Understanding the lived experience of COVID-19 for marginalised communities

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This report was produced in collaboration with the Inclusion Health Lived Experience Research Working Group, on behalf of the Inclusion Health Partnership. As part of the response to the COVID-19 pandemic, Public Health Scotland (PHS) established the Inclusion Health Partnership. The partnership seeks to identify, support and facilitate how public services will mitigate the wider (i.e. non-viral, non-healthcare-related) population health consequences of the COVID-19 pandemic for those who are marginalised and excluded. The partnership comprises organisations across the third sector, academia, health improvement and public health.

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1. Introduction and background

As part of the response to the COVID-19 pandemic, Public Health Scotland (PHS) established the Inclusion Health Partnership. The group seeks to identify, support and facilitate how public services will mitigate the wider (i.e. non-viral, non-healthcare related) population health consequences of the COVID-19 pandemic for those who are marginalised and excluded. This includes communities who experience significant and multiple disadvantages as a result of violence, trauma, exploitation and stigma.

The group's objectives are to:

- articulate the impact of the national response to COVID-19 on the right to health for marginalised communities and how their experience risks exacerbating health inequalities in Scotland
- demonstrate how an inclusive and rights-based approach to policy and practice could mitigate the negative impacts of our response to COVID-19 for marginalised communities, including those with experience of exclusion, trauma and/or violence
- influence decision makers to adopt an inclusive and rights-based approach to the redesign of policy and sustainable services.

When the Inclusion Health Partnership was first convened, it was agreed it was critical for the group to understand key messages about the impact of COVID-19. Many organisations, primarily in the third sector, were reaching out to their members and service users. This provided an opportunity to understand the experiences and issues faced by marginalised communities. The group carried out intelligence gathering work to summarise these key messages from partner agencies.[i]

The Inclusion Health Partnership planned a research project to develop and deepen our understanding of the lived experience of marginalised communities and how COVID-19 was impacting on wider aspects of health and wellbeing. The work of the Inclusion Health Partnership sought to apply an intersectional approach[ii] in understanding the unique challenges for those who are disadvantaged by systems and services. As such, this research has explored the unique needs and circumstances of individuals and considered cross-cutting issues experienced by different marginalised communities.

Due to the iterative nature of this project and to ensure that we capture rich data, the work is being carried out in two phases. This report is from the first phase of research with a small number of in-depth interviews. The findings and learning from this engagement with participants in phase one will influence the design and delivery of phase two. The second phase, to be carried out in spring/summer 2022, will seek to engage with a wider reach of participants to test and strengthen the findings from phase one.

1.1 Scope

Public sector organisations have a duty to uphold the right to health for marginalised and excluded communities. This is more important than ever as the harms from the

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[i] A summary of key findings from intelligence gathering review (as of May 2020) can be found in Appendix 1.

[ii] Intersectionality promotes an understanding of human beings as shaped by the interaction of different social locations, e.g., ‘race’/ethnicity, indigeneity, gender, class, sexuality, geography, age, disability/ability, migration status and religion.

COVID-19 pandemic are not spread equally.[1,2,3] The persistence of health inequalities before COVID-19, meant that not everyone was enjoying their human right to the highest possible standard of health in Scotland.[4] Restrictions to daily life introduced in March 2020 to control the spread of COVID-19 have had a variety of adverse effects on people's health and wellbeing. They have made these inequalities in health worse.[1]

By understanding the lived experience of marginalised communities and collaborating to use this evidence to influence stakeholders, this research seeks to support the progressive realisation of human rights in Scotland and ensure that we ‘build back better’ for all communities.[5]

The European Convention on Human Rights, which protects civil and political rights, has been enshrined in UK-wide law through the Human Rights Act 1998. There are, however, many other economic, social and cultural rights contained within international treaties that have been ratified by the UK Government, but which have not yet been incorporated into domestic law. This includes rights that can have the biggest impact on people’s lives, for example the rights to health, housing, employment, education, and an adequate standard of living. Nevertheless, by virtue of the Scotland Act 1998, both the Scottish Government and Scottish Parliament have an obligation to observe and implement these international obligations.[6]

The right to health is an inclusive human right. It is not just the health service that has a legal duty to uphold this right. All of the things that influence our health (the social determinants of health) should be **a**ccessible, **a**vailable, **a**ppropriate and high **q**uality (AAAQ) if we are to have a healthier Scotland. This research seeks to understand how the COVID-19 pandemic has impacted on the accessibility, availability, appropriateness and quality of support for marginalised communities.

This ‘Triple AAAQ Framework’, endorsed by the World Health Organization, is a set of guiding principles that can support public sector agencies to create a fairer, healthier Scotland.[7] In parallel to this, the PANEL principles of **p**articipation, **a**ccountability, **n**on-discrimination and equality, **e**mpowerment and **l**egality provide a tool for embedding a rights-based approach to designing and delivering policy and practice.[8]

By taking a peer-led research approach, whereby peer researchers are equal partners alongside academic researchers and members of the Inclusion Health Partnership, the research methodology is also aligned to the PANEL principles. In doing so, this research will contribute to shifting the balance of power so that, as both agents and participants of the project, people with lived experience are able to inform and influence the strategic design, delivery and improvement of support and services across Scotland.

1.2 CLEAR partnership

This study was supported by the CLEAR partnership.[9] Created in 2016, Community Lived Experience Action Research (CLEAR) is a partnership project between the ALLIANCE,[iii] PHS and the University of Strathclyde's Centre for Health Policy.

CLEAR supports and promotes the use of peer research to influence change, bringing benefits to peer researchers, communities and all relevant stakeholders. CLEAR's vision is human rights for all through peer research. CLEAR's mission is to use peer research partnerships to positively influence human rights-based policy and practice.

Peer research is an approach adopted by researchers who are committed to co-developing research **with** people rather than **for** people. It enables collaborative working between people and organisations. Peer research focuses on social change that promotes democracy and challenges inequalities. It is context-specific, often targeted on the needs of a particular group, and involves an iterative cycle of

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[iii] The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations (**www.alliance-scotland.org.uk**).

research, action and reflection. It can help everyone involved gain a greater awareness of the situation in order to take action.

CLEAR provides support before, during and after involvement in any research, working through local organisations as this is where the local expertise and continuity of care and trust exist. Individuals participating in peer research are remunerated for their time, skills and expertise, and their contribution is acknowledged.

1.3 Aim and objectives

The aim of this study was to qualitatively explore how the COVID-19 pandemic impacted people's health and wellbeing within marginalised communities.

This lived experience peer research project had a clear set of objectives which were:

1. To understand the impact of the national response to COVID-19 on the health and wellbeing of specific population groups in Scotland who experience exclusion and marginalisation.

2. To work with people with experience of exclusion and marginalisation to understand and identify barriers to accessing support which would help them to realise their right to the highest attainable standard of health and wellbeing (i.e. access to services, practical resources such as food and utilities, emotional support, information and advice).

3. To understand what responses would help excluded and marginalised communities to realise their right to health during the COVID-19 pandemic.

2. Methodology

In February/March 2021, semi-structured interviews[iv] were conducted with 12 participants. The interviews were carried out by peer researchers from the Homeless Network Scotland, the CLiCK Women Supporting Women project, and the University of Strathclyde.

The researchers spoke to refugees and asylum-seekers, and to people with experience of homelessness, poor mental health and selling/exchanging sex. The participants were recruited from:

- CLiCK, an organisation supporting women who sell or exchange sex
- the Mental Health Foundation Refugee programme
- CLEAR, a network of peer researchers with experience of homelessness, hosted by Homeless Network Scotland
- (HUG) Action for Mental Health – Highlands and Islands, an organisation providing collective advocacy for people with mental illness.

The 12 research participants had an average age of 45 years. Four participants were aged 18–29 years, three participants were aged 40–49 years, two participants were aged 50–59 years and three participants were aged 60–69 years. Fifty per cent of research participants identified as female and 50% identified as male. Sixty-seven per cent of participants identified as white Scottish, the other participants identified as Italian, Pakistani, African and Jordanian. Seventy-five per cent of participants recorded living in a rural area or remote rural setting and the remaining 25% recorded living in an urban city setting.

[iv] The Interview schedule can be found in Appendix 2.

A suite of research tools[v] was developed to ensure that participants had access to as much information about the research as possible so they could fully engage with the process in an informed manner. More details about the approach, that was taken to ensure the methodology was inclusive, can be found in section 6, ‘Lived experience model’, below.

2.1 Analysis

The qualitative interviews were transcribed and subsequently analysed by researchers from Voluntary Health Scotland, Homeless Network Scotland and the University of Strathclyde. The researchers analysed the 12 transcripts to identify the broad themes and ideas that were emerging from the data. This became a code framework which was further distilled to derive six key themes. These themes are:

1. Human rights and health.
2. Impact of the pandemic on mental health and wellbeing.
3. Impact of the pandemic on sense of purpose and control.
4. Access to statutory public services.
5. Access to community and social support, and social networks
6. Digital access.

Thematic analysis was then conducted using framework matrices, within Microsoft Excel, to compile and tabulate interview data. This meant using a ‘template approach’ whereby data was presented in a table of rows and columns, where each row represents a transcript and each column represents each of the six key themes identified.

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[v] The suite of research tools can be found in Appendices 3, 4, 5 and 6.

As the weight of opinion became apparent under each of the six key themes, sub-themes were derived. It is important to note that the themes are interrelated with some quotes from the responses being relevant under multiple themes. The analysts leading this phase of the project met on several occasions to discuss, further refine the data, and ensure consistency in the approach to identifying the emerging themes and sub-themes.

3. Context

This section of the report aims to give context to the six key themes that have emerged from the research and provide reference to relevant policies, strategies and legislation that could be influenced by the findings.

3.1 The right to health

In January 2018 the First Minister's Advisory Group on Human Rights Leadership was set up to make recommendations for the next steps in Scotland's human rights journey. The group had a special focus on how to strengthen the social, economic and cultural rights of citizens in Scotland. The advisory group published its recommendations[10] in December 2018. The recommendations were wide reaching and included the development of a specific act of the Scottish Parliament for human rights and for participation to be integral in the development and implementation of this act. The advisory group recommended that Scotland commit to the right to an adequate standard of living and explicitly incorporate the right to the enjoyment of the highest attainable standard of physical and mental health.

