Pandemic ethics: a public dialogue

The ethical and societal considerations of Covid-19, Covid-19 recovery and future pandemics



Hopkins Van Mil September 2021





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Foreword

We are delighted to introduce this report of a public dialogue exploring the ethical and societal issues in relation to Covid-19. The dialogue is part of a programme of research and engagement being conducted by the UK Pandemic Ethics Accelerator.

We are all living through and grappling with the enormous challenges and concerns that Covid-19 has brought. The questions we need to ask about our society, our experience of and response to the pandemic, and what our future should be like, require deep reflection and wide deliberation. The matters raised are of intense personal and public interest; broadening the debate can only enhance the policy process as it continues to seek solutions to help us through and out of the pandemic.

The UK Pandemic Ethics Accelerator brings together ethics research expertise to identify and address these challenges and to support decision-makers. Public debate is a key part of that process and deliberative dialogue, in particular, can help shape recommendations and encourage a collective responsibility. The wide expertise of a range of citizens, and an exploration of their views and values can greatly enhance our understanding of the impact of the Covid-19 pandemic. This was borne out in the dialogue described in this report, which will unquestionably help the Ethics Accelerator in its work. We also hope that it will find traction with those empowered to make key decisions on behalf of all of us.

It has been a pleasure to partner with Hopkins Van Mil in planning and delivering the public dialogue reported here and we are very grateful for the opportunity to observe and contribute to some of them.

We'd especially like to thank all dialogue participants: you have discussed and debated respectfully and insightfully, identifying key issue of continuing concern and suggesting ways forward for society as a whole as we continue to live, work and care through the COVID-19 global pandemic. You have directly demonstrated the value of public involvement in public policy matters and this will guide the Pandemic Ethics Accelerator's future work and policy engagement.



Sarah Cunningham-BurleyProfessor of Medical and Family
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Hugh WhitallProject Lead, UK Pandemic Ethics
Accelerator

Executive Summary

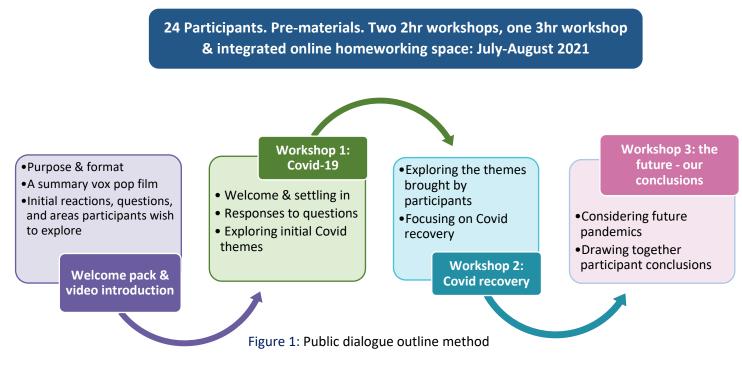
The public dialogue on ethical concerns relating to Covid-19, Covid-19 recovery and future pandemics was commissioned by the Nuffield Council on Bioethics working with colleagues at the University of Edinburgh on behalf of the UK Pandemic Ethics Accelerator ('the Accelerator') which is funded by UK Research and Innovation (UKRI).

1. Dialogue aim

The aim of the dialogue was to engage members of the public in a deliberative dialogue to identify and explore the priority issues of public interest raised by Covid-19, Covid-19 recovery, and future pandemics to inform the work of the Accelerator. It was also expected to have value to policy and further research beyond the work of the Accelerator.

2. Dialogue process

The dialogue was designed and delivered in July and August 2021 by the deliberative engagement specialists Hopkins Van Mil. It comprised introductory materials, three online workshops and an online homework space for participants to contribute their views outside the workshop setting. The method framework is summarised in figure 1.



3. Key findings

This dialogue has revealed important ethical and social considerations for the Accelerator and wider policy stakeholders to consider. Findings reflect a balance between participant led and researcher analysis and are drawn from a robust qualitative process typical of public dialogue. The dialogue has enabled the voices of participants to shine through on issues of significance. The key findings are:

- How to heal the social divisions and re-balance the inequalities that Covid-19 has exposed and exacerbated. This includes:
 - Ensuring everyone in society, particularly the most vulnerable and disadvantaged, have access to the core things that everyone needs: from food and clothing to education, healthcare, and reasonable autonomy
 - A fundamental re-think around poverty which has become extreme and intolerable.
 This might include consideration for retaining elements of the furlough scheme, the uplift in Universal Credit and for a Universal Basic Income
 - Addressing disparities in healthcare, particularly for those from Black, Asian and minority ethnic communities
 - Finding ways to ensure that individual and collective concerns are not in conflict.
 Fairness, kindness, empathy, respect, solidarity and tolerance are key characteristics of the society participants want to live in.
- Work hard to build trust and transparency into government policies and actions, with greater
 collaboration across the home nations to provide consistent and clear messaging and
 communications for citizens across the UK. This includes sharing trusted evidence and
 information, addressing perceived hypocrisies and countering negative media reporting and
 misinformation shared through social media channels.
- Meaningful public involvement should be built into policy making to create a society which is
 resilient in the face of future pandemics. This includes deliberative processes such as public
 dialogues, Citizens' Assemblies and Juries beginning at a local level and fanning into national
 level discussions, shaping future policies, decisions and actions.
- Further research is recommended by participants to:
 - Understand who has shouldered the pandemic burden and how to re-balance societal inequality
 - Capture the stories and experiences of 'the forgotten people' who will be left behind if they continue to be ignored
 - Bring clarity to how decisions have been made during the pandemic at a community, regional and national level to understand what has been effective
 - Show the impacts Long Covid has had on people's lives to identify support and treatments to minimise those impacts
 - Compare country responses to the pandemic around the globe and use the information to prepare for future pandemics
 - Study the ethics of trust: who is more or less trusted, what constitutes trusted behaviour, what would a transparent government be doing in a pandemic?

1. Introduction

The public dialogue on ethical concerns relating to Covid-19, Covid-19 recovery and future pandemics was commissioned in June 2021 by the Nuffield Council on Bioethics and the University of Edinburgh on behalf of the UK Pandemic Ethics Accelerator ('the Accelerator')¹. It was designed as a rapid online dialogue engaging a small number of participants to inform the ongoing work of the Accelerator, potential engagement with stakeholder groups, including future engagement with the public, and to test views on future research on the ethical dimensions of Covid-19. The work was managed by a Project Team drawn from the dialogue partners.

1.1 Public dialogue partners

The UK Pandemic Ethics Accelerator is a new initiative that brings UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during pandemics and their aftermath. As well as providing rapid evidence, guidance and critical analysis to decision-makers across science, medicine, government and public health, it also supports public debate on key ethical challenges.



The Accelerator is funded by the Arts and Humanities Research Council as part of UKRI's Covid-19 funding. It is a collaboration between the universities of Oxford, Bristol, Edinburgh and University College London and the Nuffield Council on Bioethics (NCoB), each of which leads or collaborates on a series of workstreams.



The Accelerator's *Public values, transparency and governance workstream* is led by NCoB and the University of Edinburgh. It is conducting a rapid synthesis of public and stakeholder values and attitudes, including this public dialogue. As a result it will develop approaches to the integration of these values with policy solutions, to promote solidarity and trust in governance systems at a time when individuals' and societies' core interests and values, including health, well-being, equity, social justice and liberty are at stake.

Hopkins Van Mil (HVM) facilitates engagement so that voices are heard, learning is shared and understanding achieved. In practice this means finding the process by which people can explore their hopes, fears, challenges and aspirations for the future. HVM's work enables stakeholders, technical specialists and a diversity of publics to work together as equals to make actionable, better informed, and powerful decisions.



Where stories, ideas & views matter www.hopkinsvanmil.co.uk

¹ ukpandemicethics.org/

1.2 Public engagement in a pandemic

The public dialogue fieldwork began in July and concluded in August 2021. Our discussions with dialogue participants began at a time when Covid-19 restriction measures were easing. By including time defined considerations (see chapter 3) we were able to ensure that participants did not only focus on the ethical implications of 'Freedom Day' but could also look back to the early indications of the virus and initial national lockdowns, and forward to potential future pandemics.

Policy makers during the pandemic have engaged the public most frequently through opinion polls² and surveys³ conducted to measure citizens' beliefs about covid, to test compliance with social distancing requirements and to understand potential take-up of vaccinations. Some deliberative engagement⁴ has taken place to inform policy and practice around specific aspects of Covid-19, such as the use of online technologies or people's views on planning for winter in a pandemic.

This public dialogue is the first explicitly focused on people's ethical considerations in relation to Covid-19, Covid recovery and future pandemics. As such it gave space for dialogue participants to explore dilemmas such as societal priorities for treatment and care; issues around civil liberties including when some in society are clinically vulnerable and shielding; the complex trade-offs when society is trying to limit the number of deaths in the pandemic; the ethical dimensions of restrictions and vaccinations – to name a few. As pandemic restrictions lift inter-generational justice is a key issue as well as equalities, equity and who shoulders the burden for the policies implemented during the pandemic. Issues of governance, transparency and fairness come to the fore. We describe participants' views in this report.

1.3 Dialogue objectives

The objectives of the dialogue were established by the Accelerator to:

- Provide an opportunity for citizens to discuss their views about the social and ethical issues around Covid-19, Covid recovery and future pandemics, according to the considerations they think are most significant
- Identify priority areas of interest and concern to shape further work
- Understand the ethical values and principles that underlie dialogue participants' views
- Produce a report suitable for sharing that will help inform current and future research enquiry and policy debates.

This participant-led approach is distinctive. It created a process design which was framed around the ethical topics raised by participants based on their concerns, hopes and key considerations.

1.4 What is public dialogue?

Before describing the dialogue process in detail, it is worth reflecting why a public dialogue approach was appropriate for a wide-ranging subject such as Covid-19 and future pandemics.

² E.g. Ipsos MORI's <u>public and sectoral polls</u> since March 2020

³ E.g. YouGov's tracker reports

⁴ Including Ipsos Mori/ Academic of Medical Sciences Winter 2020/21 under Covid-19 (July 2021); Traverse, the Ada Lovelace Institute and Bang the Table Rapid On-line Deliberation on Covid-19 Technologies (May and June 2020)

Public dialogue is not a 'we tell you this and you tell us what you think about it' information exchange. It is not a public understanding initiative, nor does it set out to test what people do and do not know about a subject.

Dialogue works when participants interact on a level playing field with specialists: academics, ethicists, those that inform, challenge and make policy, and those with lived experience of the issue under discussion. This specialist evidence is then viewed through the lens of participants' own lived experience, acting as a provocation which leads to rich and powerful insights.

In public dialogue citizens come together, with sufficient time to reflect, to:

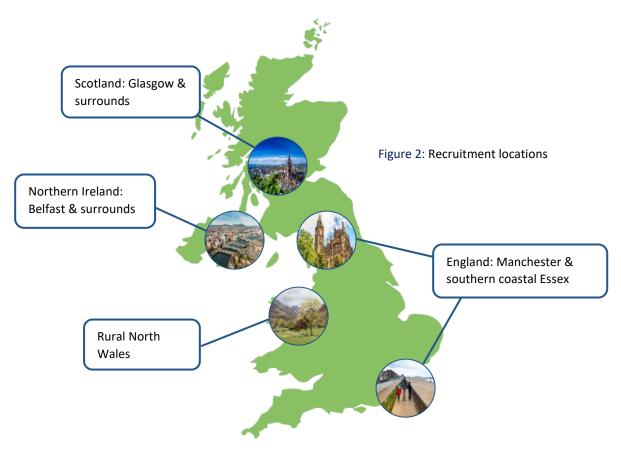
- Learn about the issues
- Talk with, not past, each other
- Consider diverse points of view
- Discover key tensions and values
- Spark new ideas

This process leads to a depth understanding of what people value, what they are concerned about, their priorities and the principles they apply to this prioritisation. HVM facilitators are key to gaining this understanding. They ensure there is a balance in small group discussions which allows people freedom to express their views whilst not allowing the process to lose the important focus on the dialogue scope or for the exercise to be derailed. This report sets out the findings that have emerged from this public dialogue process. Recruiting a diverse group of people to the dialogue ensures we hear, and participants respond to, a diversity of views. How we did this is set out below.

