associated funds to cover costs • Targeted support for new migrant communities with more limited access to social support structures • Assurances around support available for people with no current leave to remain • Proactive challenging of racist, 'Anti-Migrant' and far right information/messages

		• Communications across all services to support signposting to relevant AS&R migrant community services and broader support within communities
Single Parents/Carers	• Sustaining contact with services • Access to essential provisions and services • Abuse, domestic violence and safeguarding issues • Financial concerns – managing loss of income, access in benefits. • Social isolation and boredom • Mental Health – low level anxiety and individuals in crisis • Stigma and hate crime	• Clear and consistent information in a range of accessible formats covering: - Availability of core services around benefits and finances, mental health, abuse and domestic violence and housing - Identification of reliable information - Shielding - what shielding is and who should shield - Registration of shielding status - Availability of core services including housing, mental health and provisions within communities - Accessible information and support around home-schooling - Preparation for coming out of lockdown • Assurances and supportive communication from social care providers around managing current concerns • Targeted support for parents living in the most challenging conditions and those supporting children and young people with complex/additional needs
People with a learning disability and/or Autism	• Navigating information & guidance • Impact of legislation and guidance • Stigma and hate/mate crime • Digital exclusion – accessing key messages, core services • Continuation of risky behaviours • Mental Health – low level anxiety and individuals in crisis	• Clear and consistent information in easy read format covering: - Key guidance and information (including shielding) - Access to food, finance and medication - Shielding - what shielding is and who should shield - Registration of shielding status - Identifying scams and 'fake news' - Support available for carers - Links to community services - Managing mental health - Potential changes in post-Covid-19 world

		• Enhanced support for those who have experienced bereavement • Support for organisations around reaching out and accessing people for whom no contact details are held • Support for organisations providing supported living in accessing Wi-Fi/internet • Support for organisations around: - Access to PPE - Provision of transport for workers - Staff and volunteer training - Managing staff absenteeism • Communication across the system, encouraging signposting carers to Carers Leeds • Anticipation and implementation of intervention to support re-integration to "new normal" and additional barriers that may highlight. Additionally – how this might increase marginalisation of people living with learning disabilities
Carers	• Abuse, domestic violence and safeguarding issues • Access to essential provisions and services • Financial concerns – managing loss of income, access in benefits • Navigating information & guidance • Impact of legislation and guidance • Mental Health – low level anxiety and individuals in crisis • Social isolation & boredom	• Clear and consistent information in a range of accessible formats covering: - Managing lockdown (including those who are shielding) - Service availability (including Mental health, financial and domestic violence services) - Access to food and essentials - Post lockdown scenarios • Communicate and reinforce the NHS is still open message to carers • Need for PPE provision for family carers • Enhanced respite support for carers • Communicate the offer to Carers from Carers Leeds across the health and care system

People with Experience of Domestic Violence and Abuse	• Abuse, domestic violence and safeguarding issues • Mental Health – low level anxiety and individuals in crisis • Sustaining contact with services • Access to essential provisions and services	• Clear and consistent information in a range of accessible formats covering: - Support available - Use of codewords • Could Housing Benefit still be paid for voids that can't be filled due to Covid-19, or could existing residents (and any potential new residents) be tested for Covid-19 when a new space is being filled? • Support for services in finding accommodation • Support in identifying barriers to referrals from national DV helpline • Adjustment of messaging to ensure inclusive offer • Support for organisations in coping with potential post-lockdown surge in referrals
Men	• Financial concerns – managing loss of income, access in benefits • Access to essential provisions and services • Access to health, care & financial support • Sustaining contact with services • Social isolation & boredom • Mental Health – low level anxiety and individuals in crisis • Abuse, domestic violence and safeguarding issues	• Bespoke, clear and consistent information in a range of accessible formats covering: - Managing lockdown (including those who are shielding) - Service availability (including Mental health, financial and domestic violence services) - Post lockdown scenarios • Accessible gender sensitive service provision highlighted priorities include: - Mental health and crisis care - Domestic violence - Financial concerns
Women (including Maternity)	• Navigating information & guidance • Identification of need and sustaining contact with services • Access to essential provisions and services	• Clear and consistent information in a range of accessible formats covering: - Managing lockdown - Service availability (including crisis services) - Access to food and essentials

	• Abuse, domestic violence and safeguarding issues • Mental Health – low level anxiety and individuals in crisis	
People with Drug or Alcohol Addictions	• Continuation of risky behaviours and increased risk of relapse • Financial concerns – managing loss of income, access in benefits • Social isolation & boredom	• Clear and consistent information in a range of accessible formats covering: - Key messages - Managing substance misuse in lockdown - Mental health support - Accessing medication (including prescriptions) - Crisis support available
Gypsies and Travellers	• Navigating information & guidance • Digital exclusion – accessing key messages, core services • Access to essential provisions and services • Financial concerns – managing loss of income, access in benefits • Access to health, care & financial support • Stigma and hate crime	• Bespoke, clear and consistent information in a range of accessible formats covering: - Key messages including social distancing - Mental health and financial support - Welfare rights • Ensure data is made available to permanent and also the three permitted roadside camps
Sex Workers	• Navigating information & guidance • Continuation of risky behaviours • Abuse, domestic violence and safeguarding issues • Financial concerns – managing loss of income, access in benefits	• Clear and consistent information in a range of accessible formats covering: - Key messages including social distancing as a sex worker - Managing substance misuse in lockdown - Financial support - Mental health support