This work was further developed by the Scottish Government's National Taskforce for Human Rights Leadership,[11] which published its recommendations in March 2021. Among these, it calls for a new statutory framework in Scotland that restates the rights contained in the Human Rights Act, incorporates into Scots law the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Disabled People, the Convention on the Elimination of All Forms of

Discrimination against Women, and the Convention on the Elimination of Racial Discrimination. It also includes the rights to a healthy environment, the rights of older people, and the rights of LGBTI people.[12] The Scottish Government has committed to a new Human Rights Bill that will incorporate the four international human rights treaties into Scots law.[13]

Under the Patient Rights (Scotland) Act 2011,[14] Scottish Ministers published a Charter[15] of Patient Rights and Responsibilities which summarises the existing rights and responsibilities of people who use NHS services and receive NHS care in Scotland. The act provides everyone the right to receive health care that:

- considers their needs
- considers what would most benefit their health and wellbeing
- encourages them to take part in decisions about their health and wellbeing, and gives them the information and support to do so
- gives patients a right to give feedback and make comments, and raise concerns or complaints about the care they have received.

Health and Social Care Standards in Scotland[16] were published in 2018 and are human rights-based. These standards are important to ensure that everyone in Scotland receives the care and support that is right for them. There are five headline outcomes that the standards are expected to deliver for service users:

1. I experience high-quality care and support that is right for me.
2. I am fully involved in all decisions about my care and support.
3. I have confidence in the people who support and care for me.
4. I have confidence in the organisation providing my care and support.
5. I experience a high-quality environment if the organisation provides the premises.

In 2018, the Scottish Government and COSLA jointly published Public Health Priorities for Scotland. These priorities are relevant across all sectors and are consistent with Scotland's commitment to equality and human rights.[17] Everyone having the right to the highest attainable standard of health and equal opportunity to realise this right without discrimination underpins these priorities, which reflect the importance of place and community, early years, mental wellbeing, substance use, the economy, healthy weight and physical activity. Partnership working is at the heart of public health reform in Scotland and the public health priorities are a foundation for the whole system (for public services, third sector, community organisations and others) to work together to improve Scotland's health, and to empower people and communities.

Scotland faces considerable health and wellbeing challenges with our relatively poor life expectancy, health inequalities, the impact of COVID-19 and climate change being significant concerns. In 2020, Public Health Scotland published its first strategic plan[18] reflecting these challenges and that Scotland needs to act to prevent illness, reduce inequality and improve health. In 2021 the Public Health Scotland Delivery Plan[19] was published, detailing how the Strategic Plan will be delivered. It contains a commitment to the right to health in the programmes being delivered.

3.2 Mental health

The mental health impacts of the pandemic and lockdown have emerged as a key theme in this research. Notwithstanding COVID-19, there is well documented evidence of the bi-directional relationship between inequalities and mental health, whereby inequality negatively impacts on mental health and poor mental health increases inequality.[20] Before COVID-19, poor mental health was known to be associated with unjust and wide-ranging inequalities:

- There is evidence of a social gradient for both mental health problems and mental wellbeing in Scotland, with those living in the most deprived areas with extensive socio-economic inequalities, experiencing the poorest mental health.[21]

- Those with severe and enduring mental health problems die on average 15 to 20 years younger than the population as a whole.[21]

- There were twice as many GP consultations for anxiety in areas of deprivation than in more affluent areas in Scotland.[22]

Considering this within the backdrop of a reduction in face-to-face services and longer waiting times for specialist mental health services during the pandemic, those who are most vulnerable and have the poorest mental health and wellbeing are most at risk of being negatively impacted by limited access to support and services.

Research suggests that mental health effects, and is affected by, physical health problems. For example, those with depression are at a greater risk of cardiovascular disease and diabetes, and those with cardiovascular disease and diabetes are at greater risk of depression.[23]

Between 28 May and 21 June 2020, the Scottish Government collected data[24] on the mental health impacts of the first lockdown and found that participants,[vi] made up of a nationally representative sample, reported higher rates of psychological distress during the pandemic. In a follow-up study,[25] from data collected between 17 July and 17 August 2020, the Scottish Government found that there was a significant increase in rates of reported suicidal thoughts between the first study (9.6%) and second study (13.3%). Around 24% of the sample in the follow-up study reported moderate to severe depressive symptoms indicating a need for treatment. And around 16% of participants reported moderate to severe anxiety symptoms indicating a need for treatment. This figure was a lot higher for sub-groups with a pre-existing mental health condition, at around 49% in the first study and around 41% in the second study.[25]

[vi] A nationally representative sample of 2,514 adults, which includes people with pre-existing mental health conditions.

There were also positive outcomes for some indicators. The study conducted by the Scottish Government found that mental ill health and distress decreased from 32.6% in the first study to 28.8% in the second study. It also found that respondents' mental wellbeing significantly increased [26] from a mean score of 21.52 to a mean score of 21.81,[25] derived from responses to the Short Warwick–Edinburgh Mental Well-being Scale. These increases in overall mental wellbeing between studies included increases in the following sub-groups:

- people with pre-existing mental health conditions
- people from lower socio-economic groups
- people that lived alone.

The Scottish Government has published the 'Coronavirus (COVID-19): mental health – transition and recovery plan',[27] which sets out the key areas of mental health need that have arisen as a result of COVID-19 and lockdown, and the actions that the Scottish Government will take to respond to that need. In the plan, the Scottish Government note that:

> 'As we learn to live with the pandemic, we will continue to support good mental health and wellbeing, to help people manage their own mental health, and to build their emotional resilience. We want to ensure that people get the right support, at the right time, and in the right setting – this includes when mental illness does occur. We will support mental health recovery in a way that is personal to each individual's journey, and which focuses on their rights.'[27]

3.3 Empowering communities

Unequal distribution of power across the population is one of the fundamental causes of health inequalities.[28] Power is a complex concept which includes the ability or capacity to do, or to not do, something. It also includes exercising influence, control or force through a variety of means. Power, or lack of power, can have an important impact on people’s circumstances and therefore on their health. Power doesn’t belong to one person but exists in the relationships between people and groups of people. These power relationships can be visible and obvious but are often hidden and covert. Public bodies have a key role in reducing inequality in the distribution of power across the population.[29]

Scotland has a longstanding commitment to working with and not just for communities. There has been a clear movement towards devolution of decision making to local communities with the Community Empowerment (Scotland) Act 2015[30] providing significant opportunities for communities to be involved in decision making at a local and national level. Community Planning Partnerships (CPPs) bring together different public bodies and other local agencies to plan services better. The Community Empowerment Act requires CPPs to involve community organisations at all stages of community planning, with a particular focus on tackling inequalities. In addition to area-wide Local Outcome Improvement Plans, CPPs have to produce ‘locality plans’ at a more local level for areas experiencing particular disadvantage. Further, public bodies now have a duty to consider participation requests[31] from local communities.

In Scotland, we have been championing the use of Realistic Medicine[32] since 2017 when the then Chief Medical Officer, Dr Catherine Calderwood, published her annual report. A Realistic Medicine approach is one whereby the patient is an equal partner in their health and care. This approach encourages shared decision making about people’s treatment and care and is an attempt to redistribute power more equally between health and care providers and patients. Access to statutory services has been identified as a key theme within our research and is described later in this report. For those who face a range of explicit and subtle barriers to accessing services and support, power dynamics are all too apparent.

3.4 Access to statutory services

The lockdown measures have seen some communities experience reduced or limited access to services. This has included a broad range of services from access to libraries and community venues, access to education and childcare, refuse collection, and engagement with housing support and services. Routine healthcare treatments have been delayed or cancelled, screening for cancer and other diseases paused, GP appointments moved online, and non-urgent dental and optometry appointments cancelled. This has had a disproportionate impact on different population groups, including those who were already suffering from poor physical and mental health, people from ethnic minorities, women, younger people and children, and low-paid workers and people with disabilities.[1]

In 2011, the Christie Commission[33] called for an urgent and sustained reform of Scotland’s public services, to meet unprecedented challenges. In the wake of the pandemic and the increased demand for statutory services post lockdown, it is imperative that the Christie Commission’s suggested approaches, which are based on participation, performance, prevention and partnership working, are used to support human rights and achieve better, personalised outcomes for people.

3.5 Community networks and social support

This research has highlighted the importance of being able to access community organisations, social support and social networks. Lived experience research conducted by Voluntary Health Scotland into loneliness and social isolation, The Zubairi Report,[34] explains the role of the third sector in supporting and empowering people with skills and confidence in order to have more control over their lives and engage more effectively with society. It describes how voluntary and community sector organisations are often able to engage and develop the trust of marginalised and excluded communities in a way that statutory services sometimes find hard to do. The sector is often a conduit between service providers and service users.

Research[35] conducted by the Scottish Government into the role that the third sector[vii] has played during the pandemic has shown that organisations have been supporting communities particularly at risk due to COVID-19. These include people who:

- are isolating (57% of respondents)
- have higher health risks from COVID-19 (75%)
- were advised to shield (69%)
- have barriers to accessing essentials (73%)
- are financially at risk (59%)
- are in marginalised groups (49%).

Healthcare Improvement Scotland[36] also highlighted the importance of community-led responses in supporting communities and tackling inequalities during the pandemic. The ALLIANCE's 'Community in Action' initiative has also highlighted the vital role of Scotland's third sector, which responded rapidly and flexibly despite increased demand and limited resources.[37]

3.6 Digital inclusion

The implementation and use of digital technology and its infrastructure can both reduce and widen health inequalities and the underpinning social and economic inequalities that people face. Research conducted by Voluntary Health Scotland[38,39,40] on the impacts of COVID-19 shows that digital exclusion has emerged as a major issue alongside financial insecurity, food insecurity, mental health, and loneliness and social isolation. The research shows widespread digital

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[vii] This report examines findings from a survey of 530 third sector organisations in Scotland who supported people through the COVID-19 pandemic over March to August 2020.

exclusion whereby people do not have access to digital technology or access to the internet, mobile phones, or phone credit – or do not have the knowledge and capacity to use these effectively.

The publication of the refreshed Scottish Government Digital strategy, ‘A changing nation: how Scotland will thrive in a digital world’,[41] provided a great opportunity to ensure digital transformation is inclusive. This strategy mentions ‘No One Left Behind’, and is derived from the 2030 Sustainable Development Goals which focus on the relationship between digital, health inequalities and health literacy. It is imperative that these are operationalised to ensure that we are able to reduce inequalities in society by ensuring that everyone has access to digital technology and connectivity and has the knowledge and confidence to enable access to the support, services and information they need.