1.5 Recruiting public dialogue participants

This was a small-scale public dialogue with twenty-four people from across the UK invited to take part. Participants were recruited from a range of different locations: urban, suburban, rural and coastal. A specification and screener were used to ensure that despite limited numbers the group broadly reflected a diverse group of the UK population. As such we sampled for gender and life stage and created a boosted sample to ensure that people disproportionally affected by Covid-19 including those from lower socioeconomic groups, black and minority ethnic communities and people with disabilities were over-represented in the sample.

Our preferred approach to recruitment, given ongoing Covid-19 restrictions at the time, was working with a network of local recruiters with links into community groups. A panel approach was used to top up the community approach where necessary. To gain a sample from across the UK we focused on locations where communities have been affected by successive lockdown restrictions. The locations we drew from are set out in figure 2 including each of the home nations.



To ensure we achieved a range of perspectives on Covid-19 we asked participants 'How worried or unworried are you about the effect that the Coronavirus (Covid-19) pandemic is having on your life right now?' ⁵. We checked with all participants in advance of the first workshop to ensure that they were not prevented from taking part due to lack of equipment or broadband. All participants were offered the opportunity of joining a 'tech-support' session before the first workshop to show them the main elements of the online tools we were using: Zoom, Mentimeter and Recollective⁶. Six out of twenty-four participants took part in this session.

1.6 What did participants do?

Covid-19 has affected everyone in society. We all have views on what the impacts have been and what the ethical and societal implications are and might be in the future. Providing evidence and information to participants to enable them to think within, and then beyond their own experience, was essential to a process design which would be rapidly created and delivered. Giving people space to think about the evidence during and in between workshops was also key to our design.

The final dialogue design took the form of three online workshops together with a homework space in which participants could comment, review and respond to stimulus, ask questions and make further contributions to the dialogue in their own time. Before attending the workshops, participants were emailed a participant pack containing practical information and guidance to support participation in the dialogue. They were given links to the online homework space and asked to tell us which topics on Covid-19, Covid-recovery and future pandemics they would like to

⁵ Mirroring the question asked in the ONS survey: <u>Coronavirus and the social impacts on Great Britain</u>.

⁶ We used <u>Zoom.com</u> for the online workshops, <u>Mentimeter</u> as an in-workshop polling tool and <u>Recollective</u> as the online space for homework activities.

discuss in the workshops. These were used in our initial and mid-point discussions and informed the stimulus material provided during the dialogue.

With participants' wellbeing central to the research, we also used the pack to:

- Share contact information for their dedicated facilitator and explained that they could be contacted at any time during the process
- Provide a sheet of organisations to contact if any of the discussions proved troubling
- Explain that they did not need to share personal experiences of the pandemic if they didn't wish to, talking about societal impacts more broadly would be just as valuable
- Emphasise, in line with all social research projects, that they were free to withdraw from the research at any time.

Table 1 sets out the stimulus materials used in advance of and during each workshop.

Workshop 1: Covid-19

Pre-workshop:

- Film An introduction to the dialogue: Henrietta Hopkins, HVM; Sarah Cunningham-Burley and Hugh Whittall UK Pandemic Ethics Accelerator
- Film A Covid-19 press round up: Shaun Griffin, UK Pandemic Ethics Accelerator During the workshop:
- Presentation An overview of an ethical question and review of the ethical dimensions of topics raised by participants, Sarah Chan, UK Pandemic Ethics Accelerator
- Film A parliamentarian's perspective: Lord Hunt of King's Heath
- Film An ethical adviser's perspective: Julian Sheather

Workshop 2: Covid-19 recovery

Pre-workshop:

- OECD (2021), Risks that matter: The long reach of Covid-19
 - Data on employment⁷
 - Risks that matter film and evidence⁸
- Information on personal responsibility/ track & trace (England), trace & protect (Scotland) test, trace, protect (Wales), contact tracing service (Northern Ireland)
- Links to research: young people's anxiety levels double during lockdown⁹, University of Edinburgh
- Film Public health considerations, Margaret Douglas, Hon. Consultant in Public Health for Public Health Scotland

During the workshop:

- Presentation an overview of the potential ethical considerations of Covid-19 recovery and a review of the ethical dimensions of topics raised by participants, Jamie Webb, UK Pandemic Ethics Accelerator
- Presentation A reflection on what Covid-19 has exposed in terms of social and health inequalities and what this might mean for Covid-19 recovery, Gurch Randhawa, Professor of Diversity in Public Health and Director of the Institute for Health Research at the University of Bedfordshire
- Film lived experience of Long Covid

⁷ https://www.oecd.org/employment-outlook/

⁸ https://www.oecd.org/social/risks-that-matter.htm

https://www.ed.ac.uk/generation-scotland/what-have-we-found/latest-news/young-people-anxiety

Workshop 3: Future pandemics

Pre-workshop:

- Film reflections on the impacts of Covid-19 on education, Sir Kevan Collins, Chief Executive, Education Endowment Foundation, visiting professor at the UCL Institute of Education
- Film the ethical dimensions of public health, Margaret Douglas, Honorary Consultant in Public Health for Public Health Scotland

During the workshop:

- Presentation An overview of what the ethical considerations of future pandemics might be and reflections on the ethical and social dimensions of thinking about future pandemics, Sarah Cunningham Burley, UK Pandemic Ethics Accelerator
- Final reflections Sarah Chan, Sarah Cunningham-Burley and Ilona Singh, UK Pandemic Ethics Accelerator.

Table 1: Dialogue stimulus materials

The process plans used to frame discussions are set out at Appendix 1.

1.7 Analysis and reporting

The online dialogue workshops generated twenty-four hours of audio recordings. These were transcribed and analysed using NVivo software together with:

- data from the reflective tasks that participants completed in between each workshop
- results of the online polling questions used live during workshops.

HVM applies grounded theory to our analysis of public dialogue deliberations. We build theories from what we have heard rather than having a preconceived hypothesis to test. We make use of Sciencewise Guidelines for Reporting (July 2019) and the evaluation of previous public dialogues to inform our work. Throughout the process the HVM coding, analysis and writing team have maintained a rigorous approach and held frequent sense-checking sessions to mitigate against researcher bias.

1.8 About this report

Our reporting includes summaries of the analytical work participants did during the process combined with researcher analysis resulting from a comprehensive review of the dialogue data. We make the difference clear throughout the report.

Public dialogue is a qualitative methodology, findings do not demonstrate statistically representative analysis, nor can they be said to represent the views of a wider population. By asking open questions and following lines of enquiry suggested by participants we gain an understanding of the subtleties and nuances of participants' views, concerns, hopes and aspirations so that they can inform next steps. Given the broad scope of the dialogue, led by the topics raised by participants, those next steps are likely to include more public dialogue and engagement on focused topics as well informing the work of the UK Pandemic Ethics Accelerator and future research and policy decisions.

We use terms such as 'a few', 'many', 'several' or 'some' to reflect areas of agreement and difference. These should be considered indicative rather than exact. It is important in any dialogue process that the report reflects the voices of participants. Throughout this report we have used quotations from those who took part in the dialogue, drawn from the transcripts, to illustrate the analytical points being made and to emphasise main points. Some quotes have been edited to remove repeat or filler words. There have been no other edits which might distort the meaning intended by participants. In conducting the analysis and reporting on the findings HVM researchers have made judgements about which quotations to include. These judgements are based on a respect for what participants shared and the seriousness with which they took their role in the dialogue. Quotation selection also was made in relation to what best reflects the key themes raised, including a diversity of voices, and highlighting the key points from a participant and researcher led analysis.

The following chapters set out the report findings. We begin with topics raised by participants before embarking on the dialogue. The time defined considerations follow, setting out and reflecting on what participants have observed during the pandemic, their thoughts on Covid recovery, and considerations in relation to future pandemics. The report concludes with an analysis of the thinking behind participant deliberations, summaries of next steps and final considerations.

2. Topics raised by participants

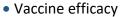
Before attending the first workshop, and again between workshop one and two, participants were asked to share the topics that they wanted to raise during the dialogue discussions in relation to:

- Covid-19: up to present day
- The Covid-19 recovery
- Future pandemics

Participants were asked to share their own topics, to help guide the dialogue and ensure that the process addressed the issues about Covid-19 that participants thought are of concern or interest.

Participants raised a variety of significant topics related to Covid-19, demonstrating an eagerness to engage and share their views on these issues. The most frequently raised topics were the vaccine roll out, government and public policy and the impact of Covid-19 on divisions in society. Table 2 outlines the topics that were raised and describes the range of areas that participants wanted to explore during the dialogue. The quotations reflect some participants' views at an early stage in the dialogue process.

The vaccine roll-out







- The use of vaccine passports
- Mandatory vaccinations for some professions
- Implications for those who cannot have the vaccine
- The decision not to get the vaccine
- Booster vaccinations
- Vaccines for children
- Misinformation/ misunderstanding around vaccines

Are Covid (passports) ethical within the UK? Over 70% of the population has had both vaccinations, so why would any business or event in the UK require proof?

Government and public policy



- Tendering of PPE contracts and secrecy surrounding procurement contracts
- Government reaction to the pandemic: was it fast enough, was enough done to prevent the spread of the virus?
- Support for unpaid carers
- The use of the track and trace app
- Implications of removing the £20 uplift to Universal Credit
- Societies trust in government: how has it changed since the start of the pandemic; Government control of society and societies acceptance of restrictions
- Linking Covid-19 to Government health priorities on diet
- Perceived move towards totalitarianism
- Public involvement in decision-making

I am concerned about the erosion of autonomy and how easily it seems that society complied with government requests. Has 'trust' now been eroded? If a similar situation occurs again, would society be so quick to comply?

Social divisions



- Increasing societal divides caused by the pandemic
- Social divisions caused by vaccination status and whether people agree with/ have trust in the vaccine
- Discrimination and xenophobia e.g., in relation to an initial tendency to refer to the 'Indian strain', now spoken of as the Delta variant
- Divisions between countries who have taken different approaches
- How to demonstrate respect for others

Now, when all the people are divided in two fighting parties of vaccinated and unvaccinated, we will never get to that point when humanity is united, when people trust, help and care about each other.

Mental health



- Effects of the pandemic on mental health
- The impact of restrictions
- Whether mental health was a consideration when imposing restrictions
- The impact of lockdown on older people: isolation
- The impact of lockdown on young people: educational and socialisation impacts
- Possibility for reform of mental health services
- The implications of the recovery on mental health

Was the impact on mental health taken seriously? Especially for the elderly being left alone for months with many having no access to the internet.

Easing of restrictions and returning to 'normal'



- Are restrictions being eased at the right time?
- Has the government taken the right approach?
- Easing of restrictions and the influx of track and trace notifications: how will businesses manage?
- Will some measures continue e.g., face masks?
- Evidence on the effectiveness of face masks
- How will society return to 'normal'?
- Living with Covid-19 in the future: what will the new 'normal' look like
- Long-term impact on how people will interact
- Preparing for future pandemics

How will society move forward living with the virus? Many services/businesses struggling due to people being 'pinged' therefore isolating. If the need to isolate is removed, will this increase the spread?

The economy and employment issues



- Rising cost of living
- Cost of paying for the pandemic: healthcare spending; impact on future generations
- Furlough scheme: was this the best option for all?
- Working from home: will this remain post-Covid?
- Support for the clinically vulnerable in returning to work
- Pay rises for key workers

Would having a
Universal Basic income
introduced at the start
of lockdown been a
better option than the
furlough scheme which
left so many people
destitute and uncared
for by Government.

Long Covid



- Effects of long Covid and recovery
- Understanding the long-term implications
- Mental health impacts
- Managing the effects of long Covid

Media reporting and social media



- Spread of misinformation around the virus and vaccination
- Impact on mental health and vaccination take-up
- Impact on trust in Government and public policy
- 'Cover-up' stories in the media coinciding with reports on track and trace failures
- Social media as a tool to spread information

Table 2: Topics raised by participants

My wife has only just returned to work after 9 months due to long Covid. I'd like a key focus to be on long Covid as no one seems to know what the lasting implications could be.

The negative media reporting about vaccinations and the side effects surrounding them which is causing lots of anxiety and stress around whether to get vaccinated.