	• Digital exclusion – accessing key messages, core services	• Support with accessing digital technology and associated funds to cover costs
Homeless/No Fixed Abode	• Continuation of risky behaviours • Financial concerns – managing loss of income, access in benefits • Social isolation & boredom • Mental Health – low level anxiety and individuals in crisis	• Clear and consistent information in a range of accessible formats covering: - Key messages - Managing substance misuse in lockdown - Mental health support - Crisis support available • Support with street engagement e.g. access to a mobile health unit
People from the LGBT+ community	• Stigma and hate crime • Mental Health – low level anxiety and individuals in crisis • Social isolation & boredom	• Clear and consistent information in a range of accessible formats
Older People	• Digital exclusion – Accessing key messages, core services • Access to essential provisions and services • Access to health, care & financial support • Social isolation & boredom • Navigating information & guidance • Mental Health – low level anxiety and individuals in crisis	• Clear and consistent information in a range of accessible formats covering: - Key guidance and messages including 'The NHS is still open' - Service provision (including alternatives to face-to face provision, financial support, bereavement and grief and DV support) - Access to essential provision - Scams and 'fake news' • System wide guidance around use of DNR forms • Support for organisations with high rates of staff absenteeism
Faith Groups	• Social Isolation & boredom	• Clear and consistent information in a range of accessible formats covering:

	• Digital exclusion – accessing key messages, core services and religious practice	- Burials and cremations during lockdown - Hate crime reporting • Support for organisations with high rates of staff absenteeism
People facing high levels of deprivation	• Access to essential provisions and services • Mental Health – low level anxiety and individuals in crisis • Abuse, domestic violence and safeguarding issues • Financial concerns – managing loss of income, access in benefits	• Clear and consistent information in a range of accessible formats covering: - Access to food and essentials - Managing lockdown (including those who are shielding) - Service availability (including Mental health, financial) • Referral support for organisations seeing increased demand for services from people who are not from their core client group • Access to testing and essential resources across all localities, including the city centre • Preparation for impact of job losses