The Digital Health and Care Strategy[42] which was jointly published by the Scottish Government, NHS Scotland and COSLA in April 2018, is currently being reviewed due to the impact of COVID-19. The principles of the original strategy included empowering citizens to better manage their health and wellbeing and the underpinning architectural and information governance building blocks for the effective flow of information. These principles will continue into the refreshed strategy. There will, however, be greater emphasis on aspects such as digital access, confidence and trust in use of digital, citizen engagement, person-led care, addressing inequalities, digital foundations (devices, architecture, skills, etc.), and citizen-held records. The refreshed strategy will embed the premise that, in order to empower and enable citizens to better manage their health and care, live independently and gain access to services through digital means, delivery of integrated care is vital.

4. Findings

4.1 Human rights and health

Human rights and health has been identified as an overarching theme within this research. In addition, many of the other themes reflect on accessing health and care services in a manner that upholds the right to health through accessible, available, appropriate and high-quality services.

The right to health is illustrated by everyone having access to the highest attainable standard of physical and mental health.[4] This research aimed to raise awareness of how people perceive their right to health and how this has been affected by the COVID-19 pandemic. The findings show that participants were not aware of their right to health or the complexity associated with their right to the highest attainable standard of physical and mental health. Participants were also unaware of the standard of service and support they should be entitled to when it came to accessing statutory services, such as housing, the welfare system, GPs, Community Psychiatric Nurses (CPNs), and a range of primary and secondary health and care services. Many participants spoke of feeling judged or treated poorly by service providers, resulting in a loss of dignity and respect.

> ‘I know I've heard people in here talking about, they don't have their own GP because they’re homeless, so they go to a service. And that's where they get their like standard medical, yeah, from, and the general view of the care there is that the medical staff are a bit jaded, and they see a homeless person coming through the door and they’re like all right, ok. You know… judgemental.’ [Participant 4]
>
> ‘Yes, on the issue of our mental health, it was so frustrating that most of us, including myself, was in the hotel for more than four or five months, locked up in the hotel, could not come out, do not have facilities in the hotel. We are not treated well, we are not treated with dignity… We do not

> even know how far our asylum cases are going, nobody's talking to us including the Home Office, not even our solicitors are talking to us. We are getting more frustrated.' [Participant 8]
>
> 'So you know, I try to sort of not, you know, get frustrated or think any negative thoughts about the situation. But I phoned up [a] couple of times, and I was informed that they would have a nurse phone me within that day or the next day, and then it never happens, and then you have to then chase them up again. And I just sometimes think to myself, well, maybe they're not looking into minor sort of… health worries or conditions? It's just sort of solely focused on, you know, like. More, I think. I don't know. I don't really know what to think. But I just sort of remember feeling a bit frustrated or about thinking, thinking, well, what's really the point in keep phoning them if they're not going to be getting back to you.' [Participant 3]

Health and Social Care Standards in Scotland are built on the principles of dignity and respect, compassion, inclusion, responsive care and support and wellbeing. These quotes exemplify situations where people who are particularly marginalised have not been able to access the support they need in a way that is most suitable to them.

4.2 Impact of the pandemic on mental health and wellbeing

The pandemic has seen a major reduction in face-to-face services and longer waiting times for specialist mental health services. People who are most marginalised and have the poorest mental health and wellbeing will have worse outcomes in terms of getting access to the support and services they need.[43]

This research has shown the negative impact that the pandemic and lockdown measures have had on participants' mental health, including feelings of fear, anxiety and isolation.

> ‘It stopped me from eating, made me have anxiety. I tried a lot of coffee, I smoked lots of joints. I became really insular, really insecure about the world, about seeing people, I had a fear about going out. I had an anxiety to actually go out of the house and the television and the daytime TV that was on it was just, almost making it worse.’ [Participant 2]
>
> ‘Was the fear that your family would die or fear that I would get [COVID-19] and the fear of being in a hospital. The things that you see on TV, everybody in and people are dying on their own and whole thought of that was something I obsessed about. Obsessed about my own death. It just makes me want to cry, the thought of that. And the whole thought of getting to never to see your children again, and be round you, and I want to get my injection, I want to see my children.’ [Participant 2]
>
> ‘Well, at first, before Christmas, there was a period where [COVID-19] with the first lockdown, it was the summer, and it was, it was ok. You could stay in your garden, you could still see a friend in your garden and that was that. At Christmas, it changed, I felt very … it drew me down, it got me into a dark, psychotic thinking.’ [Participant 2]

Participants in this research described how their mental health had affected their use of substances and physical activity.

> ‘I’ve kind of been smoking more because I was, my head was not in a good place. Now it has, kinda … I smoke like maybe five cigarettes a day now. But financially obviously we could not afford normal cigarettes, so we had to smoke a really nasty, dodgy bloody [dogs barking] ice cream van cigarettes, four quid a pack. And they were nasty. I doubt it was even tobacco in there.’ [Participant 12]

The research showed that there were both positive and negative impacts of lockdown on participants' mental health and for some it felt like they were imprisoned within their own homes.

> 'Basically, being on a house arrest for last year without ever having done a crime and having actually everything council done has affected largely my mental health because obviously it's not fit for human beings to live like that.' [Participant 12]
>
> 'Well, sometimes I feel trapped in my own home. Sometimes, just like just, just this past few week, you know, we're almost there, we're almost there, and I just feel I'm starting to get a feeling a bit of being trapped. And the first few months of lockdown, I didn't go over the doorstep for weeks and weeks. But now, I have confidence. Out walking with a mask and with social distance, 2 metres so.' [Participant 11]

However, for others the lockdown measures have offered respite from daily societal pressures and helped to improve the mental health and wellbeing of some of the participants in the research.

> 'Uhm, in some respects, I think, in the short term, I think, my health is probably improved. I know that sounds, that sounds quite strange, but I already had anxiety before [COVID-19] hit. Uhm and if I've been depressed it might have been a different story because then I might have felt isolated or, you know, lots of things like that but round about when [COVID-19] hit was the time when I really just wanted to put the world on pause for a little bit and… that's what happened, which, it sounds awful to say, because I know for most other people this is an absolute nightmare. And I also know avoidance is not a good, it's not even a good short-term strategy, never mind long-term strategy. But I think because I needed a break anyway, and because I'm kind of naturally quite a solitary person, I

> think, and I’ve heard of other people who have anxiety say this that I kind of got the personality that probably copes with this best.’ [Participant 4]
>
> ‘…in terms of my mental health actually not having to deal with everyday life in a sense of intense way was a godsend really.’ [Participant 4]
>
> ‘I've had time to do the things which I normally don't have time to do. I've read seven books, at least seven books. I made friends with the local bookseller. Well, there's two of them. And I've been buying books that interest me and reading the books. Um, I don't have, I don't have to worry about going out to meet people.’ [Participant 11]

Participants expressed fear and anxiety at having to re-engage with society once lockdown lifted and explained the negative impacts this would have on their mental health and wellbeing.

> ‘Ok, so, how the changes make me feel. If I’m, if I’m being honest, because the reasons I told you, when they talk about restrictions easing, I feel anxious because, partly because I’m worried about what’s going to happen, if it’s going to get out of control again, [COVID-19] I mean. And partly because I also know that it means, right, now back to reality, now back to normal life. And normal life wasn’t that great before.’
> [Participant 4]
>
> ‘So, I guess, like the restrictions easing... I’d say, it’s made me, yeah, it’s made me feel. You know, a lot more positive, actually made me feel quite nervous... I am like we’ve been in lockdown so long and like it’ll feel strange, I suppose... You know, things semi-going back to normal, but obviously, I think just because the restrictions are easing, you know, there’ll still be a lot of things not happening, like, for example, LGBT events, I don’t really think any face-to-face events will be happening anytime soon, even when the restrictions have been lifted.’ [Participants 5 and 6]

> ‘Obviously, in terms of like, I think, yeah, I think, you know, my family, they are dreading it [laughs] But I’m kind of, yeah, I’m in the middle... And I guess I’m just at that point when I’m not getting my hopes up, because I think until more people are vaccinated. You know, we could easily go back into a lockdown. And in some way, they are kind of doing it. They’re doing it too quick. I do feel like they’ve being quite wishy-washy, again with the restrictions. And I think the only way they could really do it, but obviously I know the impact of this would be, you know, keep everyone in a lockdown until more people are vaccinated, because I think that’s the only way that things will get better.’ [Participants 5 and 6]

4.3 Impact of pandemic on sense of purpose and control

This research found that there was often an imbalance of power between those delivering statutory services and those accessing services and support. The research also found that the pandemic and the lockdown measures had a significant impact on people’s sense of control over their lives and impeded their ability to access support and services in an equitable manner. Participants often felt that it was unclear when they would receive access to support or services and this directly impacted on their health and wellbeing.

> ‘Just not having that choice, not having the… Having my own personal… choice taken away from me, being told that I am not allowed to actually go anywhere near other human beings, like I am incapable of making my own decision.’ [Participant 12]

Access to information and knowing what the potential next steps may be in accessing support is important for people to have a sense of control of their own health and wellbeing.

There were several issues highlighted by participants in the research that suggested an imbalance of power existed between statutory services providers and themselves.

> ‘[they said] if you cannot manage that, you can use the medicine to reduce your distress in your mind. So, I start the medicine last year, and because I normally consult my GP because when I start the asylum process, I'm totally upset because I don't know about the policy of asylum. They said you’re not allowed to work, and you're not allowed to drive here. So many things they have restricted for asylum seekers. So, I'm totally upset about this policy. This is the policy of government and this policy is hit by mentally stress. And I used the light medicine, not hard, because during the night I’m not sleeping properly. I’m thinking about lots of things. What is my future here? What can I do? And because I am here for seeking asylum, so, so many things in my mind. So, I used the medicine and still I’m using the medicine to reduce the stress.’ [Participant 7]

Many respondents highlighted the negative impact the loss of their daily routine and structure, due to the lockdown, had on their motivation and general mental wellbeing.

> ‘In the sense that, you know, that you’re reliving the same day and just feeling a bit tired from, you know, like waking up and thinking, you know, what I’m gonna do today. But when I think about it realistically, like there is lots of things I could be doing and I think to myself, the lockdown has had a big impact on... on, my wellbeing and things, but I think to myself, what can I control, instead of thinking about the things that I can’t control.’ Participant 3]
>
> ‘My wellbeing was not good; I was not eating. I was vomiting and diarrhoea, physical body feeling, as well as my mind. It just wasn’t. And I felt unvalued from how I lost my diary, had a full diary. And I didn’t feel motivated.’ [Participant 2]

A participant clearly articulated the impact the lockdown was having on families and how they were unable to do things together.