3. Time defined considerations

The framework for participants' discussions during the public dialogue included three time and theme defined areas:

- Covid-19: the past 16 months (March 2020 July 2021)
- Covid-19 Recovery: July 2021 and moving forward and
- Planning for Future Pandemics

This chapter draws together participants' experiences of the pandemic up to the summer of 2021, and the many questions and reflections prompted by their discussions and the contributions of the specialist speakers. It goes on to explore thoughts on how to move towards some form of normality and concludes with views on how to prepare for any future pandemics, which were widely seen as 'when' rather than 'if' events.

3.1 Covid-19: the past 16 months

3.1.1 Doubts about the efficacy of some government actions

Living through a pandemic is unchartered territory for everyone in the UK. Looking back from the vantage point of July 2021 over the landscape of the past 16 months, there were key actions and policies that participants thought

United States of State of States of

Figure 3: Workshop 1 menti responses to the question 'Use one word to describe this year of COVID-19'

needed to be better understood in terms of their social and ethical implications. The topics below highlight these actions and policies.

Some participants thought that from the start of the pandemic, through to present day, the UK government was taking the approach of asking the public to blindly obey, without giving a clear rationale for what had informed decisions. They mimicked the government by saying, 'just follow what we're saying don't look at what we're doing, and we'll manage you through okay.' In contrast, a few participants described the pandemic situation in terms of 'there's no book for it' and governments around the world were learning on the job.

Treatment of older & vulnerable people: Returning to care homes & Do Not Resuscitate (DNR) orders

Participants had deep concerns about how the needs and interests of older and vulnerable people were being considered at the start of the pandemic. There was widespread bafflement about why hospital patients were transferred back into their care homes. Participants wanted to know what other options were considered and if the consequences of those options were fully explored: they feared that they hadn't been and were concerned that in the tumult at the start of the pandemic, critical decisions were being made in a knee jerk way.

Similarly, concerns were expressed about DNR orders being placed on patients' files without their/their family's knowledge. Participants' impression was that the need for intensive care unit beds was so urgent, that this was seen as a necessary step to clear space for patients who may have a greater chance of recovery. Again, participants wanted to understand how this DNR decision had been made and were worried about how they might be brought back in if pressure on health services increased again.

There were some patients who had multiple conditions that decisions were taken to do not resuscitate and there was a bit of debate around that from disability organisations and things at that point. I don't know if that still stands or if that is something that now there is more capacity that it's no longer in place.

Herd immunity

The term herd immunity became commonplace during the early phases of the Covid-19 pandemic. Some participants thought that as a concept it had been raised up the policy flagpole and swiftly brought back down when it was widely attacked. However, they felt the concept should be better understood in the context of Covid for how it could or could not be used given the nature of the virus. There was a sense that the concept was still floating as an option without being fully understood and evaluated and the findings shared with the population.

In the case of the mutating virus, herd immunity is not going to stand still. It doesn't with flu. We don't acquire herd immunity from flu even though we have all had it. So, I think we first need to understand whether it could be a persistent immunity or whether we would have to keep chasing it...I think we just need to know more about herd immunity before we can say that's a state that we want to get to or that we can try to achieve in one way.

Lockdown: conflicting opinions in government

One participant observed that the term lockdown, before the pandemic, was reserved for a prison situation. Several participants raised their concern that politicians were at odds on the efficacy of lockdowns, with some wanting to break the country free of their home-based shackles. While the stay at home message was widely supported and understood at the start of the pandemic, internal wrangling within government has led dialogue participants to think that public opinion has shifted to being more uncertain and potentially less likely to comply with any future lockdowns.

I recently watched that interview with Dominic Cummings when apparently Boris Johnson himself said to him lockdowns don't work. This is something nobody really seems to agree whether they work or don't work, and to what extent.

Vaccine roll-out and efficacy

Deciding who would be where in the queue to get the vaccine: some participants wanted to understand if and how economic, ethical, social and wider health factors had been included and excluded in the decision-making process. Participants understood the intention of first protecting those who were most clinically vulnerable, but some felt it was important for the public to know if other factors were considered and, if so, what conclusions were drawn from this consideration.

Economically would it not have been a better decision to put the people between 30 and maybe 50 that are at work and still bringing economy back into the country, I don't know. How was it decided that it should be the old and vulnerable rather than younger people that are working and keeping the country afloat?

As the vaccine roll out has continued and evidence of vaccine efficacy has expanded and been shared, some participants felt that efficacy promises have been overstated. They are concerned that vaccines had been presented as a kind of all protecting shield and that was not in fact the case. They knew that you could still catch Covid-19 and you could still pass it on even if double-vaccinated. Those with a chronic health condition or disability felt they should have received more realistic information from the start to make better decisions about their actions and choices.

What they didn't tell us at the time was that the injections are not guaranteed that you won't catch Covid again. For somebody like myself or anybody who has respiratory problems... although we've had both Covid injections, if we catch Covid we could still pass away, unfortunately. You could become that ill that you would need to be hospitalised again. So, I kind of don't understand, again it's about the information is not there. People deserve to know the information beforehand, rather than have the information after the event.

Mandatory vaccination

During the period of this public dialogue, there was considerable media coverage about government plans to make it mandatory for care home workers to be vaccinated. For some participants, mandatory vaccination was put in the context of other health requirements, such as travel related vaccines. They felt that making vaccines mandatory for people who choose to travel or choose to work in a specific sector is acceptable because it is their choice to travel or to work in a particular sector and if they were strongly opposed to being vaccinated, they could choose not to travel, or could change their job.

With regards to mandating the use of vaccines, pre-Covid if people were travelling abroad to certain countries, they had to have specific jabs in order to travel. People accepted this without question...If a vaccine is required to do the job safely then surely if people don't want the vaccine they will apply to another job.

But for other participants, the concept of people losing their jobs if they did not agree to be vaccinated was disturbing in terms of people's right to choose. When discussing this, participants also raised the point about vaccine efficacy – that if the vaccines don't fully prevent infection or spread, then why make them mandatory. Some thought the mandatory messaging from government was a somewhat manipulative tactic as part of its wider approach to increasing vaccine uptake.

Just watching one of them videos where you were saying about making carers compulsory to have the vaccination. With the vaccination, it doesn't stop you from getting it and it doesn't really stop you from passing it on anyway. So, I feel there should be a bit more information about the vaccine that's true. Do

you know what I mean? I'm finding that the government are manipulating it a little bit so more people will get the vaccination.

Freedom Day?

July 19th, the day when most legal restrictions on social distancing were lifted in England, was greeted with a question mark by most participants. Many thought it had come too soon and believed it could trigger another surge in the autumn and winter. Those who were clinically vulnerable felt that their lives would become more restricted, just as life for others was opening up.

For the people who are getting their Freedom Day, those who are immunocompromised are having the little bit of freedom that they had removed. So, we're going to now have to retreat again from society and take steps back. So, we're getting more curtailed as people are able to more freely move about.

Other participants were struck by the way in which freedoms could be curtailed again if proof of vaccination became mandatory for hospitality venues in the autumn. They also feared that this could lead to those who were unable to be vaccinated for medical reasons being shut out of socialising out of home and so creating societal inequities.

There's Freedom Day happening on Monday, and I have read that they are going to start making people get double jabbed before they can enter into a pub or a bar or things like that. I'm just finding it quite contradictory as how people are allowed to go to places now and then in September you're going to say, 'No, you can't go into places without getting the vaccine.' Doesn't that show that they should have waited for the Freedom Day till enough people were vaccinated and then put that law in place, I'm just finding it very weird.

There's no book for it... the country has done ok

During the discussions on what had happened in the past 16 months, a few participants shared their view that the government and health systems had done their best in an unprecedented, uncertain and fast-moving situation. Some felt that for a significant part of society, they had been protected from severely negative impacts, but they also recognised that there were also large numbers of people who had or would face difficulties.

To use a phrase, every government around the world is learning on the job, yes of course mistakes have been made, everybody can identify that. But, let's be honest, things have gone relatively well. They've done what they can, as quickly as they can, we hope. Death rate has been kept reasonably low, percentage wise. Our healthcare system is bent, but not buckled.

How the hell do you make decisions that are black and white on a very grey area? And people are trying their damnedest, I think, to do the best in the moment. And then the moment changes the next moment and then that moment where they'd made that decision is now wrong and then they're lambasted for it.

3.1.2 Balancing individual and community needs

When asked to share one impact of COVID-19 on their lives, most participants talked about separation from or the loss of loved ones. Participants were acutely aware of the physical need to be distant from those outside their households but also of the emotional cost, in the form of isolation and fear.

Some participants highlighted how older people, those with mental health problems and children and young people were the most likely to experience isolation and fear. Participants talked of older people cut off from their families and friends; children exposed to relentless coverage of the pandemic but not having the life experience that could help them to cope, and vulnerable people separated from their support networks.

I work in retail, so they would occasionally come into the shop, and they'd drive there and they were terrified to be out. Some of them hadn't been out in months and months. They were completely alone, it was really heart-breaking, and they'd stand there and talk to me for an hour because they were so lonely.

Being really fearful because, especially with my children, you couldn't protect them because it was everywhere. It was in the newspapers, it was on the news all the time.

One of my close friends who was in our group suddenly quit, it's very sad but he tried to take his life. Luckily he was resuscitated. It was pretty much as a result of the frustrations of being alone and trying to cope with the mental challenges of juggling and separation from friends and family who are on another continent.

I go to University and throughout my course, it's all been online, and I've not really had any lessons that you have to go in. So, being at home every day, it's been a different life. So, you're still adapting to it but it's different and it's negatively impacting.

The need for separation, but also its cost, were understood. But it raised questions for how society could, in the future, achieve the protection needed but reduce the depletion of people's emotional wellbeing and financial strain. Participants felt these individual and community needs could be reconciled if time and effort were given to discuss them.

I think the discussion between individual freedoms or individual choices and choices that are for the community don't have to be in conflict.

3.1.3 Fear of where government restrictions might take us

That government could intervene so dramatically in what we can do and who we can see led a small number of participants to talk about feeling scared about the future. Some participants, particularly those who had spent some of their lives in Eastern European countries, drew comparisons with their lives there and the extent of government intervention. They felt that a country such as the UK may see itself as liberal, but that the government may have tilted towards more draconian policies and behaviours that it might choose to continue if it served its purpose, such as moderating messaging on social media platforms.

Participant: I am more concerned about what's going on, all these bans on different opinions on Facebook and everywhere where you go on social media, as soon as you say something what all of people don't agree, you have been banned straight away. So you're not allowed actually to say anything against government, anything against Covid, government is just making us all scared and to follow rules, and as soon as you have different opinions, they just either delete you or you are just out of Facebook.

Facilitator: What question does that put in your head?

Participant: That makes me straight away think, I mean if you're not allowed for a different opinion, are we living actually in a democratic society? What is this?

3.1.4 UK Nations: better working together or doing their own thing?

Looking back across the last 16 months, many participants shared their observations on the different approaches of the four UK nations. Some characterised the different approaches as wasting effort and causing confusion at a time of national emergency, particularly when a key message was, 'We're all in this together'. Some participants compared the pandemic to being on a war footing and thought a more collaborative approach should have been taken.

It's not all about politics, it's about people's health, it's about people's safety, it's about our economy, and if we all work together then surely that's going to make things a lot easier and a lot better for us as a country.

Participants shared specific examples of where they felt different government policies were undermining the ability of the UK to protect itself, such as travel policies.

In the school where I work we've got lots of Asian children, from Pakistan mainly, and when they closed the border in Scotland, basically there were no flights into Scotland from anywhere, but you could still fly in from England. So, we had a lot of our parents and our families who came via England to Scotland and didn't have to quarantine, so you think, 'What's the point, really?' So, if we all did the same thing all together then it would make more sense rather than weaker areas to get around it.

But other participants saw each nation making its own decision as vitally important to tailoring government measures to their specific needs.

3.1.5 Hypocrisy

Some participants felt very strongly that government actions and decisions over the past 16 months were not informed by a consistent set of values or principles. Just as they were angered by political figures' behaviour, they were also angered by what they saw as espousing efforts to protect the NHS, but then failing deliver on this with its NHS pay rise announcements. Similar frustration was also expressed with the shift from science-based to economic-based decision making.

It comes from saying that we needed to lockdown to protect the NHS, which I 100% agree with, but then absolutely screwing over the NHS by underfunding and not giving the nurses the pay rises that they deserved. Then it came from

hypocrisy to do with...having a completely science-based decision-making process all the way along and then obviously going straight onto an economical decision-making process out of nowhere.