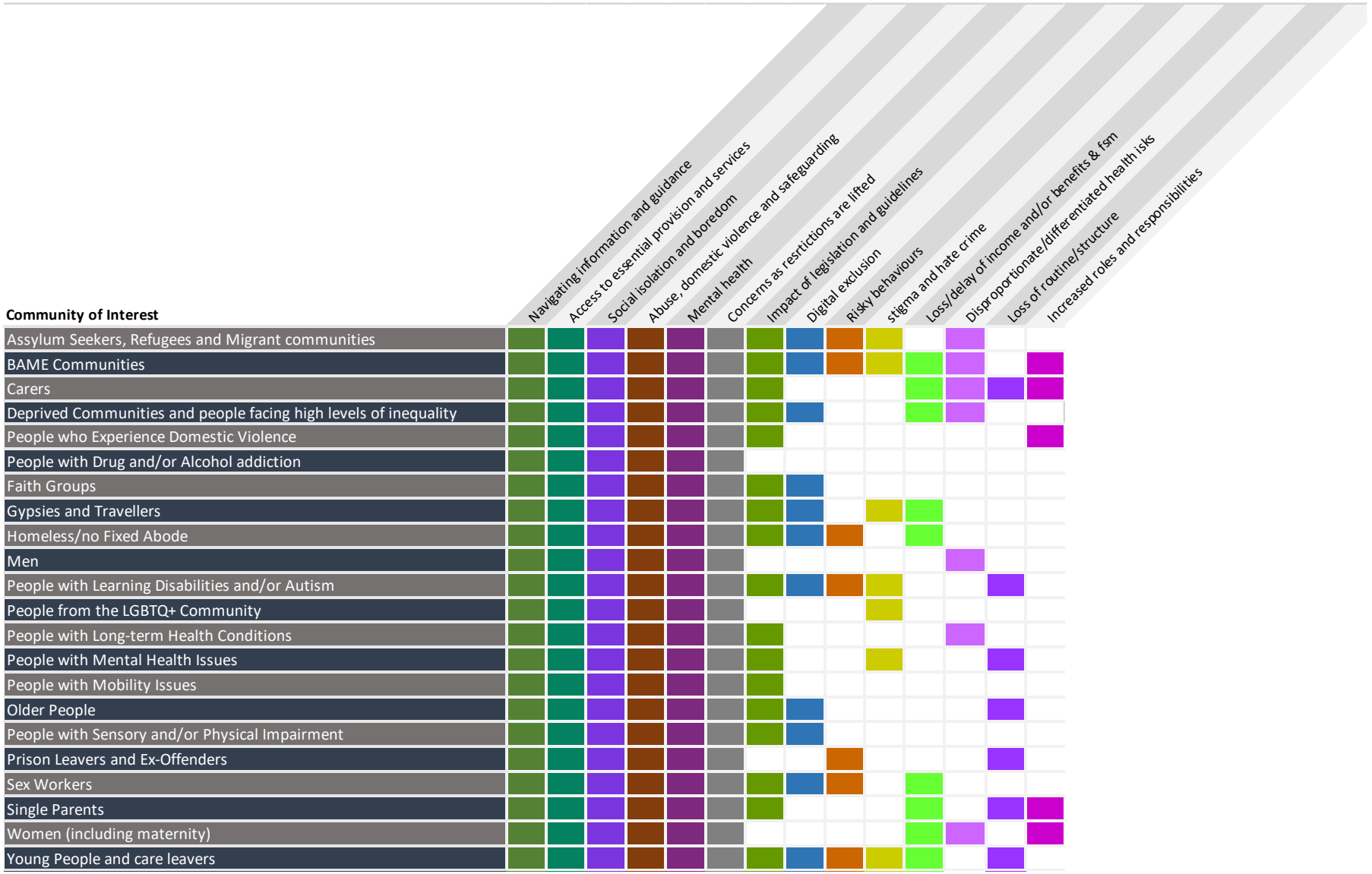


Diagram 2 Overarching Key Issues raised by Community of Interest link organisations during Covid-19

3.2. Key Challenges Faced by Organisations

The following section summarises the key challenges reported to us by organisations. Full reporting of issues experienced by organisations supporting particular communities of interest is covered in **Appendix 1**.

Key Issues pertinent to organisations working with communities of interest include:

Delivering core work and meeting new challenges
Supporting people whose inequalities and challenges are enhanced by Covid-19 and meeting new challenges including:

- Maintaining contact with known service users and reaching out to those who have 'fallen through the gaps'
- Developing meaningful relationships with new service users using online methods
- Managing increased demand for core services
- Managing challenges resulting from a reduction/closure of other services in the system (e.g. routine healthcare for people with LTHC, asylum and immigration status)
- Developing new services to meet new challenges (for example delivery of food parcels)
- Delivering services which require face to face interaction
- Tackling Hate/Mate Crime
- Tackling scams and disingenuous information.

Identifying and engaging people when there is no access to contact information
This issue is a particular concern where there are additional barriers posed by digital communication, or changes to other areas of the system. Examples include:

- Organisations supporting people with a Learning Disability who have been referred from other points in the system
- Organisations who work with people experiencing or at risk of domestic violence
- Organisations who rely on face-to-face contact (such as people with mental health support needs, some BAME groups)
- Organisations who support people who may have distrust of digital technologies (older people, Asylum Seekers, Refugees and migrant communities)

Coordination of work (including contact lists) with other parts of the system
An issue particularly relevant to those organisations supporting high numbers of people who are shielding, older people, people with a Learning Disability/Autism, People with a physical of Sensory Impairment and Asylum Seekers, Refugees and migrant communities who may experience barriers to accessing adjusted services or receive

alternative guidance. This challenge is enhanced by other areas of the system experiencing significant change and new methods being trialled.

Interpreting high volumes of complex and changing information and guidance An issue for all CoI, but particularly pertinent for groups who support high numbers of people who are shielding and those groups with variations to mainstream guidance (for example older people, carers, people with Long Term Health Conditions, people with a Learning Disability/Autism)

Relaying information (including response offer) to members and the general public An issue raised by organisations supporting people with a Learning Disability, BAME communities, Asylum Seekers, Refugees and migrant communities and people from deprived communities, however pertinent to all.

Logistics - delivery of COV-19 response and core offer (all groups) including:

- Setting up remote working
- Accessing food stock (deprived communities)
- Volunteer support - accessing multiple volunteers (all groups)
- Loss of income through enterprising activity such as room bookings (all groups)
- Accessing PPE, testing and other essential equipment (all groups, but particularly smaller organisations)
- Meeting cultural needs (BAME groups, Asylum Seekers, Refugees and migrant communities)

Access to digital technologies and appropriate training to enable services to be continued online

- Access to digital technologies and associated funds to enable core services to continue

Service sustainability (all groups) including:

- Managing the impact of staff absenteeism through sickness, shielding and self-isolation
- Access to continuation funding – a lack of information on funding existing funding applications
- Assurances from commissioners and funders regarding service adjustments (including quality standards)

Ensuring staff and volunteers have the skills, knowledge and confidence to meet the challenges (all groups)

- Ensuring staff and volunteers understand the general guidance around COV-19 and also guidance & legislation around issues such as safeguarding
- Ensuring staff and volunteers receive relevant training to perform their roles - including those working remotely

Supporting the welfare needs of staff and volunteers (all groups)

- Ensuring all staff and volunteers feel supported when experiencing high challenge and traumatic events including bereavement and grief experienced in personal life
- Support with managing staff and volunteer burnout