> ‘This is a very terrible situation, especially for me. So, you’re never able to leave the house, the accommodation, as a family to have some fresh air and family time. Only one person can leave at the time.’ [Participant 7]
>
> ‘Yes, definitely during this lockdown be totally upset about it, because we are seeking asylum process and we have four family members, here, no other friends, family in this country, in this city, and we are alone and separated after the event, you know when the lockdown start. We don’t know about the situation, how to handle because the school is closed, everything is closed, and we stay at home and we just listen to the news. Don’t go outside. Do not go anywhere. You stay at home. So initially stage we are fine. But gradually, day by day, we feel it.’ [Participant 7]

Other participants reflected on the negative impact of not being able to carry on with important social networks and supports.

> ‘There was a ladies group for mental health and wellbeing that I attended to and that went and closed. And then only offshoot of that closing, we actually all had to say goodbye to each other. And we, as a HUG member, I was driven to be a leader, to see how important this women’s group for people with mental health and wellbeing needs. I had been going there for two years, I went along as a guest speaker. And that closed down, and church closed down, so that was Saturday and Sunday. So, I found weekends absolutely hellish.’ [Participant 2]
>
> ‘I feel I think the risk is that, during the lockdown the risks you have is that you are. You do, you are not safe with people around because you don’t know who has the virus. Your rights are violated. For example, I’m a Christian, I don’t get to go to church. I don’t know, communal worship, understand?’ [Participant 8]

The lockdown and pandemic have also had implications for people’s financial situations and many of the participants in the research spoke of the financial uncertainty they faced. This led to further feelings of loss of power and control.

> ‘…and it wasn’t a nice feeling after, basically, working hard all my life, to be in a situation of poverty where somebody up there decides and all of a sudden you have got to scramble hard to actually be able to put things on your table, so you can eat.’ [Participant 12]
>
> ‘I had my livelihood cancelled for a year, so, yeah, that leaves an impact.’ [Participant 12]
>
> ‘Erm, well, yeah. And pretty much constantly falling financially short, but that was prior to [COVID-19] as well. It’s certainly got worse… So, I'm pretty much kinda month to month, there’s no opportunity to save anything obviously… erm… You know, even if I could have got my possessions from the flat before I’d moved, I couldn’t afford to put them into storage… And that’s been my main thing. On a month-to-month basis I actually don’t need a great deal, it’s not as though you can do anything just now.’ [Participant 4]

4.4 Access to statutory public services

The pandemic and lockdown measures have led to several statutory services becoming limited, withdrawn or having less face-to-face provision. These severely impacted on some people’s ability to access the services and support they require, and in a manner that they feel comfortable with.

> ‘Um. Some of it’s been bordering on catastrophic for some people that I know. And I’ve learnt that some people I thought were doing OK were actually teetering quite close to the edge and it’s been just sort of the final straw that’s tipped them over. And they [are] desperately shouting help, I

> need somebody. And there just isn’t the services there for them any more.’ [Participant 10]

Many respondents perceived statutory services to be inaccessible during the lockdown due to issues such as the ambiguity of what is deemed an emergency and not knowing when it is safe to access services.

> ‘I have a lot of back problems, spinal problems, and the Sunday before Christmas, I sneezed and couldn’t get into a braced position beforehand, and it set my back off. And I’ve been trying to manage it with a TENS machine and hot water in the shower. And finally, yesterday, I admitted that I wasn’t getting anywhere with it, so I phoned the doctors and that’s the first time I’ve been in touch with the doctors where it’s been me going to them since the start of the first lockdown. Because I’ve just tried to stay out of the NHS’s way.’ [Participant 10]
>
> ‘And also, I remember phoning up different places for your sexual health as well. And, and because of like the [COVID-19] testing at the different labs where they would normally do, like you know, different tests for that. I was told like you’re not able to get tested or have that sort of access to the health that you would like, the different tests and things that you’d have before. And that, that was a change that sort of made me feel a bit anxious or worried because some, I don’t know, it’s important to look after all aspects of your health. And I just think if you have to wait, then it’s, you know…’ [Participant 3]
>
> ‘Oh very, very much upset about the GP situation because they don’t want to give me appointments during the GP because sometimes, I need to discuss face to face… And especially the telephone number is very much busy during the first half. Like the time I start timing is nine, nine o’clock and before the lunch time is one o’clock. During this time, all the numbers are busy.’ [Participant 7]

A number of participants highlighted poor communication and follow-up contact from health services and a lack of continuity of care as issues they experienced during the pandemic and the lockdown.

> ‘Communication. I think the standard of care is probably really very good, but communication is shocking, you know. And that is the thing that I think that has made us all a little bit angry. That I think people seem to be so busy doing, they forget about telling people what they’re doing, if that makes sense.’ [Participant 4]
>
> ‘So, I do think that there was like limitations on being able to get like that sort of… support, but I do think the communication would have been, would have made things a lot diff…would have made things a lot different, and better in that way.’ [Participant 3]
>
> ‘Emm yeah, it’s just really frustrating, really. Ummmm, you know, there was times where it would put me in a “downer”, as I would say. Emmm just because, I think me being high functioning, I think I’m often forgotten about. Emm so, yes is just obviously frustrating. It just made me angry as well because, my CPN, you know, is quite hard to get hold of, you know, I can be phoning her every day for a week and I still won’t hear from her, you know, until the following week. Emm so there’s definitely, yeah, you know, the lack of support.’ [Participants 5 and 6]
>
> ‘I used to have a CPN [Community Psychiatric Nurse], but not any more. I used to be a member of the local support group… but I'm no longer a member there. And my support’s been withdrawn as I’ve got better. But there’s no, no way to go back into it. If I suddenly... something happens, and I suddenly go down again. I have no going back, it’s, I've got to start again at the beginning and work through the whole system again. So, no, I don't feel there’s, there is any access available in that respect because... I’ve have recovered enough.’ [Participant 10]

Participants also highlighted the importance of active outreach for particularly marginalised groups.

> ‘In general times outside of COVID-19, I’d like there to be a drop-in centre. Somewhere where they’re not trying to process you through a system and turn you out at the other end and say right, you’ve done the course, you are better, goodbye, which is very much what the system is doing at the moment. But a drop-in centre, well, if you are having a difficult time, you can call in. And I think that could be provided online using platforms like Zoom quite easily. And I think that's what’s missing. And it needs to be probably daily for a couple of hours every other day, for four hours so people can come and go and drop in as they feel they need it and perhaps do that if it’s decided that they need further individual support, that could be arranged through that.’ [Participant 10]

4.5 Access to community, social support and social networks

It is widely recognised that the community and voluntary sector has demonstrated speed, creativity and flexibility in responding to the pandemic as well as supporting some of the most marginalised groups who often fall through the gaps of statutory service provision.[44] Many of these organisations operate from within communities and have a trusted relationship to support people in a dignified manner in a way that statutory services have often struggled.

This research has found that community and voluntary sector organisations were in a unique position to offer a range of flexible support and services to people and were seen to provide people with access to their basic human rights in the form of food, transport, information, financial support and access to digital technology and data. The study found that most participants had most of their positive interventions identified through the community and voluntary sector pathway. Targeted interventions took place with people who identified as high risk and with multiple complex needs.

> ‘In the summertime, I already had like a CPN from before. So, I would speak to her every once a month or twice or three times in the month and at the other end of the year, from October to December ended up, ended up reaching out to a different organisation… And that was quite helpful because I felt more supported and I felt, not safer, but I felt as if having somebody, a professional to speak to, it’s almost as if, if I didn't have that then, I don’t know if I would be feeling the same way that I am, that I am now.’ [Participant 3]
>
> ‘It gave me like the extra support that made me feel grounded and comfortable, and it made me feel like, OK by not being OK. And there was somebody there that kind of understood how I was feeling or why I was feeling that way … And definitely to make me be more aware and realise that, you know, there’s, there’s good things too.’ [Participant 3]

Many participants noted the holistic person-centred support they were offered by community and voluntary sector organisations.

> ‘[organisation], which we do every second fortnight, the little stuff because of the weather last year or so, we are getting a lot of support from charities and organisations.’ [Participant 8]
>
> ‘I don’t have any other activity, I just connected a few communities, if you know about the [organisation], they help out all the asylum-seeker families for this kind of activity to involve, they guide us, how to manage your life, especially in this asylum-seeking process and especially on the long term. So once a week, Zoom meeting one hour and the integration network caseworker call us and so many families join Zoom link. And they are

> doing some chit chat and discussion and sharing the information. So, this is very good. This is very good group discussion.’ [Participant 7]
>
> ‘They provide every Friday family pack food parcels. That is good for us to do for food point of view because we don’t have enough money. If you, if you know about the government provide me only five pound a day. Do you imagine how I can manage that, five pounds?’ [Participant 7]

A participant highlighted the vital support they had received in a time of crisis and how they felt that they could access this support at any given time and how important that was.

> ‘I think that to know that you got access to services and you’re talking about [website], [inaudible] who links you on to other directions, and other ways for where people pick up. Where you pick up the phone and I say I can’t do it any more. I want to end my life. And somebody at the end of the phone that is good not talk you out of it but talk you down, talk you into the present and bring you back to the reality. The reality is so hard to face in some strengths. The fact that [COVID-19] is here, for a while there it was just emerged in my body and my brain.’ [Participant 2]

4.6 Digital access

The research showed that if participants had digital access to support and services, this was beneficial to them and provided them with opportunities and choice. People required more than adequate access to data, devices and technology. They also required appropriate digital infrastructure and support to develop their knowledge, skills and capacity to use digital technology and access the support they needed effectively.