3.2 COVID Recovery: now and moving forward

In the second workshop, participants turned their attention to looking forward towards the concept of 'Covid Recovery'. If recovery meant returning to life as it was before the pandemic, most participants did not think this was possible, finding it a 'mysterious' or at best 'amorphous' ambition. The scale and impact of the pandemic and the likelihood of future pandemics makes it an imperative to reset how we live. This section starts with considerations on how the country might move towards normality and goes on to explore what participants believe might need to be done, in terms of dealing with the health backlog, employment, education and community involvement.

3.2.1 Creating the conditions for a new normality

There was a widespread belief among participants that the world has been changed forever by the pandemic.

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Figure 4: Workshop 2 menti responses to the question 'What comes to mind when I say Covid-recovery?

There's never going to be a normal again, is there? We've got to adapt, haven't we?

This led to a strong sense of uncertainty about how the country would find its way back to some

form of normality and what that normality would look like. Some participants looked back at how most of the population complied with lockdown restrictions and thought this was driven by a clear goal to flatten the curve of hospitalisations and protect the NHS. Some were concerned that once people have got used to freedom in their social lives, any future restrictions would be seen as a backwards step and government would face more resistance. Participants thought it was important that a clear goal and transparent rationale were essential to guiding the route towards a future normality.

If you are clear, if the government is clear, then hopefully people will understand why certain guidelines have to be in place going forward. And that would be the hope at least, that the transparency would lead to people understanding how ... if we have to sacrifice a little bit of personal freedom, then well and good.

What normal will be will differ for different people, participants stressed. Particularly for those who are clinically vulnerable and those who live with them. Many participants thought that the choices of those who continue with measures such as mask wearing should be supported, otherwise they risk being shunned or even victimised as outliers.

She kept her mask on because her dad is in that position where it's better to stay away from risks and he was one of them that was told to stay at home and avoid going out unless you really have to. All the kids in school used to say to her, 'Why don't you show us your face, is there something wrong with you'.

Some participants were struck by an observation by one of the specialist presenters about how the country might move from making decisions based on science, towards decisions that are more focused on the performance of the economy. They felt that this transition was already happening in quite an abrupt and under explained way and were concerned about its repercussions.

The question will be when do you get to decide that the science gets ignored when it was being used for something so serious all the way along. It's obviously suddenly an economic issue... I actually agree with the lockdown but if you are going to put everything on hold because of this particular science issue when does it suddenly switch to becoming something else.

Many participants put forward their hopes for a holistic approach to moving towards normality – one that saw government investing in supporting the economy, jobs and welfare. These participants did not want to see a return to austerity as a way of dealing with the economic impacts of COVID.

In terms of coming out and recovering from this process, I think we'd hopefully receive quite positive decision-making in terms of what's next for the economy, investment in jobs, investment in local businesses, investment in welfare, looking to try and get back to some sort of normality.

In contrast, a small number of participants thought it was now time to shift towards vulnerable people taking responsibility for protecting themselves to allow society to 'open up'.

Those with underlying health issues should take reasonable precautions to protect themselves i.e. wear face masks, get fully vaccinated.

Let's just get back to normality. Those who are vulnerable, let them take extra care. They know what to do now.

3.2.2 Actions needed to move to normality

Addressing the non-Covid health backlog

As participants contemplated the country moving from a place where almost all aspects of life are dominated by the pandemic to some form of normality, the non-Covid health backlog was a headline concern.

Many participants expressed frustration with what they saw as the wholescale 'explosive focus' on Covid-19, whilst people with other health conditions were left to languish with delayed

diagnosis and treatments. They worried how long it would take to catch up and how many would become seriously ill or die whilst they were waiting.

How long do we just put Covid on the pedestal and ignore all the cancer patients and all these people who are waiting for urgent operations?

Some participants thought a slower emergence from lockdown should be considered to help the NHS move from coping with Covid-19 to coping with the health backlog.

Should we sacrifice some indoor entertainment activities in the meantime to allow the NHS time to deal with the backlog of all health issues? The governments could continue to support these businesses and reopen them through time in a carefully measured approach.

The principle of universal free healthcare is seen as part of this country's DNA. So the fact that during the pandemic some of those who could afford it had resorted to private healthcare because NHS services weren't available felt like a tarnishing of this principle. It was seen as a further contribution to the inequalities exposed by the pandemic.

You paid your national insurance all your life and rely on the National Health Service, because of this pandemic, because it's been pushed back and pushed back, you suffer. Yet if you can afford to get it done privately and have the finances to do it, you can do that. As a society, it just doesn't make sense at all.

The prospect of extensive privatisation of the NHS and local authority services was raised by a few participants, who feared that the vast costs related to the pandemic would force the government to find radically different ways of financing health and care services.

I've also got a concern, that the government could potentially use this as a way to say, 'Oh well, the NHS and local authorities and things are struggling, we're going to have to start to privatise large sections of them.' They'll bring in private investment. And while I believe there is some scope in some areas for private investment, I think it's very important that our NHS remains to be our NHS. That it is a service which is free healthcare at the point of need.

Addressing mental health in the wake of Covid-19

Some participants saw Covid-19 as a tipping point for mental health. They thought that mental health would attract more acceptance and support because the impact of the pandemic on the mental wellbeing of so many people was widely reported. They felt the issue had become, more than ever before, part of public discourse,

I was just hoping that there'll be reduced stigma around mental health issues. Hopefully, that might be one of the outcomes of all of this because I've seen it impact a close friend of mine, so maybe people will be a lot more sensitive to these issues around mental health.

Others thought it was important that government and the NHS should be mindful that opening up society might cause some people to struggle. Participants said that as social contact and social opportunities are revived and greeted with excitement and joy by some, that there should be support available for those who find it difficult to cope with the change.

Some things need to be driven from government directive to help with that, rather than just saying, 'Everybody is free, go and do what you usually did.' I think, for mental health aspects, certain factors and people are going to require help in doing that.

Long Covid

Many participants felt that how the country deals with long Covid as it moves towards normality was an important indication of our ability to learn from Covid-19's impacts.

Some felt that given the existence of long Covid, continued discussion of a herd immunity approach was reckless and wrong. They felt that it particularly risked the long-term health of young people as this comment from a participant with chronic fatigue syndrome highlights,

If we're allowing the herd immunity strategy and if we're going to start unleashing this onto the younger people, we're going to have more people having a similar life that I've had.

How people with long Covid would cope financially was a concern raised by many participants. Some had heard that the Department of Work & Pensions was not recognising the condition as a serious illness and so people affected weren't entitled to support.

There was an article the other week there about another lady who had long Covid...She didn't get any benefits, which means that long Covid, as well as affecting you personally and everything that you need to go through, it's also affecting the fact that you're losing part of your salary from this as well and you're not having access to benefits.

For others, the high profile of long Covid is an opportunity for it and other fatigue related conditions to benefit from investment in research and for wider acceptance and understanding in society - particularly among employers. Some also thought that the improvements some people with long Covid have achieved through holistic 'Eastern' approaches to medicine rather than the 'Western' reliance on pharmaceuticals would be better publicised and change the profile of the condition from one of hopelessness to hope.

What Covid has done has brought a focus onto ME, chronic fatigue syndrome, and post-viral fatigue, which is welcome because, for a number of years, it was dismissed as being all in your head. Also, employers were not sympathetic towards it. I've had to leave employment because of my health. And I was dismissed on capability grounds from a second employer because of the struggles that I've had with my health.

My hope is that, with looking at these new treatments and new ideas and going maybe to Eastern medicine rather than focusing on Western medicine, it could potentially make a big difference in everyone's life if these kinds of things are seen to work... But I think it just needs promoting a bit more, because it's made such a difference in my wife's condition, but you only really know about it if you research it. Whereas, just now, if you've got long COVID you've got fatigue. It's all negative, so it'd be great to get some positives out there as well.

Covid and work

One of the most talked about impacts of Covid on employment was the switch to working from home. For many participants, the change was a positive one: they felt safer in their home environment and found that it gave them more time for other activities and reduced their commuting costs. Participants also thought that the coming winter (2021) may bring further lockdowns, so if employers called a halt to homeworking, as some had experienced, it may have to be reinstated within weeks anyway.

If people are happy to work from home and it's suitable for the employer then why can't that arrangement continue? I think there will potentially be the need for further lockdowns in the winter months, and businesses will possibly need to revert to a home working model.

Some participants thought it was important to give people who are clinically vulnerable the right to continue to work from home if they chose. They were worried that people may be forced from their jobs if they didn't feel safe in their work environment.

I think there needs to be an option, particularly for those who are clinically vulnerable to be able to continue working from home. Some people are considering leaving their jobs as it's too risky for them to return to a workplace.

Employers' duty of care to employees who work from home was also discussed. One point raised was the perspective that some employers are felt to be taking advantage of their staff and not compensating them for the costs they incurred whilst home working, such as increased utility bills.

I have had that conversation with a few people. Is your office paying you electricity and your heating, your water? Which you would obviously get for free in your office. A lot of people have said, 'No, they don't pay me extra for that.' I think that's unethical in itself.

The prospect of working from home leading to wider changes in employment practices was raised. Some participants talked about the prospect of employers responding to the move to home-working by reducing its local workforce and outsourcing work to lower wage level countries.

If people are able to work from home how does that affect who is hired to which company from which country, how is pay going to change? For instance, if someone who's paying London wages, at £30,000 let's take a random example, if they can just get someone from Mexico as a random example and pay them £18,000 and they work from home, what's the ethics of that?

Education

Participants were particularly concerned about the impact of the pandemic on the beginning and end of the formal education process: those in their first years and those who are working towards qualifications. For those in their early years, participants were worried about both the damage of a disrupted school year on early learning and the loss of access to wider services such as breakfast and after school clubs that provide nutrition and opportunities for socialising. They

also worried about how loss of early year education could be made up, given its foundational status.

I've quite a lot of primary school teacher friends and the more I see and speak to them, the more you realise how important the primary education is. The easiest example I always heard is, education's a pyramid and you can't put blocks on top of blocks that aren't there. So, if you're missing your very early blocks down below it's very, very hard to build on things.

Many participants talked about not knowing what, if any, plans are in place to help children to catch up. They also thought these plans needed careful consideration because some measures, such as repeating a year, may cause negative psychological impacts.

Especially in my son's primary school, a lot of kids in his class have fallen behind, to the point where they might have to re-take the whole year again. So, they're moving forward, and the kids are left behind, so that is a great concern to me as a parent.

Some participants also discussed the issue of the pandemic generation qualifications being tarnished because they could be seen as incomplete or reduced in status compared to previous years.

Local community groups

The pandemic has shone a light on the contribution local community groups make to society. Participants reflected on the role local groups had played in helping to manage the shocks inflicted by the pandemic: community larders, volunteers doing shopping for shielding households and helping facilitate the vaccine roll out.

Some participants were worried about how community level groups would continue to be resourced as emergency funding began to be withdrawn.

There are no longer the funds available to support these organisations to deliver the types of services they're looking for. And while they're not looking for the same level of it, they are still looking for the third sector to support vulnerable people within the community.

For some participants, a positive legacy of the pandemic could be a re-awakened valuing of community-based organisations. They thought that if hard choices needed to be made in the future about where funding was needed for services, making more use of local level knowledge would lead to more action and less waste.

You're going to get a much more useful result because they [communities] are more likely to take action as opposed to just making recommendations. So, there's something about training communities to do it objectively, strategically and involving more of the communities, as opposed to just leaving it to a hallowed few at the top without accountability.

Communities can be amazing if you just give them the chance.

Vaccine passports

In chapter two we shared participants' initial views on the vaccine roll out. During the dialogue, the prospect of vaccine passports being introduced in September 2021 was being widely discussed in the media. For most participants, this was not a positive prospect. Their concerns included the burden of enforcing their use falling on hard-pressed businesses and the ease of buying false documents on the dark web. Some were also concerned that the passport would be brought in without a suggested end point and so could become some form of permanent check or surveillance system.

I think it's questionable anyway, but in terms of recovery, when will they finish? Is there an end point to them? I think it's quite important that the public knows when they'll end and at what point.

But the greatest concern was that they would exacerbate divisions in society. Participants foresaw the use of vaccine passports shutting some people out from social locations and occasions either because of a choice they made about what to put into their body or because they were medically unable to be vaccinated.

Come September, if the Covid passport comes in and only double-jabbed people can go to certain places and do certain things. How does that make the people that can't do the things that they've been doing at the moment?