Planning for what comes next (all groups)

- Plan for the phasing out of lockdown – and how can we work with existing assets (Local Care Partnerships, Covid-19 Structures etc.) to accommodate needs of CoIs
- How can services be delivered in a way which adheres to social distancing guidance (consideration of limitations of workspaces)
- Long term availability of resources (PPE, medication etc.)
- Managing greater demand, changes to service user & staff behaviour, anticipated new ways of working and lack of service user engagement with NHS services, most notably:
    - Mental Health services
    - Domestic Abuse
- Capturing learning and developing services

4. Recommendations and Next Steps

The third sector in Leeds has been instrumental in the response to the Covid-19 pandemic. The sector is diverse, complex and dynamic. Partnership working and fast mobilisation of networks enabled the sector to see and even (at times) mitigate the impact of lockdown and as restrictions began to ease. Strategic coordination provided meaningful pathways for communications in both directions.

Continued support and collaboration from all partners is key in meeting the post lockdown challenges, but more so, action is needed to tackle underlying inequalities facing people and communities which have been born out during the Covid-19 crisis. It is essential that we get this right, not only for organisational survival but for the health, care and wellbeing of the diverse communities of Leeds.

Below are some recommendations relating to key themes which have emerged from the Communities of Interest work.

Communications, voice and influence

- Continue to strive for clear, consistent communication in accessible and inclusive formats. Supported by the development of shared systems of communication to promote unrestricted flow of information across the system.
- Support mechanisms to enhance (and sustain) the influence of disadvantaged communities at strategic and community level through the CoI network.
- Work with communities as assets across the system to make sure that people are at the heart of decision making in the city.
- Adopt asset-based approaches to enhance the sharing of knowledge and information between organisations
- Fund accessible and inclusive resource produced by and WITH people and communities.

Personalised approaches to health and care

- Invest in services which will enable the system to meet the increased strain on mental health services, domestic violence services and family carers posed by COV-19.
- Adopt an asset-based approach to embed mental health within all elements of future service planning and delivery.
- Adopt asset-based approaches to plan and deliver better and more joined up care, and support for all people of Leeds, with a particular focus on those experiencing the greatest disadvantage.
- Work with assets across the city to shift in relationship between health and care professionals and people.

Digitalisation and Technology

- Develop an easy-to-use toolkit for health and care professionals that will help them make decisions about when digital services are suitable for individuals
- Develop an information resource for service users to inform them about their digital options; ways of accessing help and support; and the questions and issues they might wish to consider during conversations with healthcare providers.
- Build on the city-wide work already underway around the Accessible Information Standard and consider how it can help to progress the digital agenda and bridge the gap of access for the most disadvantaged.
- Invest further in the 100% Digital programme so that it can continue to achieve its ambitions

Maintain the scope, diversity, capacity and sustainability of the Third Sector in Leeds

- Actively champion the third sectors contribution to Leeds Covid – 19 response
- Ensure that the third sector is central to considerations as we reset to the new norm – building on positives such as partnerships and environmental improvement and minimising negative impacts as a result of Covid-19.
- Identify opportunity to maintain and direct resources, especially funding, that is available to the sector.
  - embracing diversity and recognising the role of organisations of all sizes
  - support sustainability through advocacy and operational changes
  - commitment to long term funding stability
- Maximise the contribution of volunteers across the Leeds system.

"Conversations with partners have provided stark examples of how inequality can manifest itself during a period of crisis. The evidence contained within this report is tied to people's experiences during the Covid-19 crisis, but the inequalities have been known about for generations.

The third sector in Leeds has provided a lifeline for many people and communities during the pandemic. While the challenge is on a larger scale, the dynamic response of the sector to meet the challenge is again nothing new; with limited financial resources the third sector in Leeds has long been serving the needs of people who have fallen through the gaps.

*The time for conversation has passed, we must now come together as a system, demonstrate that we have heard the voices of those experiencing the greatest inequality, put these voices at the heart of future decision making and take **bold** action to make Leeds a fairer city"*

Pip Goff, Volition Director Forum Central

Appendix 2 - Examples of recent work to tackle health inequalities highlighted at Stabilisation and reset group