> ‘Yes, I do because this is where being because of benefits of being online. I found out about [organisation], which is just that. We did go to my

friend’s, who is 74, and he didn’t want to get on the internet on his phone, and the lady sat outside his door and prepared him for what he needed to learn. And he is 74 years old, so there’s no age limit.’ [Participant 2]

‘No, actually, because I was online with the ladies, we started talking about saving and online banking, something I said I was hesitant, online banking terrified me, and get hacked I would get this would happen. I’d lose my money. I actually benefited from learning from my support worker to bank online. I’ve saved a £1,000 pounds, it’s incredible.’ [Participant 2]

‘I never realised it would become as important as it has. Never. About six months ago, when I, a year ago, when I got this laptop and printer, and I’ve even got my printer linked up to my laptop, Wi-Fi, we did that last week. And to do these things I… it makes me feel that I could create an office at home. Yes, because you see things online that you wouldn’t see on Facebook, oh, I’ll link into that, and then you’re linking to something else. So that this something, I was so scared of a year ago. My friends laugh at it now, I used to say “I can’t do it. I can’t do it”. My son notices the difference too, I’m a lot calmer. I would give them the help number for AbilityNet. I gently would and when they can come back to your home. They can literally sit beside you and teach you. And I see adverts for it on Facebook and I hope that older people can link in and feel confident, and most of them do, which is for the joy of seeing their grandchildren. I do it. With my grandchildren.’ [Participant 2]

‘Yes, so, because of that we started a women’s group on a Monday. It’s just in it’s new. And it’s on Zoom. It enables other people to come on, and I’m a bit of a leader. I can believe that. Pardon, we started the woman’s group, this actually been going now for five weeks. Yes. There’s nothing better than that person to person. I think as you spoke about before, the online group has allowed people to take part that would never be able to meet personally, because they’re in that…the west coast, they’re in the different islands and personal health conditions…’ [Participant 2]

> ‘I've been encouraging others to do it. My friends from my previous group, and asking them to link, it’s changed the way we are, but people seem to love me and want me there and, and you’re valued, you guys smile. You actually end up in steady serious talk. But I’m laughing with women. I just think that’s amazing. I’ve got women that take me unconditional and I’m not needing to drink with them and fall out with them. It’s amazing to be wanted, to be someone that can see me on the screen. You are valuing me. It’s that goes with the new way of…It’s always new, cause I’m older. It’s new for me.’ [Participant 2]

Participants also highlighted the negative aspects of using digital technology such as a lack of privacy, or safe space to speak comfortably.

> ‘… if I said this to my therapist before that I sometimes feel, I don’t feel comfortable… speaking about things because, like because I stay in a flat and I feel like you can hear more, more things, so because it’s done from home. So, I have to make sure that my windows are closed, that the living room door’s shut and things. Because before like, you know, you could go to like the place where, where they work from like the office or like the room where they have the conversations and like it’s a safe place, like nobody you know is there or going to hear, overhear anything.’
> [Participant 3]

5. Discussion and conclusions

This peer research has provided us with an understanding of some of the issues faced by marginalised groups during the COVID-19 pandemic and resulting lockdowns.

One of the key messages to emerge from the research was that many participants from the marginalised groups involved in the study were not aware of their right to health. This may have been due to the right to health being a complex concept and the use of a closed question in the questionnaire. The complexity of this concept requires much more time and consideration to ensure that participants are supported to reflect on both what this means and how it relates to their personal circumstances. While participants spoke of examples where their rights were undermined through their experiences of stigma or exclusion when accessing services, this was not necessarily considered in the context of their right to health. Ensuring that there is greater understanding of what is meant by the right to health is key to realising and upholding these rights for individuals from marginalised communities.

The research highlighted the importance of health and social care standards and the need to ensure these standards are understood by service users and met. It also suggests the need for training of statutory services to provide support in a dignified manner that would allow all service users to be free from stigma and discrimination, and ensure rights are respected. The research also highlights the importance of building up the knowledge and capacity of people, especially those from marginalised communities, to access their rights and be able to challenge the system when their rights or needs are not met. These findings suggest there is a need to do more to ensure everyone’s right to health is respected and realised through appropriate legislation and implementation of policy.

The mental health impact of the pandemic and lockdown was highlighted as a major issue in this research. Interestingly, this impact was both positive and negative, with some participants valuing lockdown measures which offered respite from daily societal pressures, and others anxious about emerging out of lockdown back into society. The reduction in face-to-face mental health services during lockdown emerged as an important concern. This suggests that although there are obvious benefits from digital mental health support, we need to recognise that for many people with mental health problems, it is difficult to replace high-quality face-to-face mental health support.

The pandemic and the lockdown measures significantly impacted people’s sense of control over their lives and impeded their ability to access support and services.

There were different aspects to this, including a lack of information and the financial impact of the pandemic, which led to greater uncertainty and a loss of control for many people. In addition to this it is widely recognised that marginalised and excluded people often already experienced low levels of purpose, control and access to support and services and that this has been exacerbated by the pandemic. This suggests a need to engage and empower individuals and groups, who are already disproportionately affected, to help them become more resilient to the pandemic.

A key finding to emerge from this research was in relation to accessing statutory services. As previously mentioned, the pandemic and lockdown measures led to several statutory services becoming limited, withdrawn or having less face-to-face provision. In addition, a range of issues were highlighted including poor communication, lack of follow-up contact from health services and of continuity of care. It highlights that services need to be more accessible and flexible, meaning that they should actively work to support and meet the needs of service users to ensure equity of access.

The study highlighted the value of community support and social networks. It shone a light on the holistic support provided by the third sector within communities, which needs to be maintained and supported in a sustainable manner. Those who need support should have access to it in a format they need and when they need it, and the third sector is well placed to support communities.

Finally, the research highlighted the important role digital technology played in relieving their loneliness and social isolation during lockdown and the pandemic. It suggests the need for a hybrid approach to how services and support are delivered, and could offer people a choice in how they access the help they need. This includes a range of methods such as face to face, online, through calls and video conferencing, as well as signposting to services and ensuring people were satisfied with the support and the method through which it was delivered. However, participants also highlighted the negative aspects of using digital technology, such as a lack of privacy, or a safe space to speak comfortably. If this hybrid approach is being implemented, there is a need to consider those who find it difficult to access digital platforms and ensure all forms of digital exclusion are addressed.

It is important to note that the findings from this research reflect intersectionality and inextricable connections between the different themes that have emerged. The findings represent cross-cutting themes which are all interrelated and influence health and wellbeing outcomes in different ways for different participants. This complexity is key, as many of the findings and associated recommendations in section 7 reflect on the need to address cultural and systemic issues.

To ensure that this research is impactful, it is key that these connections are recognised and considered in any further work and recommendations to be taken forward.

The work of the Inclusion Health Partnership seeks to apply an intersectional approach in understanding the unique challenges for those who are disadvantaged by systems and services. This will be an ongoing focus of learning and development for phase two of this project.

Planning and development of the approach for phase two of the project has now commenced, with an indicative timescale for reporting findings by autumn 2022. Analysis from this report is currently informing the identification of cross-cutting themes to be explored in phase two. The research team are working with partner organisations to develop a range of participative approaches to further our understanding of what responses would enable the right to health for excluded and marginalised communities to be realised.

5.1 Learning and reflections from phase one

Phase one of the research had a small sample size but was still able to give us rich data and deepen our understanding of the issues faced by marginalised communities. There were similar cross-cutting themes highlighted for different groups which adds to the validity of the findings.

Working with participants in phase one has helped us to understand some of the barriers to participation and will inform the way we work in phase two. The lived experience model which has been developed through this research is a key tool for phase two and could also be used in wider research projects seeking to understand lived experience.

Practical considerations, such as remunerating participants for their time and contribution and ensuring they have no out-of-pocket expenses for transport, data or childcare for example, is important. But it is also imperative for the research approach to be accessible. For example, significant time was taken during this project to build relationships between participants and researchers. This time ensured that participants were provided with as much information as possible to be informed about the purpose of the research and understand their contribution. It was also key that the researchers understood the flexibility that participants required to ensure that they could engage in a meaningful way. This included ensuring that participants felt empowered to ask questions themselves or share information which they felt was relevant. It also included flexibility so that participants could choose interview times that most suited them, sometimes with last-minute changes depending on their circumstances.

The approach adopted in this research has sought to ensure that participants have as much power as possible to take the time that they need to prepare and contribute in a way that meets their needs. It has highlighted the need to provide a safe and private space to speak to the researchers and to allow time for trust to be built between researcher and participant.

One of the key limitations of this research has been the voice of women with experience of selling or exchanging sex. There have been steps taken to engage and support the participation of this group but unfortunately this has been difficult to facilitate, as competing demands on women’s time impacted on their availability during the data collection phase of the research. Learning from this work has highlighted issues around safety and security, ensuring that the specific barriers experienced by women who sell or exchange sex are reflected in the research approach. For example, ensuring that childcare needs are met, that they have anonymity and access to safe spaces where they are relaxed and protected from others influencing their involvement. This has highlighted the importance of taking a gendered approach to issues and the solutions offered, to make services accessible. The different barriers to participation experienced by women will be a key consideration for phase two.

Another limitation of this research was using a closed question to explore participants' understanding of their right to health. Considering the complexity of this and the depth of understanding which is required to ensure that barriers to the right to health are understood, more time and exploration is required to be able to answer these questions. Phase two presents an opportunity to explore this issue more deeply and potentially facilitate group discussion where these issues may be more appropriate, for some.

One of the themes highlighted in this research was the difference between access to statutory and voluntary services. As we develop phase two of the project it is worth exploring further to understand why people feel stigmatised when accessing statutory services. What is it about the approach or delivery of these services which can cause people to feel stigmatised? Understanding the experiences of marginalised communities when engaging with different services is key to developing our understanding for how services can be accessible, available, acceptable and of high quality.

Lastly, in phase two, consideration must be given to the complexity of the issues which are being explored through this research and how the weight of different findings can be reflected in the analysis. While there was consensus around the key themes which emerged from phase one of this research, we were unable to accurately report on the weight of opinion associated with each theme. In phase two, it is anticipated that larger volumes of both qualitative and quantitative data will be collected. As a result, further analysis is required to ensure that the weight of opinion associated with different findings can be reported confidently.

6. Lived experience model

This research was carried out in a way which has sought to ensure that participants are supported, empowered and informed about the process. The methodology focused on the approach being as inclusive and participative as possible, working through local organisations as this is where the local expertise exists and there is continuity of care and trust. The following principles have underpinned engagement with all of our participants.

These principles will inform, and be developed through, phase two of the project:

1. Always build in financial support to provide expenses for participants and ensure that costs associated with transport, energy or data, and childcare are not a barrier to engagement.

2. Prepare your participant by providing in advance an access-to-interview guide, information about wider support services, biographies of interviewers and background information about the study.

3. Construct an interview guide and test your questions with local partners who are best placed to build trust and safety.

4. Consider cultural and power dimensions of the interview situation. By taking a person-centred and inclusive approach it is important to recognise the individual needs of each participant. Working with partner organisations that have established relationships with communities can support the development of trust between researchers and participants.

5. Ensure flexibility around interview times, when engaging virtually ensure options for which platforms to use and offer support for translation and interpretation.

6. Build genuine rapport with your participant, ensuring as much time as possible is spent building the relationship as this is key to accessing rich data.

7. Provide a support sheet with accessible phone, 24/7 freephone, and online services.

8. Talk less and listen more during the interview.

9. Allow flexibility to adjust the interview guide.

10. Be prepared to support unexpected emotions.

11. Create spaces before and after the interview to support concerns or feedback and reflective practice.

12. Always acknowledge participation and remunerate the individuals in money or vouchers – whatever is best for them – for their time, expertise and contribution.