3.3. Future pandemics

A resignation towards the inevitability of future pandemics was clear in participants' comments. Given this, they considered learning the lessons from how the Covid-19 pandemic has been dealt with by governments, the NHS, employers, communities, families and individuals to be of prime importance.

3.3.1 Governance and information

Picking up on points made in section 3.1.4 about UK home nations, governmental considerations for future pandemics included learning lessons around the home nation governments working in a more consistent way. Participants said this would lead to more trust across the whole nation's governance structure rather than trust being placed in one nation's actions over another's. The view was expressed that developing a trusted governance model for future pandemics is essential, including in relation to sharing knowledge and providing citizens with trusted information sources that are clear to everyone. As we have seen, some participants were pleased that each home nation had autonomy to put in place their own Covid-19 management policies, and felt that their governments had conveyed information well. Participants nevertheless felt the knowledge and evidence behind those policies should be consistently used and shared with citizens throughout the UK.

Listening to a very small group of people in these last 3 meetings, how much of a lack of trust we have in the government. Now, if it's only between 25 of us, is this the whole country that's feeling this way? And if so, if there's a future pandemic, should we be just listening to our own government? Should there not be other people that are putting in more information and letting us know more

information, the same for all governments? We want to know what's happening to the country as a whole, but in ways that we understand it.

This raised reflections about how people know what information to trust. Many stressed the need in the future to address the issue of (social) media creating its own narrative, creating confusion in society and playing into the lack of trust people have for the government. They balanced this view with a desire to mitigate against misinformation in the face of future pandemics,

In the future the media needs to play its part by not spreading conspiracy theories about where the virus came from, how it started, was it a bat, was it a fish, whatever. I suppose, don't release the information until you know the facts. That's what I think. Just stop spreading fear. There's all sorts of lessons that need to be learned from this.

Equally some participants raised the need for caution in being overly-controlling of the media and social media so as not to allow, through a genuine desire to provide people with trusted information in a crisis, a state-managed press or social media in the future.

Be a bit careful. We aren't communist China, we do want an open media.

3.3.2 A resilient health system: robust in the face of future pandemics

Participants thought how NHS services are delivered, away from a hospital centric model - which was seen as a hotbed of transmission - towards more community delivered care, would mean healthcare in the future would be less disrupted by future pandemics,

Should more be done to improve community healthcare so people can be treated in their homes where possible therefore reducing strain on the hospitals?

The confusion over PPE procurement and allocation at the beginning of the pandemic, in health and care settings, was also still firmly in participants' minds as they considered future pandemics. They said that the health and care system should always have enough effective PPE in place to provide protection for staff should another pandemic materialise.

I'd say everything from making sure there's PPE and we're not running round the world trying to find it and locate it, so the health services can provide the service they are there for safely, because we were so underprepared on that side of things this time round. Hopefully they'll learn lessons from that.

As we have seen, concerns were consistently expressed in the dialogue about the back-log of medical interventions, treatments and care for those with non-Covid related ill-health. Participants want it to be understood that in any future pandemics this neglect of all other health matters, prioritising Covid treatment over any other health care, is not acceptable.

I'm very thankfully in a position where I have no need of assistance from the NHS myself currently, but I could only just imagine how panicked somebody might be if they required some assistance and kept getting told that it was delayed or

cancelled or whatever happened. We'd have to do better if another pandemic hit. Health is, at the end of the day, one of the most important things people look at.

Suggestions were made to address this issue in the future, including:

- a clear timeline in place so that people know, with certainty, when they will receive the treatment they need - particularly for conditions that can rapidly worsen if not addressed early such as cancer
- parliament being involved early in allocating additional funding to help alleviate delays and queueing systems.

Participants also suggested that the NHS should learn now from the experience of other countries which have done more to continue their non-Covid healthcare through the pandemic, for example, in France where a few participants said that they understood cancer treatment had continued in centres which were not open to Covid patients.

3.3.3 Employment in a time of pandemic

Other discussions dwelt on the concept of how employment practices might need to become more agile to help limit viral infections in a society where pandemics may be more frequent. Some thought that there should be more flexibility in the working day to reduce rush hour and work space crowding. Rather than the pre-Covid concept of Monday to Friday 9am to 5pm timings, employers should explore how to enable a wider range of working hour options.

My other hope is that workplaces become more agile. So, my workplace, I've worked from home for about a year now and I think we're just going to continue, we're not being forced to go back to the office or anything. But I know a lot of workplaces are trying to force people back, and maybe they need to rethink and look at maybe their business plan and look at more agile work they can do.

Some participants put forward the idea of a winter-month work and school at home approach to limit the spread of viruses. They saw this as a way of limiting people's interaction with others, reducing the need to be in situations where transmission is more likely at the time of year when the NHS is trying to tackle seasonal flu as well as potentially other viruses.

Should we maybe consider everyone working/schooling from home from beginning of Dec to the end of February every year to help combat flu season and rise in Covid cases over winter months? Until such times Covid or other future similar viruses are not an emergency situation?

3.3.4 Financial security

As we have seen many participants were concerned about the spotlight Covid-19 has shone on the inequalities that exist in society. Some were impressed by the government's response to providing support through the furlough scheme and wanted to ensure that the government could in future afford to act in similar ways should the need arise. A few participants felt that a Universal Basic Income (UBI), put in place now would have two significant benefits – it would:

- 1. Provide support for those who are now coming off furlough schemes and/ or losing the £20 uplift to Universal Credit put in place during the pandemic
- 2. Ensure that there is a scheme already budgeted for and in place should a future pandemic prevent people from working.

So, I think if they introduced a UBI, or something along those lines, it would start to address some of the inequalities within society, and it would give more of a building block and something that's always in place to help. We don't need to borrow quite so much going forward, for pandemics and things like that.

4. What lies behind the thinking?

4.1 Pandemic ethics

So far in this report we have shared an account of what participants' felt about the topics raised in the dialogue when thinking in terms of defining moments in time during the pandemic, from the first lockdown through to considerations on future pandemics. From this chapter onwards we shift our analysis to the significant themes that have arisen from these considerations. These have been collated through a balance of the conclusions participants drew during their discussions, combined with post-dialogue researcher analysis of what was discussed. We did not seek or find consensus through the dialogue, but much of what was said transcends difference in perspective or opinion and there was a lot of common ground.

The underpinning ethical values and principles that participants brought to dialogue discussions are shared in this chapter. Figure 5 shows HVM's analysis of the priority participants place on respect, tolerance and solidarity in society. They saw this as growing from concepts such as collaboration, addressing social inequalities, ensuring people have access to the things they need to enable them to thrive, rooted in understanding for the needs and concerns of others. We speak to each of these elements in this chapter.

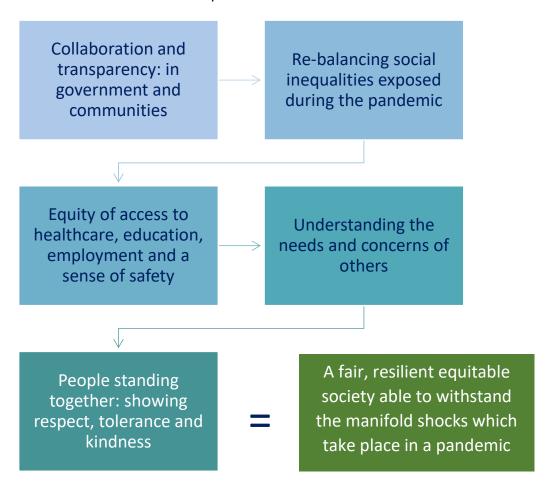


Figure 5: Priority ethical points underpinning participant discussions

4.2 Collaboration and transparency

We have seen in the previous chapter that participants felt that collaboration between UK governments during the pandemic might have led to clearer, more transparent information and evidence. A collaborative spirit permeating society was highly prized by many participants. This was seen in terms of collaboration across all UK governments, not just in terms of creating policies, but to ensure those policies provide the just societal protections necessary for everyone in society.

I just hope that if something like this happened again, that the governments would work more collaboratively with each other across the nations, rather than the points scoring, and just sing from the same hymn sheet. And it's not all about politics, it's about people's health, it's about people's safety, it's about our economy, and if we all work together then surely that's going to make things a lot easier and a lot better for us as a country.

I think moving forward we need to work together more. I think there are too many divisions. In the UK alone there are four individual governments. Personally, I don't think that will ever be addressed, to be honest. I think that, as four individual governments, we need to look at how we can work together to get through this pandemic and how we deal with future pandemics.

We know from the findings on Covid-19 recovery that participants valued community during the pandemic. They referred to what they had observed in their own neighbourhoods: individuals, charities and third sector organisations working together, stepping in to provide support for their neighbours who were struggling as a result of Covid-19. Collaboratively and altruistically addressing what needs to be done for those who need help and support is a principle which participants felt to be important in a discussion on ethical considerations.

People realising that, yes, things can be a bit hard and unfair, but it's maybe not that tough. If we can have a bit more of a sense of community to pull together to help each other out rather than everyone being their own island that would be nice. Yes, generate a sense of community again.

Such collaboration, at national and local government levels, was seen to be achievable if there is trust and transparency in society. It was also seen that working collaboratively is a route to transparency as information sharing has to be part of any meaningful partnership working. Transparency was also considered an important underlying ethical principle for participants.

In my local authority, we set up community boards. We also have community councils, we have tenants and residents' associations, and the community board acts as a vehicle to bring all of them together. That's a really good interface between the community and the local authority, we all know where we are and what everyone is doing.

We all need to communicate with one another in small group and also as local communities to get things across and take action as and where needed.

Good, clear, transparent communications were seen as ethical considerations key to building trust across the country and in communities. A lack of transparency was seen to be counter to the desire for trust in governance, decision making and policy making to which participants aspired for society but had not always witnessed during the pandemic.

Just try and remove the shroud and the black box behind which policies have been formulated, especially during this time. I think it would be great if things were a lot more transparent.

For example, one participant in the first workshop questioned how decisions were made to move people from hospital to care homes without a testing regime in place. They felt that lack of explanation of this policy from politicians, and the fact that many people then caught Covid-19 because of the decision, was an ethical dilemma that needed to be solved around transparency in the decision-making process.

Procurement processes during the pandemic for key medical equipment such as PPE and ventilators, for example, underlined transparency as an important ethical issue. It highlighted what participants perceived to be a lack of accountability and proper governance procedures, which also undermines trust.

Having a proper process in place for the procurement of contracts, ensure that there's accountability for decision making. A general openness and transparency in decision making so it all goes back to trust. It's not a case of awarding contracts to peers and pals with an individual interest as opposed to the overall interest of everyone else.

4.3 Re-balancing social inequalities

We will see in Chapter 5 that social inequalities were a significant consideration in the public dialogue. Participants feel that the ethics of equality and equity are a significant priority. This includes ensuring that everyone in society, particularly the most vulnerable and disadvantaged, have equitable access to the core things that everyone needs. At the most basic level this includes food, clothing, education, healthcare and autonomy. Participants shared what they had witnessed and seen in media reporting during the height of lockdown – that those who already face many life challenges through deprivation, were affected to an even greater extent by the pandemic. They raised the example of home schooled children who did not have access to appropriate equipment to follow any online learning that was being offered, with some only having use of a parent's smart phone as their sole means of accessing lessons and teaching resources.

This fundamental disparity between those who have access to everything they need for a fulfilling life, and those who do not, has been put under the Covid-19 spotlight and been found to be too extreme to be tolerable. Participants said that while they see this as an ethical priority, it is not being visibly addressed.

I'm thinking about the poverty side of things, with children, with families, you know. It's affected them really badly. What are they going to do about these children? They need to catch up, they are just so far behind, more than they were before. How are they going to

go about helping these children? Educationally and mentally, their well-being as well. They keep talking about it, but have they got a plan?

A lack of equality of opportunity and access was also discussed in the context of healthcare, particularly in relation to a lack of consistent access for people from Black, Asian and minority ethnic backgrounds.

There was the issue of the equity of access for individuals who maybe historically have been underprivileged and lacked access to things like critical healthcare, and even those with pre-existing conditions like cancer. One of the gentlemen from the videos who was just speaking about, for example, the BAME community, who probably require some reasonable adjustments to ensure that they have equity of access to healthcare, especially during this time where I think the priority has been assigned to those who maybe suffer directly from Covid. So, yes making sure that things are prioritised right for all these groups.