Organisation	Summary of actions / project
Leeds Community Healthcare NHS Trust	Leeds Mental Wellbeing Service is aiming to deliver targeted interventions for older people. This service is looking at access for older people by geographies and what they can do to increase their access to this service. As people get older, other healthcare professionals may not think of referring to this service, and now more than ever this is needed.
Leeds and York Partnership NHS Foundation Trust	Whilst face to face activity has continued in the majority of our services dependant on need and risk, we have moved to more reliance on technology in some of our community based services. Each individual service user assessment has recognised the potential for access to technology to be a barrier for some of our service users particularly in times of distress and deteriorating mental health. The response has been to individualise and flex our approach to care support and delivery where at all possible. We ensured that inpatient service users had access to technology to enable them to stay connected with family and other key individuals in their life. In our reset of our community services we are working to ensure that all service users have appropriate access and where digital may exclude them exploring how we can enable this not to prohibit or limit care and support.
Leeds Teaching Hospitals NHS Trust	Revised access routes and patient pathways have been proactively agreed for people with learning disabilities and autism who need elective cancer or urgent surgery as it is recognised that due to Learning Disability and/ or Autism some patients may be unable to: • follow the recommendations for self and household isolation • tolerate swabbing • describe symptoms such as loss of taste or smell • attend without the support of a family member or carer
Leeds City Council (Adult Social Care)	Leeds City Council (Adult Social Care) has been assessing the impact of telephone support as part of the COVID-19 response. Given the increased reliance on telephony support over face to face support, our initial view is that this has worked well as we have been able to undertake face to face visits where needed / where telephony based support may not have been sufficient. However we are undertaking brief quality assurance exercise just to establish whether this view is

	correct and whether there have been any unintended consequences. We continue to flex approach to closely meet the needs of individuals such as the work in Holbeck on the managed approach. We support a number of women who are impacted by the managed area and we have been supporting them to access housing, benefits and other support.
Public Health	Public Health have developed strong, clear, evidence based health messages that have helped effective communication and dissemination of key covid-19 messages to local communities. These have been promoted through various different channels - local radio, social media, local services, local employers, volunteers, Third sector partners and community leaders. Key video messages, in particular, that have been translated in the top 10 most spoken languages have been effective in communicating key messages to parts of the community that weren't being reached. These have been championed by local leaders and communities and shared regionally and nationally.
Children	The Baby Steps service works with vulnerable pregnant women and families and they have continued to provide antenatal and postnatal support during this time. This support has been provided over the telephone and via digital means and where this has not been possible they have delivered physical resources to people's homes. The transition to family support services has reportedly also increased during lockdown for these families
Yorkshire Ambulance Service NHS Trust	We are looking at how we can deliver targeted interventions for homeless people. In addition seeing how we can support sub-regional partners with appropriate health inequalities data; our aim is that this will then help partners to assess the most appropriate interventions to help people with ongoing care needs. There has been some fantastic multi agency working in the city which has resulted in over 200 homeless people being taken into safe temporary accommodation. Part of this approach has seen a street paramedic working closely with multiple agencies to ensure that people's needs are met in a holistic way. He has managed many of their health needs and also facilitated remote access to other healthcare professionals when necessary. We have responded to immediate health needs to identify those most at risk of complications from COVID-19, so that they could be supported to self-isolate when necessary.

Primary care	Our focus has been to encourage all practices in Leeds to consider the role they can play in tackling health inequalities. This has been a regular theme in our daily primary care briefings (now three times a week) and our weekly (now fortnightly) live video conferences. Our approach includes: - reminding practices to undertake risk assessments for all staff, with a focus on those at higher risk such as BAME colleagues - asking practices to consider the impact of social distancing and COVID-secure workplaces on contracted services such as those who provide facilities management support - regularly reminding primary care colleagues of the importance of proactive case management of clinically high risk patients such as those with at least one long-term health condition.
Forum central: Health and Care Third Sector	We are keeping a **log of our 300 member service updates here** **Learning Disability** groups are developing a mutual aid approach to recovery with part of our website accommodating sensitive material organisations can share e.g. building and individual risk assessments, recovery plans and guidance. https://timetoshineleeds.org/projects/shine-magazine is to helping older people feel connected and able to contribute. The magazine is both online and offline. The printed edition goes to older people who don't have internet access. Time to Shine is partnering with Leeds City Council and the 33 hubs across the city to distribute it to older people who are most isolated and vulnerable alongside food parcel deliveries. Based on demand reported from our member organisations and a subsequent survey Mindwell is progressing Leeds branded paper-based simple self-care, crisis and useful contact information for circulation to people who are digitally excluded and/or receiving community care parcels for food and medicine due to shielding, low income and other needs via 33 third sector organisations. We are providing a digital champions session focusing on supporting people with sensory impairments, in partnership with 100% digital and mhabitat. Covid information in an alternative formats including easy-read, alternative languages including BSL films and Film Tutorials and links is available to download **here**

Appendix 3 - Model for re-framing inequalities in health

In Leeds, we are prioritising working with people who have a greater likelihood of poor health the more of these factors that apply to their lives. This is particularly important during the Covid-19 pandemic when some people have a much greater risk of infection, complications or even death.

How People Treat Me on an individual and institutional level

Some people who experience the greatest inequalities have historically been excluded or marginalised based on how they live, who they love, where they were born, what they look like or who they pray to.

'Communities of Shared Interest' is the collective term used to describe the groups of people who share an identity (for example people with a shared ethnicity) or those who share an experience (or example survivors of domestic violence).

Communities of Shared Interest tend to emerge from experience of exclusion from mainstream communication, thinking or planning. The are a source of vital expertise on planning for inclusion and addressing barriers to inclusion.