13. Ensure that you can support all learning styles and that support paperwork can be accessed both online and in paper form.

7. Recommendations

The research will be useful to public sector service providers who support people from marginalised communities. It has highlighted some of the long-standing barriers that individuals continue to experience when accessing services and support.

The recommendations have been developed to address the themes emerging from phase one of the research. These themes will be further explored in phase two and may lead to changes in the recommendations listed below.

The six themes below, that have been highlighted in this research, are reflected and addressed in the recommendations detailed below:

1. Human rights and health.

2. Impact of the pandemic on mental health and wellbeing.

3. Impact of pandemic on sense of purpose and control.
4. Access to statutory public services.
5. Access to community, social support and social networks.
6. Digital access.

The cross-cutting nature of these themes, and the complexity of how access to support and services can impact on the right to health, means that the recommendations include both strategic and systemic considerations, as well as practical issues of service design and delivery.

7.1 Summary recommendations

Service design and delivery

1. The lived experience of people from marginalised communities should be proactively sought to inform the design and development of services. This is to ensure that services meet their needs and that barriers to access are identified and addressed for those who experience stigma and exclusion.
2. Services should commit to understanding the communication needs of service users and ensure timely and person-centred responses as appropriate. This may include regular communication, providing a point of contact for service users and follow-up contact as required.
3. Services should ensure a choice of approaches and methods to communication with all service users to meet their diverse needs.
4. Services must tackle digital exclusion by ensuring individuals have access to data, technology and are able to develop skills to use digital services effectively.

5. Health or community support professionals should actively seek immediate feedback from service users in an effort to understand if their needs and rights have been met by their engagement.
6. Services should commit to continuous improvements by consistently and effectively seeking feedback from service users and ensuring clear and accessible complaints procedures.

Workforce development

7. Training resources should be developed to support services and policy-makers to take a human rights-based approach to developing and delivering services.
8. Discrimination and stigma must be tackled by considering the knowledge, understanding, training needs and experience of the workforce. Support must be provided for the workforce to build their knowledge and understanding. This should include understanding and addressing attitudes and values as appropriate, and reflecting on opportunities for continuous improvement.
9. Strategic and organisational leaders need to show commitment and leadership, to ensure trauma-informed services are developed and delivered.

Upholding human rights-based approaches in policy and practice

10. Duty-bearers should ensure that all service users are supported to understand their rights, entitlements and responsibilities when accessing services. This support should be provided across all statutory services at the point of access and during ongoing care and support.
11. Leaders across the public sector must commit to organisational culture and policies that support the delivery of services that tackle stigma and uphold the right to health for everyone. Tools such as the AAAQ framework and the PANEL principles should be core to service design and delivery.

12. Public sector organisations must improve partnership working across sectors, including sharing resources, information and intelligence to uphold the rights of marginalised communities.

13. Consider opportunities to use participatory approaches which involve service users and partner organisation in decisions about the allocation of resources.

7.2 Recommendations – additional detail and examples of relevance

This section has been developed to provide further detail and consider examples where the recommendations in section 7.1 could be applied. The detail within this section has been informed by the expertise and experience drawn from the Inclusion Health Partnership and the working group for this research. The detail below is intended to provide further points for reflection and consideration which support stakeholders to consider how the recommendations could be implemented. Where specific examples of policy or practice are identified, these are not exhaustive.

Service design and delivery

1. The lived experience of people from marginalised communities should be proactively sought to inform the design and development of services, to ensure that services meet their needs and that barriers to access are identified and addressed for those who experience stigma and exclusion.

Duty-bearers, including statutory public bodies, should:

- reflect the principles in section 6 as an example of good practice for ongoing research, locally and nationally
- seek to continue to adapt their approaches to engaging with communities to ensure that the voices of those with lived experience from communities who are marginalised are heard

  - ensure transparency in all decision-making processes to continually engage and inform communities about decisions responding to identified need.

2. Services should commit to understanding communication needs of service users and ensure timely and person-centred responses as appropriate. This may include regular communication, providing a point of contact for service users and follow-up contact as required.

   - Services should commit to ongoing and responsive communication to ensure service users are fully informed and involved in their care and support.

   - Services should consider the cultural interpretation of key messages and ensure appropriateness and relevance for marginalised communities.

   - Services should always use plain language that is clear, concise and appropriate to the audience, avoiding use of complex vocabulary. The Plain English Crystal Mark campaign[45] is an example of a tool that can help with this.

   - Service users should have access to high-quality interpreting and translation services. Health services should adhere to the NHS Scotland Interpreting, Communication Support and Translation National Policy.[46]

3. Services should ensure a choice of approaches and methods to communication with all service users to meet their diverse needs.

   - Service users must have choice and control over their preference for communication methods. Choice and preference for communication may change over time and this should be supported and enabled.

   - Services should ensure the effectiveness of different communication channels and formats.

4. Services must tackle digital exclusion by ensuring individuals have access to data, technology, and are able to develop skills to use digital services effectively.

    - Services must recognise the opportunities and challenges associated with digitisation. In line with A Connected Scotland, services must tackle digital exclusion, ensure that ‘No One is Left Behind’ and ensure accessible data, technology and skills for how to use digital services effectively.

    - It must be recognised that digital choice and flexibility are key to ensuring that marginalised communities receive the support that they need in a way that meets their needs and rights.

5. Health or community support professionals should actively seek immediate feedback from service users in an effort to understand if their needs and rights have been met by their engagement.

    - Proactively seeking feedback from service users at each point of engagement would help to redress the balance of power by ensuring service users are able to share their experience of engaging with services and seeking support.

    - As appropriate, services should seek to support service users to continue to engage by being responsive and providing opportunities for ongoing care and support to meet their needs.

6. Services should commit to continuous improvements by consistently and effectively seeking feedback from service users and ensuring clear and accessible complaints procedures.

    - All health and care services should publish how they are meeting their responsibility, set out in the Patient Rights (Scotland) Act 2011, to provide opportunities for people to share feedback, comments, concerns and complaints.

  - Services must provide evidence on how they are actively promoting opportunities to give feedback directly and indirectly (e.g. platforms such as Care Opinion).

  - Processes must be put in place to ensure there is a culture of service improvement and openness to receiving complaints (including anonymous complaints) and ensuring there is no negative impact on the experience of the complainant.

Workforce development

7. Training resources should be developed to support services and policy makers to take a human rights-based approach to developing and delivering services.

   - The Fairer Scotland Duty (Part 1 of the Equality Act 2010) places a legal duty on particular public bodies to pay due regard to how they can reduce inequalities caused by socio-economic disadvantage when making strategic decisions. Public sector bodies should be supported to build staff capacity to better deliver on this duty in practice, to embed this duty in service delivery and share learning.

   - Specific work should be carried out to identify and develop case studies which share examples of practice and highlight learning from statutory organisations that are developing and implementing human rights-based approaches.

8. Discrimination and stigma must be tackled by considering the knowledge, understanding, training needs and experience of the workforce. Support must be provided for the workforce to build their knowledge and understanding. This should include understanding and addressing attitudes and values as appropriate, and reflecting on opportunities for continuous improvement.

  - An awareness and understanding of the experience of homelessness, or the stigma associated with mental health or for women who sell or exchange sex, is essential to ensure that services address the barriers that individuals from marginalised communities experience.

  - Organisations should seek to understand the knowledge, attitudes and training needs of their workforce to ensure appropriate learning and development is provided.

  - Processes should be put in place for recording and monitoring instances of discrimination within services, from both staff and service users.

  - Staff should have access to training and development opportunities that address stigma and discrimination. This should be developed with people with lived experience and be relevant to the context of the service being provided.

9. Strategic and organisational leaders need to show commitment and leadership to ensure trauma-informed services are developed and delivered.

  - Leaders must commit to providing the support and resources required to train professionals in trauma-informed practice. The NES Trauma Training Framework and Programme provides a suite of resources relevant to the totality of the Scottish workforce. This is based on the principle that ‘trauma is everyone’s business’.

Upholding human rights-based approaches in policy and practice

10. Duty-bearers should ensure that all service users are supported to understand their rights, entitlements and responsibilities when accessing services. This support should be provided across all statutory services at the point of access and during ongoing care and support.

  - For example, services must provide training to all staff on the Patient Rights (Scotland) Act 2011 and specifically the Charter of Patient Rights and Responsibilities (updated 2019) which sets out in detail the rights of patients, service users and carers to be actively involved in their own health and care and in improving the services they use.

  - Based on inclusive communication principles,[47] service users must be given access to this information in a variety of ways and this should be available on an ongoing basis, i.e. different formats, mediums and languages.
  - Services should work to increase awareness and transparency around expected standards of services, for staff and service users, e.g. Health and Social Care Standards.

11. Leaders across the public sector must commit to organisational culture and policies that support the delivery of services that tackle stigma and uphold the right to health for everyone. Tools such as the AAAQ Framework and the PANEL Principles should be core to service design and delivery.
    - For example, commitment to a charter to reduce stigma, which recognises the experience of marginalised communities and how this can exacerbate health inequalities, would support the design and delivery of inclusive and accessible services.
    - Equality Impact Assessments should be embedded in service design and decision-making processes. This should recognise that marginalised communities are not homogenous groups and recognise the intersectionality of experience and characteristics.
    - Work needs to be done to support local systems and services to build capacity to consider and embed the AAAQ framework to inform the delivery services which uphold the rights of communities.
    - Services should identify opportunities for participative approaches to service design and development, ensuring that service providers are accountable, addressing discrimination or unconscious bias, empowering

service users to inform decision making (at any level) and ensuring compliance with service users' rights. Services will be in a stronger position to uphold the rights of service users.

12. Public-sector organisations must improve partnership working across sectors, including sharing resources, information and intelligence to uphold the rights of marginalised communities.
    - Services must share resources, information and intelligence so that people do not need to recount their situations and are supported to access services that meet their range of needs. For example, implementing multidisciplinary teams from across organisations and services.
    - Public bodies, locally and nationally, must work collaboratively to find solutions sooner to the challenges presented by disparate patient and service user information management systems across a variety of sectors and services. For example, SCI Gateway for primary and secondary care and other electronic record management systems typically used in local authorities.
    - Health and Social Care Partnerships must work to overcome barriers associated with joint commissioning and leadership. Services must be developed in a way that supports partnerships with third-sector and community-sector organisations, who are best placed to reach and engage successfully with the most marginalised communities.
    - Services should proactively promote participation requests as a means of strengthening participation in decision-making processes to improve public services, including health and care services.
13. Consider opportunities to use participatory approaches which involve service users and partner organisations in decisions about the allocation of resources.