It's making sure it's not just equality we're dealing with, it's equity. So, we're bringing everyone up to the same level and providing the adequate support, the extra support, for those who need it.

4.4 Feeling safe and secure

Ethical considerations on feeling safe build on what participants feel about equality. They discussed that feeling safe in life is something that many take for granted, but Covid-19 has shown that it is not a given, with many feeling very unsafe, either due to the pandemic, or because of underlying insecurities exacerbated by it. Safety means many things for dialogue participants as summarised in figure 6. In the time of a pandemic, that is led by the need to be protected from illness, but Covid-19 has exposed other forms of safety which equally risk safety as society finds a way of living with Covid-19 and coping with future pandemics.



Figure 6: Summarising the key ethical points raised around safety

Health

Health considerations include people's reflections on 'Freedom Day' and that what might constitute freedom for one person e.g. not having to wear a mask or being able to attend big events; reduces the safety of someone else. This might be because they are shielding, in which case their feelings of safety to go out and about are severely reduced if no Covid protection measures are in place. Or they work in an environment in which they might not feel safe due to the number of people or how people behave in their work environment.

With regards to inequalities, this again will come to the fore as restrictions are eased. Many people can't afford not to go to work, however in doing so they are potentially being exposed to the virus, particularly those working in hospitality and entertainment, with large groups of people in restaurants, pubs, nightclubs and large events. Once alcohol is involved then social distancing will be difficult to maintain.

As we have seen in previous chapters, in participants' consideration of the NHS back-log, feeling less safe because of a physical or mental condition for which there seems no immediate available treatment is also a factor here.

Safety in employment

Participants raised questions around safety and employment. How, for example, to protect those whose jobs make them vulnerable in future pandemics, for example in service industries such as hospitality and leisure; and the cultural industries including the performing arts? People working in these industries were severely impacted by the pandemic, particularly given that many are not employees, being either freelance or working in the gig economy on zero-hour contracts.

I guess that focus has got to go to our economic market in different industries. How we'll fund people, what sort of mental health fallout that'll be because a lot of people might have been in certain industries all their life and now they lose their jobs and it would almost like the end of the world to them.

Many workers in these industries were not eligible for furlough scheme support and it was felt they are even less secure as a result, creating a tranche of society who are more vulnerable than they were before the pandemic. This includes those who received some support during the pandemic, for example an increase of £20 per week uplift in both Universal Credit and Working Tax Credit but will be left without this when the scheme ends on 6 October 2021.

It will come to a point where the government will start saying 'we can't help anymore'... I think it's important ethically to think about this if they've lost their jobs as well.

Financial stability

Security in employment is linked with financial stability and, for some participants, an underlying sense of self. A lack of security about what will happen next with no job or regular income leads to frightening considerations around where such a lack of stability and certainty could lead, including a fear of homelessness.

I don't feel safe...because the rules are changing, restrictions are changing, like today they can tell you stay at home, don't go out, then they tell you now maybe you will need to have this passport, now you need to do this. I have been without a job since January because of all this, I don't feel safe. I can lose my home, I can lose everything, I'm going to be on the road. So, what's next? I don't feel safe as a person.

Participants also reflected on the insecurity of coping when there isn't enough household income to buy food.

It's just what I've seen around, families who are struggling, and people had communal centres and places where they could just go and pick up, even schools, where they could just go and pick up food. I found that very disturbing with this Covid lockdown thing.

One person described people who had been affected financially as the 'forgotten people', people who are already are at a disadvantage in society. For example, those who lost their source of income and are continuing to feel the consequences of that and are likely to for some time to come.

There was a lot of disparity between people actually losing their source of income and not being able to carry on in the way they'd become accustomed to living. And I'm not sure if there was the support for those people at that time. Because it's okay if you manage through Covid, but a lot of people didn't manage financially, the mental health suffered. I think these are like the forgotten people because even though the lockdown things have eased up, these people would have still suffered from when it was first implemented with the loss of earnings.

Unclear, insecure routes to knowledge, information and evidence

Throughout the pandemic participants have heard governments speaking about being 'led by the science.' For some participants, particularly at the beginning of the pandemic, this has provided a degree of certainty and security, feeling that this information can be trusted. However, as the pandemic has continued there is a sense that always being 'led by the science' actually gives a false sense of security, particularly if the science isn't certain and when ethical considerations do not seem to be taken into account in policy action. It leads to questions over whether a scientific rationale is the only rationale that can be applied to decision-making. Participants said that science on its own does not give people a feeling of being in safe hands, they also need to know that other elements are being taken into consideration such as the human impacts of decisions only informed by science.

Every time I've heard the government speak or do a presentation on the telly they always come out with the scientific facts, slide about this, slides about that. Not once have I heard anybody mention the ethical implications of going into lockdown. It was all, 'We went into lockdown because the science said this, the science shows that.' So, yes, there are ethical implications to everything they're doing but not once did I hear anybody on the government side of it say this is why we're doing it, and this is how it's going to affect you. We go into lockdown

because the scientists have said this is what we need to do to contain it, not how it's going to affect people or how it's going to affect the vast majority of people.

For one participant there was an additional aspect to this — about feeling less safe when government powers expand, and decisions, communications and actions at a national level encroach on individual freedoms, including freedom of expression. This was of particular concern when this is not what is expected of a western democracy, for example having moved to the UK from a more restricted and controlled society.

That makes me straight away think, I mean if you're not allowed [to have] a different opinion, are we living actually in a democratic society? What is this?

4.5 People standing together: empathy, respect, tolerance and kindness

As a result of the pandemic participants felt that a key thread for their ethical considerations was around kindness. They said that a society which respects and understands the needs and concerns of others, in their street, in their communities, across the country was important to them.

Communities need to display solidarity to each other and just to pull together as human beings really.

There was a recognition in discussions that a 'kind' society can't be forced but can happen organically in the face of adversity and crisis.

I think it needs to be natural. It needs to birth itself. I think we've witnessed that through the pandemic, that suddenly everyone was on the same boat so to say, and we all therefore had the same feelings and experiences. It's a very difficult one to try and force a society to be cohesive.

Participants said they have been changed by the pandemic. They said that there needs to be a recognition that the experience has had consequences, large and small, for how people interact with each other, and people now react to situations in different ways. They felt that there needs to be understanding across society that people are not the same as they were before the pandemic and take this into account across all aspects of life, from policy and planning right down to individual actions. One participant related this to how they feel about attending a family event and that it might surprise people that they are not behaving in the same way as they did pre-pandemic. They wanted an acknowledgement of the change and for society to develop empathy and tolerance in response.

We all feel different things. I'm going to a wedding next Friday and I'm very, very worried about going. I was always a huggy, feely sort of person and now I've gone the opposite. It's just having tolerance and empathy for one another, it's very important. And we're all different.

There was a call for:

Empathy kindness and generosity to all.

4.6 Fairness

Linked to the analysis of the underpinning principles and values that have informed participants' thinking, there are some substantial societal considerations raised by participants during the dialogue. Fairness was one such consideration. Our analysis shows that fairness is an important concept for participants, and a key theme that ran through many of their discussions. From hearing about how people fared during the pandemic from their co-participants in the dialogue, people said that it hadn't felt fair that some shouldered more of the burden in the pandemic than others. This felt unjust, particularly as the pandemic touched everyone's lives in one way or another. This was also apparent from the news and media reporting. Participants remembered seeing footage of queues at food banks, data on job losses and some people suffering much greater ill-health than others for a variety of reasons.

Participants said that it is not fair that people in care homes died in such great numbers; that many of the elderly became so cut off from human contact; that young people and children lost out on important learning and opportunities to socialise and 'be young'; that some people could access financial support through governmental schemes and others could not; and those who are already in poverty were more affected than those who are not.

They knew from experience that some people had lost loved ones to the virus while others barely saw any illness or adverse health effects from Covid-19 amongst friends and family. For many participants thinking about a more equal society which delivered fairness was a significant ethical consideration.

Some sections of society clearly had, and still has, you know, more of a negative effect because of the pandemic than others. So, sharing of burdens. Are we going to, say, if this happens again, it's all going to be shared equally? Or are we, as a society, happy that some sections of society have more of a burden than not?

Participants raised the fact that people shielding, frequently on their own, have had a very different experience in the pandemic than those who have been able to go into lockdown with their close family, and so at least spend more time with them.

People are people, regardless of their needs and disabilities. How do we stop some people saddled with all the restrictions maybe, and health needs, more than others? Is that fair? Are we happy, as a society, to tolerate that? They may be small in number, you know, a certain part of society. Are we happy to sacrifice a few for the good of many?

Discussions also raised issues of class and social divisions creating unfairness. They spoke of this in terms of how people have found ways to cope financially in the pandemic which will lead to a lifetime of debt, entrenching unfairness in how we all recover from the effects of the pandemic. They saw this in a sense being perpetuated by government decisions to stop the furlough scheme and tax and benefit schemes in October, leaving the most vulnerable even worse off and unable to recover.

People in lower social classes are going to lose £80 a month on their benefits now during a time where it's probably most essential to support them in their daily

living. So, I think we're already seen decision-making in terms of starting to try and repay government debts, but they're taking the money from the most vulnerable in society to start repaying it, and I think this is completely the wrong time to do so. I think it's like everything else in life where the lower social class always pays first in terms of decision-making.

A very serious concern expressed by many participants throughout the dialogue was that the effects on the vulnerable are pervasive and long-lasting. The ethical implications of this are profound for them, particularly when they believe that community and support organisations are being asked to step in without any additional funding and local government does not have the money or power to address the issues.

4.7 Language exacerbating social divisions

Participants during the dialogue discussed the fact that the language used during the pandemic is frequently counter to the fairness they wish to see. They have observed an increasing use of language which puts people into silos and exacerbates difference rather than bringing unity and social cohesion. They said this sometimes resulted in misunderstanding as well as division. One participant spoke of 'herd immunity' being used as a short-hand phrase and having heard others in the dialogue using it as such. This, they saw, created unnecessary divisions and tensions.

Herd immunity is one of those phrases that's so open to interpretation because, in a way, you can hear the language as people say, 'Well, herd immunity, survival of the fittest,' but, equally, herd immunity can be seen as protection of the vulnerable. And, unfortunately, when the term is used and it's not explained or put into context, people get whatever interpretation they're going to get, and none of them is wrong, just different interpretations of the same thing. And it causes so much stress, it bruises people.

Some felt that the language used by politicians has been seen to be divisive. They gave examples of leaders in one home nation criticising the actions of another, or of one political party 'sniping' at another to score political points. Participants said that in a pandemic, creating divisions through party politics was inappropriate and wrong. They also spoke of politicians using divisive language to speak about the actions of some in society. One such example is quoted below:

If you look at the news from yesterday, you have Michael Gove calling people 'selfish' for not taking the vaccine. I'm already double-vaxxed. I think as many people as possible should take the vaccine, but I don't think our leaders should be calling people selfish for not taking it. They shouldn't think that's the right way to get around or get through to people.

Given all participants had discussed about social inequalities and divisions, participants were disappointed that pandemic language seems to be putting people into boxes, for example the vaccinated and the unvaccinated; people who comply with restrictions and people who don't; those who are shielding and those who aren't; those who could access online schooling at home and those who couldn't; those on furlough and those not; those who worked through the pandemic and those who did not.

I hear people and some language people are using, 'Well, I've done this, and they haven't done that. The people across the road, they haven't done this. The younger people don't do this. Old people do that.' It's the language that I've heard increasingly people using that I feel is quite divisive. I think history suggests that when those conversations start, they're not easy to get away from.

4.8 Prioritisations

How government and the NHS has prioritised people and actions is a mysterious process to many dialogue participants. As we have seen, vaccination decisions are one area where clarity is needed on why and how some age groups were prioritised above others. Participants also wanted to know, and felt it was important that society understands why priority funding is given to some areas, but others are under-funded or not receiving funding at all. It becomes even more confused when suddenly money is found for a certain policy initiative when it was previously understood that no more funding was available.

It was just obviously that things are unfunded, but when they want to find money for something, they will find it. So, why are these things like the NHS and third sector health and social care, why are they not really the priority, when other things seem to be prioritised over the top of those? So, there's money available when they want to find it.