Who I am in demographics

This includes my age, gender, disability, ethnicity, sexuality, religion, faith or beliefs. These are characteristics protected in law.

Being at higher clinical risk

People who have been identified as being at higher clinical risk that the rest of the population. This can be because they have a specific medical condition or a combination of conditions. Within this group, some people have a significantly higher risk than others and may be shielding.

Where I live and how I live

What money I have available to me makes a significant impact on my ongoing health. As does the job I do, my education level, who I live with and how we interact. When these are negative, it can have a direct impact on my mental and physical health, and the choices I make about staying healthy.

If where I live has multiple "deprivations" – where more people are likely to have lower incomes, there is poor quality housing or poorer environmental factors – such as noise or pollution. Or if my area does not have a strong community or social infrastructure – this can negatively affect my health.

My legal status also impacts on the health options I have.

Appendix 4

People's Voices Group

Your healthwatch Leeds

"The concern for how long this will go on and the likely impact on my job and potential impact on family's health"

Healthwatch Leeds Briefing:

Mental Health Under Lockdown

People's Voices Group

healthwatch Leeds

Healthwatch Leeds Briefing: Mental Health Under Lockdown

Mental health has long been one of Healthwatch Leeds' key focuses, so when the country went into lockdown in March 2020, it seemed even more important than ever to keep hearing people's views on how the crisis was affecting their wellbeing and the kind of support they would like to get.

One of the ways we did this was through online surveys, which garnered over 1000 responses during the first and second weeks of May. So that we could capture the experiences of all our communities, we also contacted our third-sector colleagues to get their feedback about how their service users are coping with lockdown.

Section 1: How does it feel to live under lockdown?

Nearly half of the people we spoke to told us that the lockdown had affected their mental health, with a further 16% saying they had been affected "a lot". They told us about four key factors.

1.Feelings of social isolation and sadness at being separated from families

People most commonly told us they were saddened at not being able to see loved ones, or simply not getting the day-to-day interaction they normally would:

"The separation from seeing our daughter and grandchildren has over the 6-7 weeks gradually worn us down, especially reducing my wife often to tears"

Important family support networks have been put under strain.

"My daughter has anxiety and depression and is in lock down with her two year old in a first floor flat. The isolation is getting to her and I am unable to go to her to help with my grandson as I normally would."

"My mum and dad both have dementia and live in their own homes. Both have deteriorated mentally and physically during lockdown and have missed my visits and care. In turn my own mental health has suffered and I have struggled coping with the fact that I am missing so much of the very precious time they have left."

2. Increased anxiety

When describing how they feel, people most commonly said they were "anxious". They sometimes linked their anxiety to fears of catching the virus or a sense of purposelessness. This is the case both for people with and without existing mental health conditions.

"Anxiety has flared up, particularly in the first few weeks of lockdown. Isolation makes depression harder to manage. More difficult to be optimistic."

3. Strain on family relationships and the extra stresses of caring for loved ones

Living under lockdown has changed family relations in lots of ways, sometimes putting a strain on people's well-being.

"Due to lockdown we seem to argue everyday about everything."

This was also the case for carers whose duties have become even more intensive under lockdown and for parents who were trying to balance home-schooling and work.

Sometimes, the lockdown was making it harder for both children and their parents to access the services they need.

"My son is severely learning disabled and autistic and on sertraline for anxiety. Taking away everything that supports him for so far 6/7 weeks has been horrendous."

4. Fears for jobs, finances and the future

Uncertainty about "what the future holds for us" troubles some respondents, as do worries about unemployment and money.

"The concern for how long this will go on and the likely impact on my job and potential impact on family's health"

People aged 19 to 25 were more likely than the general population to report extremely negative feelings and symptoms.

"It's affecting me massively - I live in town with no outside space in a small flat. It's difficult to get out anywhere, especially in nature. I have struggled with anxiety and depression all my life, and was starting to recover before lockdown. Now I am back to having very poor mental health."

The challenge for our city:

How do we proactively support people so that they know they are not on their own when it comes to coping with lockdown's challenges?

Section 2: What would help?

Young People's and Care Leavers' Mental Health Under Lockdown

During the first and second weeks of May, we asked young people in Leeds aged 11 to 25 about how lockdown was affecting their mental health.

We also surveyed 19 care leavers about their experiences. Their feedback is given in green.

These were our key findings:

- Most young people say lockdown is having a negative effect on their mental health.
- It is having a more severe effect on over-19s compared to people aged 18 and under – except among care leavers, who are more likely to say they are coping well if they are aged 19-25.
- The majority of young people are aware of MindMate.
- Most young people aren't getting support with their mental health at the moment.

Who did we speak to?

In total, 47 young people told us about their experiences.

- 4 of them were aged 11-13.
- 11 of them were aged 14-16 (plus 1 care leaver).
- 9 of them were aged 17-18 (plus 6 care leavers).
- 18 of them were aged 19-25 (plus 10 care leavers).

The remaining 5 (plus 2 care leavers) didn't tell us their age.

How would you say lockdown is affecting your mental health?