    - If using participatory budgeting services, organisations should follow the principles set out in the Participatory Budgeting Charter for Scotland.[48]

7.3 Recommendations for phase two

People from marginalised communities are not a homogeneous group. Careful consideration should be given to the development of the communication, participation and support materials, resources and methodologies for phase two of this project, to enable as wide a group of individuals as possible to participate. Specifically, the following factors should be considered before lived experience work is started.

Participant support

All direct lived experience work should be at a pace led by the participants and fit with their lives and circumstances. Adequate resource needs to be allocated to allow participants to be remunerated for their time and contribution. This will allow flexible approaches and timescales to accommodate changing needs and availability.

Participants should be offered different levels of participation in phase two, including in the planning and design stages, so they have choices and options as to how they want to engage and can move through different levels if circumstances change. Participants should be supported before, during and after all work.

Remove barriers

Resources that directly remove barriers to participation, and the process for accessing those resources, should be agreed in advance. This might include, but is not limited to, translators, childcare or other carer expenses, travel and all other out-of-pocket expenses.

Protect participants

Researchers, engagement and other workers involved in phase two should be aware that participation in lived experience work has the potential to trigger previous negative experiences and trauma. Clarity and transparency on purpose, roles, responsibilities and expectations for both participants and those working with them is essential.

Participants should have a clear understanding of what being involved in the research will entail, what will happen to the information that they share and how it might be used.

Service user experience

Phase two should seek to understand in more detail the varying experiences of participants in accessing both statutory and community-led services. This research report highlights stark differences in these experiences and this needs to be understood further.

In addition to considering the accessibility of services for marginalised communities, an equalities perspective should also be considered.

Understanding the right to health

Phase two should seek to further explore the understanding and awareness of the right to health for marginalised communities. This should include consideration of intersectionality within and across marginalised communities.

This exploration should consider what having the right to health means and what is required to ensure that communities can realise their right to health. Phase one began to explore this concept but this report highlights the need for more time and consideration of this issue.

Appendices

Appendix 1: Key findings from Intelligence Gathering Overview (as of May 2020)

- The theme that emerged across all groups was **mental health**. Social isolation, fear, loneliness and anxiety resulting from COVID-19 have negatively impacted this.

- **Rights to Life** – compromised through support packages being reduced or withdrawn with life-limiting impacts and intensified by discriminatory discourse in the media.

- Exacerbated by a loss of income, difficulty in accessing benefits and confusion around eligibility, **poverty** is a major concern as is yet to be realised as we approach the end of the current furlough scheme. In many cases **food insecurity** has been brought about by poverty but also by lack of access for many reasons, such as changes to their support arrangements, shielding, distancing and reduced provision. Some groups are experiencing long-term food insecurity brought about by loss of income.

- Some groups, such as people with learning difficulties, literacy issues or dementia, had a lack of **understanding** about COVID-19 itself but also shielding, distancing and what it means for their daily lives and the services they access.

- Technology can help us to connect, understand and plan for changes to routine as a result of COVID-19. Therefore, those experiencing **digital exclusion** are further disadvantaged when social spaces with free internet access are closed or they are unable to obtain or use technology that could help them.

- **Support services** operating differently or being reduced has caused anxiety resulting from changes to staff or routine for vulnerable groups.

- **Gender-based violence** has increased incidence with lockdown measures reportedly being used as means to control partners and further isolate them. Scottish Women's Aid (SWA) reports that abusers are using measures imposed to combat the pandemic as a tool in their abuse. For example, by increasing their control of women's movement, keeping them isolated, threatening to expose them to the virus, or discouraging women from seeking help by telling them that services are not operating or that the police will not respond. Leaving an abusive relationship does not mean the end of the abuse. Women who do not live with their abuser may feel increased fear because their abuser knows that they will be spending time at home, increasing the risk of stalking. SWA is also concerned about the impact of coronavirus on children and young people experiencing domestic abuse, who may not be able to attend school or nursery – the places many of them feel safest.

- **Transport** provision has impacted the ability of some services to reach clients and for clients to make necessary journeys.

- Some groups (notably those with no recourse to public funds, people in the justice system, homeless people and those living in poverty) can find **housing** and **containment measures** challenging if they are living in small or crowded spaces as it can be impossible to self-isolate. They also have less space to store food resulting in more frequent shopping trips. Poor quality housing can also exacerbate health problems. There is a potential 'wave of homelessness' approaching once mortgage holidays and eviction freezes end as people's mortgage and rent payments have continued to accumulate over this period of lockdown.

- Women and mothers have been disproportionately hit when it comes to employment, having lost their jobs or their hours, and having been furloughed at a higher rate than men. Women are 50% less likely than men to qualify for sick pay.

- **Systematic delays**, for example court proceedings for domestic violence, where to send an alleged abuser while awaiting a trial date, or, for transgender people, delays or cancellations on essential gender-affirming treatment, which many have been waiting years to access.
- **Loss of safe spaces** where LGBT people can seek support and can often access advice and medication, is making life more difficult.

Appendix 2: Semi-structured interview questions for phase one

Introductions

Researcher

- Introduce self and Public Health Scotland/Strathclyde University/Homeless Network Scotland
- Explain this part of the research and potential next steps
- The interview will be recorded, then transcribed, to look at your responses in detail, but everything you say will be confidential and your name will not be identified in any findings. Check if participants prefer to have visual connectivity off (as in PIS).
- Are you happy for the interview to be recorded? (informed consent)
- Explain interview can be stopped at any time.

Just to confirm before we start, if you are happy to, can you tell me your:

- Age
- Gender
- Ethnicity
- Urban/rural

Questions

1. a) Do you feel that your health and wellbeing has been affected by the restrictions put in place because of COVID-19?
   b) If so, can you tell us in what way?

c) What has the impact been on people close to you, for example your partner, family and friends?

Prompts/notes

By restrictions we mean things like social distancing, shielding or self-isolating at home, changes to services that you rely on, or having to get tested or contacted about testing for COVID-19

2. How do you typically spend your day?

Prompts/notes

Insight into degree and impact of isolation/loneliness/lockdown fatigue and level of resistance

3. a) Are you aware of your right to health?
   b) Do you feel that your right to health has been impacted since COVID-19?
   c) If so, can you tell us in what way?

Prompts/notes

Fundamental human right to enjoy the highest possible standard of good health, free from discrimination or obstruction and applicable to everyone.

4. a) Are you able to access the health and care services that you need?
   b) Are you able to access the housing services that you need?

Prompts/notes

For example:

- cancellation of medical appointments or treatment
- reduction or withdrawal of support from social care providers
- challenges with accessing housing support

- cancellation of other services, such as community groups, support networks etc.

5. a) Has the way that you access health and care services changed since COVID-19?
   b) If so, how has it changed?
   c) Has the way that you access housing services changed since COVID-19?
   d) If so, how has it changed?

Prompts/notes

For example: relying more on family/friends/volunteers, using telephone or video appointments, using the internet for information etc.

6. a) Since COVID-19, have you experienced a crisis where you needed help or support?
   b) What was your experience of seeking this help/support?
   c) Was the support you needed available?

Prompts/notes

What has the participant's experience of seeking support from their landlord been like?

7. What types of support would help you to feel healthier, and safer, during COVID-19?

Prompts/notes

8. a) What is your main way of communicating with people close to you e.g. partner, family and friends since COVID-19?

Prompts/notes

Telephone, letter, email, social media (such as WhatsApp, Facebook, or Messenger), Zoom or similar platform or face to face (socially distanced outside visits to/from people).

b) What is your preferred method of communication/getting information about COVID-19?

Prompts/notes

TV updates/news, social media, websites, newspapers, updates from family or friends, updates from trusted organisations, e.g. religious organisations, charities, or voluntary groups**.**

9. a) Do you have a device, and data, that allows you to access the internet?
b) Do you feel confident about using digital services/technology?
c) If not, what kind of services would help you to become more confident?

Prompts/notes

Devices might include mobile phone, SMART TV, tablet or computer, consider cost of data plans, reliability of connections and demand on data (i.e. other household members sharing data or high data requirements for particular activities, such as schoolwork).

10. a) Are you, or have you at any point found yourself, falling short financially since COVID-19?
b) Can you tell us what the impact of that has been?

Prompts/notes

Loss of income from employment, increase in household expenses, increased cost of food, increased cost of fuel, issues with benefits system, helping others financially etc.

11. a) Do you feel that your alcohol/cigarette/drug consumption has increased since COVID-19?
b) If so, what the impact of that has been?

Prompts/notes

12. a) How do you feel about the easing of lockdown restrictions in Scotland?
b) What do you feel represents the biggest risk right now for you, your partner, family or friends?

Prompts/notes

Important to make distinction that we are asking about Scotland as other parts of UK have different approaches?

Closing

- Is there anything else you want to say, or anything you feel we have not discussed today that you'd like to add?
- Discuss after care – support services we can point them to. Ensure they are ok after the discussion. Confirm they have received a copy of the after-call 'support sheet'.
- Hand over after-care support sheet.

Appendix 3: Participant information sheet

Background

As part of the response to COVID-19**,** Public Health Scotland, in partnership with Homeless Network Scotland and The University of Strathclyde are carrying out this research to be able to understand how the COVID-19 pandemic and the period of lockdown has affected the access, availability and appropriateness and the quality of services and support you have received during this time.

The right to health is a fundamental part of our human rights and of our understanding of dignity and respect. As human beings, our health, and the health of those we care about is very important to us and something most of us think about daily. It does not matter about our age, gender, where we live, our ethnic background or our previous experiences, we consider our health to be our most basic and essential asset. On the other hand, when we are ill or feeling unwell this can keep us from going to school or to work, from attending to our family responsibilities or from participating fully in the activities of our community. In short, our health is fundamental to our ability to thrive.

This research is being carried out in partnership with people who have experienced homelessness, people who have experienced severe and multiple disadvantage through any type of violence, trauma or exploitation, and people who experience stigma and exclusion. This research aims to understand how the pandemic and the national response, including lockdown, have affected your life and your right to health. We would like to also find out about the barriers you have come up against that have made the services you need harder to access.

Your right to health is very important to us and all public sector organisations have a duty to uphold it. This is even more important during this pandemic which has presented testing times. Helping us understand the effect on your health and wellbeing by sharing your lived experience is very important to us as the information you provide, along with information from other organisations, will help us to work together and help influence the design and delivery of improved support and services across Scotland in the future.

Thank you for your interest in our survey. Please read the following prior to agreeing to take part.