4.9. Trusted behaviour

There was discussion in the dialogue about who in government had demonstrated the most trustworthy behaviour during the pandemic. Participants felt that Wales and Scotland in particular had been clearer than the UK government in its messaging and explanations of decisions. Participants from these countries said they were pleased that they had their own First Ministers who they felt were doing well at explaining a difficult situation clearly and without fuss.

Mixed messaging is still happening in England but here in Wales we have clear guidance from Welsh Government. That's not changed throughout.

The briefings by Nicola Sturgeon were clearer and more concise than the communication from Downing Street. Nicola Sturgeon gained a lot of respect from many due to this whereas Boris Johnson's approval rating is practically non-existent in Scotland.

The general feeling is that Mark Drakeford and his team have handled it really, really well. He's certainly been led by the science, and the decision-making appears very transparent, and it's backed up with facts. There's a lot of love in Wales for Mark Drakeford.

Trust and acting in ways in which people feel is appropriate for decision making in a crisis is important for participants. Some also drew comparisons between the behaviour of English and Scottish political figures during the pandemic. They saw the 'do as I say, not as I do' implication of Dominic Cummings' and Matt Hancock's actions as damaging to people's trust in government and government decisions.

5. What comes next?

5.1 The need for society to pull together

As people moved through each of the dialogue workshops, we noted a shift in participant thinking, from an initial focus on individual choice to a more collective response to adversity. The more participants deliberated on the social and ethical implications of Covid-19, the more they focused on empathy, solidarity and respect. They enacted, through the dialogue, the ethical dimensions that they would like to see in governance and decision-making at local community, regional and national level decision-making. This included showing great respect for fellow participants, even when the views expressed in small groups were not shared by everyone. This led them to reflect that society needs to 'pull together' to recover from Covid-19 and as a route to becoming more resilient in the face of potential future pandemics. They called for more acceptance in society for people's decisions and choices in recognition that everyone is different, people respond differently to crisis and that shunning or using divisive language to describe behaviour different from one's own was not the route to healing the harms caused by Covid.

I hope we get to a new normal, ethically as well. The divisions between the two groups of people who are vaccinated and people who are not vaccinated for example. Hopefully we can get to a new normal and everyone's accepting of everyone's decisions.

Many examples were given of how local communities are working together and will continue to do so into the future. Participants saw this as a way of trying to mitigate against the fear they have, as shown in the previous chapter, that the vulnerable in society will remain at risk and continue to be exposed to unfairness indefinitely.

We had all the very vulnerable children in, we worked with them, and made sure that they had food, food and clothing and we are going to keep that up, that will happen always. And I think it's very important that on the ground this is what we're doing. And it would be lovely, I don't know what they do in other parts of the country but we're all helping one another where we are. And just pulling together.

5.2 Areas of interest for further research

Several further research areas were suggested by participants for the UK Pandemics Ethics Accelerator and other research communities and policy makers. These are summarised in figure 7, but it should be noted that participants did not receive extensive information on what research is already being done into Covid-19, recovery from it and future pandemics. As such the summaries provided may already encompass work that has been initiated. Of primary importance to many dialogue participants was the importance of understanding who in society has shouldered most of the burdens during the pandemic as summarised in the following quotation,

Poke about really spending some time to look back at different sections of society. See who has carried the burdens more during the pandemic, whether that's fair, and the steps if it did happen again. Steps you'd be taking to address those inequities and inequalities for those sections of society that have had a really much more difficult time perhaps compared to other sections of society.

Conduct research to:

Understand who has shouldered the pandemic burden and make recommendations on how to re-balance inequalities

Capture the stories and experiences of the 'forgotten people' who will be left behind if they continue to be ignored

Bring clarity on how decisions have been made during the pandemic at a community, regional and national level to understand what has been effective

Understand how best to inform future decision making e.g. following the science vs. factoring in other elements such as emotional wellbeing, non-Covid conditions and economic considerations

Show the impacts long Covid has had on people's lives to identify support and treatments to minimise those impacts

Compare country responses to the pandemic around the globe and use the information to prepare for future pandemics

Figure 6: Summarising the research studies proposed by participants

Study the ethics of trust: who is more or less trusted, what constitutes trusted behaviour, what would a transparent government be doing in a pandemic?

5.3 More public involvement

Part of the package of discussions participants had on research also included a great interest in involving citizens from across all sections of society in policy and decision-making processes. They said they felt there was lots of scope for more public dialogue such as the process they had experienced focusing in on some of the specifics of the ethical considerations of the pandemic. They were particularly keen for people to be involved in discussions on contentious topics and areas for which society has no clear solutions as yet. Hearing citizens' voices will, in participants' minds, ensure that decision-making is rooted in the reality of every-day lives.

The governments are very much in their ivory tower, and it would be good to see more of the governments out within the communities, and engaging more with the actual communities, and doing more around food for thought sessions, listening groups and different kind of focus groups on different topics to engage in opinion.

People spoke of Citizens' Assemblies, Juries, referenda and local groups feeding into broader national groups to inform policy and bring fresh thinking to decision making.

There should be more public involvement, as opposed to having these, just before they announced the news, 'This is what we're going to do.' And you've got a couple of journalists and everybody else asking these questions.

Have a public platform and get the community involved locally. Let's have these public discussions. Then bring all that, and pull that altogether, and then give that to the central government and say, 'Well, look, this is what the community in Manchester are saying. This is what the community in Newcastle are saying. This is what the community in Edinburgh are saying.' Let's pool everything together and then come with a consensus, to say, 'Well, look. This is what the public are saying. This is what the public are demanding.' Let's get a policy built from that, so all of us can be involved.

This is reflected in some of the answers to the last menti question that participants were asked in the final workshop, 'Give one word of advice to the UK Pandemic Ethics Accelerator':

Find a way that everyone can work together in the future

Engage with as many voices as possible as everyone's experience has been different

I hope you do more of these workshops so that you can create a platform where the public can help in decision making.

Dive into much more personal experiences to get an idea of the different impacts of the pandemic.

Make sure what you decide to work on makes a difference both at Government and a public level!

5.3.1 What it felt like to take part

Given participants' eagerness for further public dialogue to be a key part of any next steps taken, it is fitting to share here what participants felt about taking part in the dialogue. As people signed up to be involved, we asked if they would be willing to take part in further research led by the Accelerator's *Public values, transparency and governance workstream* in the future. Two participants of the twenty-four involved originally declined this invitation, but at the end of the dialogue were eager to reverse this initial decision and sign up for future research.

I have really enjoyed participating in this project and would love to be involved with any future projects. It was great to hear everyone's different experiences and opinions. Thank you so much for the opportunity.

All those involved strongly agreed with the statement, 'Overall I am pleased to have taken part'. They also all agreed or strongly agreed with the statement: 'The presentations, films and Q&A with specialists were helpful in providing information on the ethical dimensions of Covid-19 and balanced answers to our questions.'; 'I felt comfortable sharing my experiences and contributing my views in my small group.'; and 'The facilitators made it easy for me to participate.'

Thank you for letting me share and listen and see some very helpful and interesting things about Covid. The whole thing was extremely well presented, and the facilitators were excellent and the speakers too. I have never been on anything like this before. It has definitely given me 'food for thought'. I would love to be included in any other similar things in the future. I work in a school from a very deprived area of England and will take back some ideas to them in September. Thank you.

6. Final considerations

To end we draw the threads of this report together by summarising the main ethical and societal considerations running through this report. This is intended to make it clear how this report informs current and future research enquiry and policy debates.

Individual vs. collective concerns

During the dialogue participants moved from individual to collective concerns, mirroring the shift they would like to see in policy decision-making and governmental actions.

They do not feel that individual and collective needs have to be in conflict. They said that individual choice is a useful challenge to government unilateral action and given time and effort individual and community needs can be reconciled.

Kindness, empathy, respect, solidarity and tolerance are key terms which participants brought together as they thought increasingly about the needs and concerns of everyone in society.

Learn from this experience

Participants said that if any good is to come out this pandemic it will be from society learning from this extraordinary collective experience, finding better ways of living with a greater concern for the needs of the vulnerable, the elderly, and working in solidarity to share the burdens of crisis situations more equitably throughout society.

How the country now supports those with long Covid and addresses the significant backlog of treating non-Covid health conditions were both seen as indicators of how successful the learning from the Covid situation has been.

Retaining some elements from our Covid coping strategies for example, flexible home working and appropriate financial support for those who are more vulnerable or at risk in society are important to some participants.

Healing social divisions

Fairness is a key element in what participants consider essential in the post-Covid society they want to see. They are concerned that the social divisions highlighted in the pandemic are pervasive and will be long-lasting. Research to understand causes and preventative measures, and policies to address these inherent inequalities and injustices were called for.

Trust and transparency in governance and decision making

Recognition that hard decisions need to be taken during a pandemic, but that without trust and transparency over governance and decision-making it is equally hard for society to accept that the right decisions are being taken. A concern that hypocrisy has too often filtered into government actions and decisions, and this further undermines trust. Developing a trusted governance model for addressing future pandemics is seen as essential.

Concerns that (social) media creates its own narrative in a pandemic. Participants said this creates confusion and mistrust across society and plays into the lack of trust people have in governmental decisions.

Feeling safe

Participants were clear that 'feeling safe' is a basic requirement for everyone in society. Safety includes a number of factors: health, employment, money and knowledge and ensuring people's actual and perceived safety should be factored into policy making which provides resilience in the face of pandemics.

As we saw in Chapter 5, ensuring further research is carried out to inform the learning process, is something participants were very keen for the Accelerator to take further. Participants want to know that citizens are engaged as a matter of course in meaningful decision-making and deliberative processes to inform how society tackles future pandemics. They valued the experience and feel that the lived experience and common sense they bring to governance processes is essential for future decision making to be as effective as possible.

Collaboration

Collaboration was seen as a cornerstone of providing consistency of approach across the UK. Participants were concerned that unnecessary confusion was caused in a time of national emergency, for example through differences in style and messaging between the home nations, and this was counter to the message that 'We're all in this together.'

Collaborating on this public dialogue was meaningful and important for participants. We end with two quotations stressing the value of citizens' views informing and shaping next steps for society.

I just hope that we can go on from this and work together as a society. We could do more discussions like this which will make a difference.

Let the people share their views. See what they're thinking, like we're doing today, and let's measure the public pulse and say, 'Okay, these are what the views of the public are.' Get all the government together. Whether it's England, Scotland, Wales, or Northern Ireland. Put their heads together and say, 'Look, this is what the public have discussed, and this is what they want to be going forward.'

7. Acknowledgements

Hopkins Van Mil is enormously grateful to those who took part in the public dialogue. Their commitment to the process, and to considering complex and, at times, emotionally challenging ethical and societal ideas so seriously; as well as their lively and engaging contributions, has been much appreciated.

Many thanks too to the specialists who agreed to be filmed to create stimulus materials in a tight timescale. They generously gave their time and shared their thoughts, making an important contribution to informing dialogue discussions. We thank Philip Hunt, Baron Hunt of Kings Heath; Julian Sheather, ethical adviser; Margaret Douglas, Hon. Consultant in Public Health; Sir Kevan Collins, education specialist. We are equally grateful to Gurch Randhawa, Professor of Diversity in Public Health; Ilina Singh, Principal Investigator and Sarah Chan Co-Investigator at the UK Pandemic Ethics Accelerator who gave fascinating presentations to the group and answered participant questions.

It has been a delight to work with the UK Pandemic Ethics Accelerator Project Team: Hugh Whittall, Sarah Cunningham-Burley, Shaun Griffin and Jamie Webb. They expertly guided the process, providing insightful comments to the HVM team, as well as presenting at the dialogue and responding to participants questions with clarity and empathy.