45 young people told us how lockdown is affecting their mental health.

- 31 said it was having a negative effect.
- 8 said it was having a mixed effect.
- 4 said it was having no effect.
- 2 said it was having a positive effect.

Care leavers were proportionately more likely to say they were coping well with lockdown.

10 out of 19 care leavers who answered this question said lockdown was having a negative effect. 2 said the effect was mixed, while 7 told us lockdown was having no effect on their wellbeing.

Negative effects

Out of the 31 young people who said lockdown was having a negative effect on their mental health, 14 talked about symptoms or feelings that were particularly severe (as opposed to 4 who said the effect was quite mild). For example:

- "i feel very hopeless and like i have nothing to do and it means i am struggling very much."

6 of the 31 also talked about how lockdown made their existing mental health issues worse, for instance:

- "It's affecting me massively - I live in town with no outside space in a small flat. It's difficult to get out anywhere, especially in nature. I have struggled with anxiety and depression all my life, and was starting to recover before lockdown. Now I am back to having very poor mental health."

They most often described their experiences in terms of:

- Feeling trapped or frustrated (7 people)
- Feeling lonely (5)
- Anxiety (5)
- Depression (3)
- Feeling purposeless (3)

Similar feelings were expressed by the care leavers who were having a negative experience of lockdown.

Mixed effects

8 young people told us that lockdown had had been negative in some ways, but positive in others, or that they had learnt to cope with it better over time. Some have good days and bad days.

- "It's affecting me positively because I've had more free time for mindfulness and self care. It's affecting me negatively because I find myself worrying about the future and the **uncertainty** is making me anxious more often."
- "Some days it's ok, other days it's not. There's not many distractions from your thoughts and people post on **social media** now more than ever."
- "Positively in that I don't have to do my gcses anymore so that stress is gone. […] It is getting a bit worse in that I'm definitely more **self critical of my appearance** (less active, more time to look in a mirror) and I'm missing being social with my friends"

Positive effects

A couple of our respondents feel that lockdown has benefited them.

- "It is actually improving my mental health and I fear it will decrease when quarantine is over"
- "Lockdown is giving me more time to myself which relaxes me and makes me feel less stressed"

Are you aware of the MindMate website?

Most of the people we spoke to were aware of MindMate (38 out of 45 young people and 13 out of 19 care leavers).

If you have had online/messaging or phone mental health support from any organisation in the last few weeks, can you tell us what this was like?

Of the 16 young people who answered this question, 8 said they hadn't been given any support.

Here are the comments from people who have had support:

- "The **market place** - and it was ok"
- "The **market place** & **Safezone** have been super helpful for me"
- "The **Market Place** It was better than I thought it would be, pretty much the same just shorter"
- "I have support from my **university**, I am in regular contact with the mental health advisor."
- "Counselling. With a **private counsellor**. It my usual appointment but now over the phone so dont get to connect as much."
- **"Kooth online support**, I have an account but don't use it as often as I probably should. When I have used it its great."
- "I have tried talking to **child line** and looked **online** for support - wait times for support is extensive due to demand."
- **"Young Minds text service** has been very nice and i found calling **Samaritans** was very calming and more helpful than my therapist."

Three care leavers told us they had received support with their mental health under lockdown (one person had support from two places). Most of this support came from health services:

- Community nurse
- "a woman from the mental health services"
- Therapeutic social care team
- College care manager

Did our respondents' ages have an effect on how they felt?

Young people aged 19-25 were more likely to report lockdown having a negative effect compared to people aged 18 and under.

58% (14 out of 24) of under-19s said lockdown was having a negative effect. Of these, 43% (6) described experiencing severe rather than mild feelings and symptoms.

On the other hand, 83% (15 out of 18) of 19-25 years olds say lockdown has affected them negatively, with 53% (8) describing severe feelings and symptoms.

A much larger proportion of the over-19s we spoke to mentioned an existing mental health condition (5 out of 18) compared to 11-18 year olds (1 out of 24).

The older group were also much more likely to talk about feeling trapped (5 out of 18) than the younger group (1 out of 24).

Of the 8 young people who told us about receiving support, 3 are from the 19+ age bracket.

On the other hand, care leavers aged 19-25 were more likely to say they were coping well with lockdown than their younger counterparts.

None of the 11 to 18-year-old care leavers we spoke to were receiving mental health support.

Mental Health Under Lockdown: the Wider Population

During the first two weeks in May, we spoke to 959 adults in Leeds about their mental health.

How has lockdown affected your or your loved ones' mental health?

Nearly half of our respondents told us that lockdown had affected their mental health "**a little bit**". Just over a third said it had **not affected** them at all. 16% said their mental health had been affected "**a lot**".

Are you aware of Mindwell and how best to look after your Mental Health during this time?

70% of people told us that they weren't aware of Mindwell.

Have you tried to get support/help for your mental health?

Just over a quarter of our respondents told us they had sought out mental health support from a range of sources, including GPs, third-sector organisations, friends and family, colleagues, mental health services such as IAPT and the Community Mental Health Team, ambulance services, private therapy, counsellors and CBT practitioners, and via apps and other online resources.