Introduction

The lead researchers are Neil Quinn from the University of Strathclyde and Derek Holliday who is a Peer Development Lead at Homeless Network Scotland. There may be other partners carrying out these interviews, but you will be notified and introduced to them prior to any interview taking place to ensure you are comfortable and feel safe to share information.

What is the purpose of this research?

Public Health Scotland, Homeless Network Scotland and the University of Strathclyde are carrying out this research to be able to understand how the COVID-19 pandemic and the period of lockdown has affected the access, availability and appropriateness and the quality of services and support you have received during this time.

Do you have to take part?

No, it is your decision whether you take part in this research or not. If you do not wish to take part or want to leave the research program at any time this will not affect any other aspects of the way you are treated. Please let your researcher know if you wish to opt out.

What will you do in the project?

You are being invited to take part in an informal one-to-one interview. The interview will take approximately one hour and will be carried out on a date and time that is convenient for you and that has been agreed after several communications with a member of the research team. Due to the nature of the ongoing situation, interviews will take place either online (Zoom/Skype) or via telephone, or one-to-one if permissible and safe at no cost to yourself and by your choice of preference.

The aim is to help us understand how the lockdown may have affected you or your family's access to quality health and support services during this period. We will be asking you 12 questions about your experiences to better understand the support that would help and what needs to change to improve that experience. You will receive the questions before the agreed interview takes place, this is to allow you the appropriate time to understand your involvement, have the suitable time to discuss any concerns and more importantly feel safe and confident in your contributions to this research.

As part of your involvement in supporting the research, as mentioned before you will not be financially impacted for your involvement and we will be able to offer reimbursement should any costs arise. Taking part in the research will be acknowledged through a one-off payment of £40.00. This is a standard process for contributions to our work and a personal thank you for your invaluable support. This would be done sensitively through a direct transfer into your personal banking or savings account or this can be added to a shopping/store voucher of your choice.

The researcher – if you agree – will audio-record the interview. You can also keep the visual connection turned off if you prefer. The information you share will be confidential in that it will be anonymised in the final report. The only exception to this is where the researcher is concerned about you or another person being at risk of harm. In this case the researcher will ensure that support can be provided. The researcher will always try to discuss this with you first. We will also give you the contact details of a local support organisations should you require anything after the interview is complete.

Why have you been invited to take part?

You have been invited to take part in our survey because we are interested in your feelings, experiences and journey around how COVID-19 (Coronavirus) and the period of physical distancing and various social restrictions (lockdown) have affected you in your everyday life. We are especially interested in capturing this information from people with lived experience of homelessness, people with experience of feeling excluded and people who have experienced trauma and/or violence in their lives.

What information is being collected in the project?

You will be asked by a researcher to answer 12 questions (a semi-structured interview). You should now be familiar with your researcher due to previous meetings. These questions will be asked via an online platform or maybe via face-to-face contact. The questions will be around how you feel about your health and wellbeing, if your use of alcohol, drugs and tobacco have increased and your access to services during the lockdown period of the pandemic, which started in March 2020. We will also be asking about internet access and how you feel the lockdown restrictions have affected you financially. You cannot be identified by any of this information.

Data collection, storage and security

All data associated with the research study will be managed in a responsible manner which adheres to the General Data Protection Regulation (GDPR) and The Data Protection Act 2018 directives. We will ensure that information relevant to the research is recorded and this information is kept precise, up to date and confidential.

Throughout the research project, we will follow the principles of anonymity by not using anyone’s name or other personal details. Participants will not be identifiable in any final report.

Audio recordings and subsequent transcriptions will be stored with labels as generic code, e.g. ‘Participant 1’. At no time will names or details of participants be stored alongside this information. All audio recordings will be deleted from the audio recording devices upon transfer to a password-protected data storage facilities at Homeless Network Scotland and Women's Support Project. Upon transcription of the audio recordings, audio recordings will be erased from the storage.

All files and documents will be stored by Homeless Network Scotland and Women's Support Project in password-protected storage facilities. Any written consent forms will be scanned and also saved by these agencies. Any original documents will be confidentially destroyed. Where audio recordings and consent forms are collated by partner agencies, agreement will be reached that original files will be deleted once receipt of files is confirmed by Homeless Network Scotland.

Electronic consent forms will be stored for three years following the completion of the study.

Appendix 4: Consent form

I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.

- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any negative consequences for myself.
- I understand that I can withdraw my data from the study at any time until the submission of the **data collection**.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made available to anyone beyond the researcher and their supervisor.
- The only exception to this would be if the information disclosed is related to serious harm or immediate danger, in which case the researcher would need to pass along this information.
- If this should happen, the researcher would discuss this with me at the time.
- I consent to be audio recorded.
- I consent to be a participant in the project.
- Do you need any support in preparing for your interview? **Yes** **No**
- Due to the social distancing requirement, research interviews will be held virtually. Please select your preferred platform to be used:

  Microsoft Teams **Zoom** **Telephone**

Name:	
Signature:	
Date:	

Appendix 5: Researcher biographies

Neil Quinn

Neil Quinn is a Reader in Social Work and Co-Director of the University of Strathclyde’s Centre for Health Policy. He is committed to working in partnership with service users and communities and has 25 years’ experience in social work, community development and public health at a local, national and international level. He has undertaken a number of qualitative studies, including participatory research projects on people’s lived experience. This includes a study on the right to health for asylum seekers and refugees and people with lived experience of homelessness funded by Public Health Scotland. He has also conducted the Sanctuary study with asylum seekers and refugees. He is currently conducting two qualitative studies on COVID-19, one on the impact of social distancing on the relatives of care-home residents and the other on mental health disparities as a result of COVID-19.

Derek Holliday (everybody calls me Doc)

Why I am taking part today?

I want to live in a country where we support people based on their potential and aspiration, not how they present or their postcode!

I am here today as I passionately believe that everyone, irrespective of their journey or current circumstances in life, should always be included, supported and given every chance to be part of their community, society, life and health.

Everyone has something to offer, share or untapped potential waiting to be opened. No plight should ever be a continuous wall to shut you out and exclude you from hope.

My role today

My role is to listen, learn, acknowledge, encourage and support you on the day. I will be facilitating a phone interview/discussion for which your voice, story and insight are invaluable and important.

Something about me

I was a volunteer advocacy worker with Navigate, a ‘welfare mitigation’ enterprise. This was set up to offer support to some of the most vulnerable citizens in Glasgow with regards to supporting them through the aggressive inhuman landscape of housing and welfare support, especially challenging for people experiencing homelessness or mental health, and for asylum seekers.

I am a person of considerable lived experience. I have been homeless, I have been lost, and I have been trapped in systems that should promote equality and positive health choices but instead inspire suicide ideations and disconnectedness from oneself.

I am a Peer Development Worker with the Homeless Network Scotland, but I was an active homeless and mental health advocate for others that could not find their voice or a service that would acknowledge them. I support genuine collective lived experience action research, providing platforms and safe spaces for those impacted to be able to contribute to better service delivery, planning and protections both at a local and national level.

Anna Cook

A bit about me

I’m Anna, the Development Worker at CLiCK which is a Scotland-wide partnership of organisations supporting women who sell or exchange sex. My job here is all about ensuring that women’s voices and experiences inform and influence how CLiCK and wider services work. I do that through things like anonymous consultation, one-to-one work and exploring creative ways for women to tell their stories and of course research like this. Recently, that has involved talking to women about their needs and experiences during COVID-19, working alongside them on creative projects around things like self-care, podcasting and anonymous surveys. I’ve been in the violence-against-women sector for a few years, working at Women’s Aid and before that I worked in homelessness, working with young women experiencing homelessness and trauma for a number of years.

Why I am taking part today?

We are all the experts in our own lives and experiences, but women who sell or exchange sex aren’t always given the chance to have their voices heard or listened to by decision makers. I’m passionate about being part of a process where people who don’t always get the chance to participate in the decisions that affect their lives become the focus. I really believe that we should all be working in ways that centre the importance of lived experience rather than services deciding what is best for people.

My role today

I’m here to listen to and support you through this interview/discussion. I hope to provide a safe space where you feel comfortable talking about your experiences in a way that works for you.

Appendix 6: Participant support sheet

You can make an appointment to discuss this with your doctor, or another member of the team, at any point in the future. Or you may wish to contact one of the following organisations:

Organisation, and contact details	**Description and website address**
Breathing Space 0800 83 85 87	A free and confidential helpline for anyone in Scotland who is experiencing low mood or depression. **https://breathingspace.scot/**
Samaritans 116 123 (Jo@samaritans.org)	A confidential emotional support service available 24 hours a day **www.samaritans.org/?nation=scotland**
Scottish Women's Aid 0800 027 1234	Scotland's domestic abuse and forced marriage helpline **https://womensaid.scot/**
Respect 0808 801 0327	Advice and support for men experiencing domestic violence and abuse. **www.respect.uk.net/**
The National Association for People Abused in Childhood 0808 801 0331	A UK-wide charity supporting adults who were abused in childhood. **https://napac.org.uk/**
Parentline Scotland 0800 028 2233	A helpline for anyone caring for or concerned about a child. **www.children1st.org.uk**
Clear Your Head	A Scotland-wide support service with links to mental health supports. **www.clearyourhead.scot**
The Spark 0808 802 2088	A Scotland-wide support service, FREE confidential (Mon-Thu 9-5pm) **www.thespark.org.uk/**
The Muslim Women's Support Centre 0808 801 0301	The Helpline is a listening ear and signposting service for Muslim women across Scotland. **https://mwrc.org.uk/what-we-do/helpline/**

Organisation, and contact details	**Description and website address**
The Scottish Refugee Council 0141 223 7979	A new telephone advice service for people across Scotland looking for advice and information on refugee and asylum issues. **www.scottishrefugeecouncil.org.uk/**
Mental Health Foundation	A variety of resources to support mental health **www.mentalhealth.org.uk/coronavirus**
NHS 24 111	Helpline open 24 hours, 7 days a week. **www.NHS24.scot**
CLiCK 0300 124 5564	Partnership of organisations supporting women[viii] who sell or exchange sex or sexual images on line through live chat, helpline, one to one support and online resources. **www.click.scot**
Rape Crisis Scotland 08088 01 03 02	A national helpline and email support for anyone affected by sexual violence, not matter when or how it happened **www.rapecrisisscotland.org.uk/**

[viii] Support is inclusive of trans women and non-binary people.

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The members of the partnership include:

CLiCK/Encompass Network

Health and Social Care Alliance Scotland (the ALLIANCE)

Homeless Network Scotland

HUG (Action for Mental Health)

iHub, Healthcare Improvement Scotland

Mental Health Foundation

NHS Fife

Public Health Scotland

University of Strathclyde

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