Understanding the lived experience of COVID-19 for **marginalised communities**

Summary report

March 2022

Published by Voluntary Health Scotland on behalf of the Inclusion Health Partnership.

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Acknowledgements

We would like to thank all the participants who gave up their time and expertise for this research. We would also like to thank the community organisations that have supported participation with the research.

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. This 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.[1] This paper is a summary report from the first phase of that research.

The work of the Inclusion Health Partnership sought to apply an intersectional approach[i] 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 has considered cross-cutting issues experienced by different marginalised communities.

The findings and learning from this research will influence the design and delivery of a second phase of the project.. The second phase will seek to engage with a wider reach of participants to test and strengthen the findings from phase one and understand the ongoing impact of the pandemic for marginalised communities.

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 COVID-19 pandemic have not been spread equally.[2,3,4] The persistence of health inequalities, pre-COVID-19, meant that not everyone was enjoying their human right to the highest possible standard of health in Scotland.[5] Restrictions to daily life introduced in March 2020 to control the spread of COVID-19 have had a multitude of adverse effects on people's health and wellbeing, and have made these inequalities in health worse.[2]

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.[6]

1.2. Aim and objectives

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

This lived experience peer research 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. (In other words, 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.

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[i] 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.

2 Methodology

This study was supported by the Community Lived Experience Action Research (CLEAR) partnership,[7] a partnership project between the ALLIANCE,[ii] PHS and Strathclyde University'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.

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.

In February/March 2021, semi-structured interviews were conducted with 12 participants. The interviews were carried out by peer researchers from Homeless Network Scotland, the CLiCK Women Supporting Women project and the University of Strathclyde. The interview schedule can be found in Appendix 2 of the full version of the phase one research report.[1]

The researchers spoke to refugees and asylum seekers, people with experience of homelessness, people with poor mental health, and people selling or 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 to 29 years
- Three participants were aged 40 to 49 years
- Two participants were aged 50 to 59 years
- Three participants were aged 60 to 69 years.

50% of research participants identified as female and 50% identified as male.

67% of participants identified as white Scottish, while the other participants identified as Italian, Pakistani, African and Jordanian.

75% of participants recorded living in a rural area or remote rural setting and the remaining 25% recorded living in an urban city setting.

Researchers spoke to refugees and asylum seekers, people with experience of homelessness, people with poor mental health, and people selling or exchanging sex.

[ii] 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**

3 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 and was further distilled to derive six key themes shown below.

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.

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.

Interviews were transcribed and subsequently analysed by researchers from Voluntary Health Scotland, Homeless Network Scotland and the University of Strathclyde.

4 Discussion and conclusions

This peer research has provided us with a greater understanding of some of the issues faced by marginalised groups during the pandemic and resulting lockdowns.

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 reflect on the need to address cultural and systemic issues.

The six themes are reflected and addressed in the recommendations in the next few pages.

‘In general times outside of COVID-19 I’d like there to be a drop-in centre. Somewhere were 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. I think that’s what’s missing. And it needs to be probably daily, or for a couple of hours every other day, or for four hours so people can come and go and drop in as they feel they need it. And perhaps if it’s decided that they need further individual support, that could be arranged through that.’ [Participant 10]

‘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]

4.1. Human rights and health

Human rights and health has been identified as an overarching theme within this research. The right to health can be described as everyone having access to the highest attainable standard of physical and mental health.[5]

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 concept requires 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 marginalised communities.

> **'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]**

The research highlighted the importance of health and social care standards and the need to ensure these standards are met and understood by service users. 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. It 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.

> **'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... 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]**

Many participants from the marginalised groups involved in the study were not aware of their right to health.

4.2. Impact of the pandemic on mental health and wellbeing

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, while others were anxious about emerging out of lockdown back into society.

The reduction in face-to-face mental health services during lockdown also 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.

> ‘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]

> ‘… 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]

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.

> ‘... when they talk about restrictions easing, I feel anxious because, partly because I’m worried about what’s going to happen... 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]

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.

4.3. Impact of the pandemic on sense of purpose and control

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, 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 impact of 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.

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]

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 can lead 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]

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

4.4. Access to statutory public services

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 from health services and lack 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.

> **'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]**

> **'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]**

> **'I used to have a CPN [Community Psychiatric Nurse], but not any more... 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.' [Participant 10]**

A range of issues were highlighted when accessing statutory services ... poor communication, lack of follow-up from health services and continuity of care.

4.5. Access to community and social support, and social networks

The study highlighted the value of community support and social networks, and highlighted 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.

> **‘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]**

> **‘... 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.’ [Participant 7]**

> **‘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 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 now.’ [Participant 3]**

Those who need support should have access to it in a format they need and when they need it.

4.6. Digital access

Finally, the research highlighted the important role digital technology played in relieving their loneliness and social isolation during lockdown and the pandemic. It enabled individuals to connect with others further away than usual, helping them to create new networks, and this was most helpful to those when usual spaces and opportunities could not be accessed. It suggested the need for a hybrid approach to how services and support are delivered, and could offer people 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.

Participants also highlighted the negative aspects of using digital technology, such as a lack of privacy, or 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.

'... the online group has allowed people to take part that would never be able to meet personally…' [Participant 2]

'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]

There is a need to consider those who find it difficult to access digital platforms and ensure all forms of digital exclusion are addressed.

5 Summary recommendations

This 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.

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

More detail on the recommendations can be found in the full version of the phase one research report.[1]

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.

More detail on the recommendations can be found in the full phase one report at https://vhscotland.org.uk/understanding-the-lived-experience-of-covid-19-for-marginalised-communities

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 Availability, Accessibility, Acceptability and Quality (AAAQ) framework and the Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality (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 organisations in decisions about the allocation of resources.

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. A suite of research tools was developed to ensure that participants had access to as much information about the research as possible.[1] This way they could fully engage with the process in an informed manner. 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 research.

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 there is a choice of which platforms to use and offer support for translation and interpretation.
6. Build a genuine rapport with your participant. Ensure 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 you can support all learning styles and that support paperwork can be accessed both online and in paper form.

7 Recommendations for phase two and further research

People from marginalised communities are not a homogeneous group. Careful consideration should be given to the development of communication, participation and support materials, resources and methodologies for phase two of this research, to enable as wide a group of people 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 research highlights the need for more time and consideration of this issue.

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