They occasionally identified gaps in the support they were offered:

- "I have support from my GP - but only in the sense of getting my prescription for antidepressants. I am also waiting for autistic specific therapy for depression and anxiety - the service is closed until the lockdown is over."
- "My local CMHT, LPDN and my GP all of which were disappointing, mostly because I'm considered to be well managed/high functioning."
- "It has been harder to build a relationship with my psychiatrist as we started appointments in lockdown and I have yet to meet her face to face"
- "didn't get past online triage"
- "All [my GP] offered was sleeping pills and tranquilisers - which I didn't want"

- “I accessed a helpline suggested by my manager. This was a very helpful one-off conversation but left me feeling even more isolated as there is no ongoing regular support”
- “IAPT and they have given me a list of options. They will get back to be within 12 weeks”

The majority of people who haven’t accessed support said this was because **they didn’t feel they needed it** or they were confident in their ability to manage their own mental health.

However, two other very common themes emerged. One was a sense that “**other people need help more than me**” and our respondents didn’t want to “waste people’s time” during the crisis. Another was that respondents **believed services had closed entirely** or did not know what support they could expect (for example, “GP surgeries seem closed or too busy with covid-19 patient queries”).

Some people had previously had **poor experiences**, which put them off seeking support:

- “Don't see any point. I've never been helped previously”
- “System was already overloaded before lockdown”
- “I have needed it in the past and was put on a waiting list forever. So now I sort myself out.”

A few people also felt that, although their mental health had been affected, once lockdown was eased their health would improve again.

What kind of mental health information or services would you like to be able to access during lockdown, while face-to-face care is not available?

When people responded to this question, they were more likely to suggest help from **mental health professionals** rather than peers would be helpful. For some, it was important that this support be **ongoing**, rather than limited to a handful of sessions (“talking to someone regularly and checking in rather than just a one-off call to a suicide/mental health hotline”). They were also generally open to getting support over the **phone or by video call**. For example, “the best is face to face. The second best is talking on the phone. Reading stuff online is not useful as you are still locked inside your own head”.

Some people also said they would be interested in **self-help resources**, often (but not always) suggesting these should be delivered online. Examples people gave were free yoga and mindfulness sessions, activities that help to occupy the mind, walking routes, and interviews with people with lived experience of mental ill health. Several people emphasised how important it was to them that the information provided felt **truthful and trustworthy**.

A few comments also mentioned the **difficulties of seeking help for a loved one** who does not acknowledge that they are mentally unwell.

Again, sometimes people's answers were shaped by **poor experiences** they had had in the past while accessing support. There were some suggestions that the first contact with services was particularly crucial:

- "if you need to ring LYPFT you shouldn't be scared to do so in case you get told off by one of the receptionists who's manner/attitude […] makes you feel like you shouldn't be calling for help"
- "the threshold you need to cross to get help is, in itself, a cause of stress and anxiety and a barrier"

The challenge for our city:

How do we communicate that services are open and people aren't being a "burden" when they ask for mental health support?

How do we make even more people aware of Mindwell?

Section 3: Where are the pressures and barriers for communities?

Our third-sector colleagues have told us about the extra mental stresses and barriers to support which some of their service users are experiencing.

Adults with learning disabilities can be reluctant to give out their phone numbers and email addresses because they worry about being scammed. They find video calling intrusive. A lack of digital skills can also be a barrier.

Carers have not been able to access their usual coping mechanisms and have been affected by having to care 24/7. There has also been anxiety around the safety of loved ones living in care homes.

Some **homeless** people have had to delay their plans to move out of their shelter, setting back the progress they have made. People who have **extra needs around accessing housing** do not always have a phone or change phones often.

People from **BAME communities** who are living with mental health conditions can be reluctant to share their contact details, sometimes due to paranoia around technology.

Refugees and asylum seekers do not always have phones.

Disadvantaged families are experiencing anxiety around finances and have expressed concerns about the effect not being able to play outside is having on children.

Older people are particularly reliant on landlines and, when they do have devices, they are not always confident users. Hearing difficulties can make phone conversations hard.

Organisations working with **women** have seen increasing numbers of new and recurring domestic abuse cases.

Men who access men-only support groups are sometimes struggling with relationships with their wives and close family and with social isolation.

Recovering addicts have relapsed in some cases. Some people in urgent need of drug and alcohol rehabilitation have not always been able to access it.

The **deaf** community continues to experience barriers when accessing health care generally due to a lack of accessible information and interpreting.

People who receive **end-of-life** support and their families are anxious about not seeing loved ones before they die.

People with **eating disorders** have found it harder to access support from their GP, which in turn has affected their mental health.

People with **cancer** diagnoses are struggling with social isolation and the new financial procedures they have to navigate.

The challenge for our city:

How do we target communities so that the inequalities gap doesn't widen?

How do we adapt our offer so that everyone is supported, no matter what means of communication works best for them?