Appendix

Workshop 1 process plan: Covid-19: the past 16 months

Time	Agenda	Process	Expected
5:50-6:00	Participant and speaker/	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom	Outcomes Participants and
	observer	session early to check-in and check their video/mic.	speakers/
	check-in	Open <u>www.menti.com</u> on smart phones/ tab on	observers
		their computer. Explain about the code.	set up and
		Reminder that one of the homework tasks was to	ready
		think about topics you'd like to discuss during the	
		dialogue. As we're settling in you could take a	
		minute to recall what you'd noted down. We'll be	
		discussing this in our first small group discussion.	
		Participants encouraged to get a pen and paper and have their participant pack with them. Once settled	
		they can mute/ turn video off/ get drinks and snacks	
		before we start promptly at 6pm.	
6:00-6:15	Introductions	Warm welcome to the first workshop, setting the	Participants
	& workshop	tone for the session:	know the
	purpose	LF: Hello and welcome to this first of three online	purpose
		public dialogue sessions exploring the social and	and format
		ethical implications of Covid-19. Reminder of the	of the
		information in the participant packs.	webinar
		In a moment we will look at what to expect for the	
		next two weeks, but first, let's introduce the team	
		who'll be with you: We'll use the 'pass the baton' approach:	
		Our name, our organisation and why we are here	
		tonight.	
		Then pass the baton to the next person to	
		introduce themselves.	
		You'll get a chance to introduce yourself when we go	_
		into our small groups. Asks Accelerator team	Get
		members and all observers to introduce themselves:	participants back into
		 Name, organisation, role, passing the baton to the next team member 	the space
	Menti.com	the next team member	with
	Wichia.com	Shares this evening's programme	reminders
		Shares the points to help the discussion	and
		previously shared with the participants in their	information
		packs	

Time	Agenda	Process	Expected Outcomes
		A reminder of the research question (will happen at each workshop)	Learn a bit about the people
		M1: Please use one word to describe this year of Covid-19 And as we are going to be spending some time	we're talking to
		together, and it's good to know a bit about who we are talking to please: M2: Write one short sentence about yourself	
		Just a few words with something you feel you can share with us about you, and/ or what you are interested in. Remember we'll be sharing our screen	
C-15	24	in a minute so make the sentence appropriate.	
6:15 6:15-6:30	Move to small Warm-up	groups RECORDER ON	Participants
(15mins)	discussion	Let's start with introductions: Facilitator to select each participant in turn: 1. Introduce yourselves. Share one impact of Covid- 19 you have experienced or noticed on people's lives? Prompts • Share your own life examples (no pressure to do this – as participants choose to) • Share examples you've heard/ seen/ read in the news and on social media	to get to know each other Gain an understandi ng of the impacts people have experience d – and
		This is an initial conversation – there will be more RECORDER OFF	what they think is important to raise initially.
6:30	Move to main	room	
6:30-6:45 (15 mins)	Introductory presentations on ethics in relation to Covid-19	LF introduces speakers & TS records all presentations for playing at future sessions/ uploading to Recollective: Speaker: An overview of what an ethical question is. A review of topics raised by participants with a response from the speaker on how that comes in to the scope of this work to identify and prioritise the social and ethical implications of Covid-19.	Understand ing on what an ethical question is.
6:45	Move to small		
6:45-7:00 (15 mins)	Gathering our questions	RECORDER ON Q1: What questions do you want to explore on Covid-19 and the social and ethical implications of the last 16 months? Prompts: What do you want to know more about?	Questions generated around Covid-19
	<u>l</u>	That as you mant to know more about.	

Time	Agenda	Process	Expected
		 What did you find most interesting or relevant? What do you feel about the topics raised for discussion? Do you have questions about any of these topics? While this workshop is focused on what has happened with Covid-19 to bring us to today, feel free to discuss question you want to discuss throughout the workshop process. What are the 2 main questions we want to bring to the specialist panel after the break? Can be a volunteer if that feels appropriate. Otherwise, the facilitator to do it. RECORDER OFF 	Quick factual questions answered. Ethical questions are turned back to the group to reflect on later in the process.
7:00	Move to main		
7:00-7:10	Break		
7:10-7:30 (20 mins)	Speaker panel Two filmed provocations	RECORDER ON LF go round each group. Ask one question first, then do a second round with the second question. Pick up questions that can be answered. Questions that can't be answered either for time/ content reasons will be responded to before the next workshop and answers shared on Recollective. Speaker panel responses to the questions. RECORDER OFF 1. Lord Hunt of Kings Heath: a parliamentary perspective 2. Julian Sheather: a provocation think piece on the range of issues involved	Key questions answered, others to be answered in Recollective Understand ing of the broader context in which our deliberation s sit
7:40	Move to small	groups	
7:40-8:05 7:40-7:55 (15 mins) 7:55-8:05 (10 mins)		 RECORDER ON Q2: What do you feel are the important factors when you think about what you've heard this evening? What have you heard this evening that feels particularly significant about how the pandemic has been handled? What have you heard this evening that feels particularly significant about its impacts? What key issues would you like to hear more about/ understand better in future workshops? 	

Time	Agenda	Process	Expected
			Outcomes
		Facilitator to create a summary sheet of 3 main	
		points to be shared on Recollective.	
		To be shared on Recollective after the session for	
		review by all groups.	
0.05		RECORDER OFF	
8:05	Menti	www.menti.com	
		MQ3: One point you will take from this evening	
8:10	Describertion	into our next workshop on 31 st July?	
8:10	Recollective	On the homework space	
		Briefing as below on what to do before we meet on	
Reflective	Described:	31 st July	-
task in	Recollective	Review the materials from this evening's discussion	
own time		Review the key points from each of the small group	-
		What topics do you want to suggest for our next di	iaiogue
		session – important – do this by Thursday am	araad fram
		 Review the answers to the questions that have em this discussion (will be posted by Thursday of this v 	_
		chance for the Accelerator team to respond)	week givilig a
		• •	oro vou aro
		, .	ere you are
		,	
			rk & trace
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			1011133003
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		 Look at additional materials (optional – dive in whe interested): Infographics on employment OECD risks that matter film Information on personal responsibility/ trace (England) trace & protect (Scotland) test, trace (Wales) contact tracing service (Northern Interest) Research on young people and mental heal Review the news reel Review the filmed interview from Margaret Douglandshealth 	ck & trace race, prote reland) Ith issues

Workshop 2 process plan: Covid-19 recovery

Time	Agenda	Process	Expected Outcomes
9:50-10:00	Participant and speaker/ observer check-in	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer. Explain about the code. As we're settling in you could take a minute to think about Covid recovery as that's the focus of our discussions today. We'll be discussing this in our first small group discussion. Participants encouraged to get a pen and paper and have their participant pack with them. Once settled	Participants and speakers/ observers set up and ready

Time	Agenda	Process	Expected Outcomes
		they can mute/ turn video off/ get drinks and snacks before we start promptly at 6pm.	
10:00-	Introductions & workshop purpose	Warm welcome to the second workshop, setting the tone for the session: LF: Hello and welcome to this, second of three online public dialogue sessions exploring the social and ethical implications of Covid-19. Reminder of the information in the participant packs. In a moment we will look at what to expect for the next two weeks, but first, let's introduce the team who'll be with you: We'll use the 'pass the baton' approach:	Participants know the purpose and format of the workshop
	Menti.com	 Reminders of who is on the team from HVM Asks Accelerator team members and all observers to introduce themselves: Name, organisation, role, passing the baton to the next team member Shares this morning's programme Shares the points to help the discussion previously shared with the participants in their packs A reminder of the research question (will happen at each workshop) M1: What comes to mind when I say 'Covid-19 recovery?' 	Get participants back into the space with reminders and information
10:10- 10:20 (10 mins)	Introductory presentation on ethics in relation to Covid-19 recovery	LF introduces speakers & TS records all presentations for playing at future sessions/ uploading to Recollective: Speaker: An overview of what the ethical considerations of Covid-19 recovery might be – including addressing the social inequalities which Covid-19 has exposed/ heightened/ brought sharply into focus. A review of topics raised by participants with a response from the speaker on how that comes into the scope of this work to identify and prioritise the social and ethical implications of Covid-19	Understand ing on what the ethical dimensions of Covid-19 recovery might be.
10:20- 10:30	Social and health inequalities	Speaker: A reflection on what Covid-19 has exposed in terms of social and health inequalities and what this might mean for Covid-19 recovery.	A focus on social and health inequalities
10:30	Move to small		
10:30- 10:50 (20 mins)	Gathering our	RECORDER ON Given what you have just heard:	Comments generated

Time	Agenda	Process	Expected Outcomes
	comments/ thoughts.	 Q1: What do you think are the key social and ethical considerations (and issues) around Covid 19 recovery might be? What topics interest you and why? What key ethical implications need to be considered? Why are you raising this point? Q2: Of the points we have discussed, which two do you want to take to the panel? Volunteers to present. RECORDER OFF 	around Covid-19. Moving participants from questions to comments on ethics/ social implications
10:50	Move to main	room	
10:50- 11:15 (25 mins)	Speaker panel Break	TS records all presentations for playing at future sessions/ uploading to Recollective. Note on the panel members - including speaker who brings experience of long Covid. We'll have a film on their experience after the break. RECORDER ON LF go round each group. Ask for one comment/ point first, then do a second round with the second point. Reflections from the panel on the comments/ points raised – highlighting the ethical questions/ dimensions the comments raise. RECORDER OFF	Key questions answered, others to be answered in Recollective
11:20	Break		
11:20- 11:30	Long Covid	A filmed interview from the perspective of someone living with long Covid and its consequences.	Considering the implications for Covid recovery
11:30	Move to small		
11:30- 11:55 11:30- 11:50 (20 mins) 11:50- 11:55 (5 mins)		RECORDER ON Q: What are your hopes/ concerns for Covid recovery? • Note the hopes • Note the concerns • Why are these hopes/ concerns for you • What matters most to you? • What matters most to society more broadly? Facilitator to create a summary sheet of 3 main points to be shared on Recollective. To be shared on Recollective after the session for	
		•	

Time	Agenda	Process	Expected Outcomes	
		RECORDER OFF		
11:55	Move to main	room		
11:55- 12:00	Menti	www.menti.com MQ2: One point you will take from this morning into our next workshop on 7 th August?		
12:00	Close	Explain that the homework space will give them the explanations they need for the homework task – things that need to be completed before 7 th August when we meet for our final session.		
Reflective task in own time	Recollective	 Review final three points from each small group Review the presentations from this morning Final news reel on the future Filmed interview with Sir Kevan Collins on education Review anything else from since the programme struction you'd like to think more about 	three points from each small group resentations from this morning el on the future iew with Sir Kevan Collins on education hing else from since the programme started that	

Workshop 3 process plan: Future pandemics and final considerations

Time	Agenda	Process	Expected Outcomes
9:50- 10:00	Participant and speaker/ observer check-in	Participants are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer. Explain about the code. As we're settling in you could take a minute to think about future pandemics as that's the focus of our discussions today. We'll be discussing this in our first small group discussion. Participants encouraged to get a pen and paper and have their participant pack with them. Once settled they can mute/ turn video off/ get drinks and snacks before we start promptly at 10am.	Participants and speakers/ observers set up and ready
10:00- 10:15	Introductions & workshop purpose	Warm welcome to the third workshop, setting the tone for the session: LF: Hello and welcome to our final workshop exploring the social and ethical implications of Covid-19. Reminder of the information in the participant packs. In a moment we will look at what to expect for this final workshop, but first, let's remind ourselves who is on the Zoom: We'll use the 'pass the baton' approach: Reminders of who is on the team from HVM	Participants know the purpose and format of the webinar Get participants back into the

Time	Agenda	Process	Expected
	Menti.com	 Asks Accelerator team members and all observers to introduce themselves: Name, organisation, role, passing the baton to the next team member Shares this morning's programme Shares the points to help the discussion previously shared with the participants in their packs A reminder of the research question (will happen at each workshop) 	outcomes space with reminders and information.
10:15-	Introductory	M1: What has been on your mind in relation to Covid-19 since we met last Saturday? LF introduces speakers & TS records all	To remind
10:20 (5 mins)	presentation	presentations for our records. Speaker: An overview of the headline themes discussed in the last workshop.	people of where we were, having discussed covid-19 recovery.
10:20- 10:30 (10 mins)	Future epidemics and pandemics	Speaker: An overview of what the ethical considerations of future pandemics might be. Given all that has been discussed so far reflections on the ethical and social dimensions of thinking about future epidemics and pandemics.	A focus on the social and ethical considerations of future pandemics
10:30	Move to small g	rouns	pariacrines
10:30- 10:50 (20 mins)	Gathering our comments/thoughts.	RECORDER ON Given what you have just heard: Q1: What do you think might be the key social and ethical considerations (and issues) around future epidemics and pandemics? • What topics interest you and why? • What key ethical implications need to be considered? • Why are you raising this point? Q2: Of the points we have discussed, which two do you want to take to the panel? Volunteers to present. RECORDER OFF	Comments generated around Covid- 19. Moving participants from questions to comments on ethics/ social implications
10:50	Move to main re		
10:50- 11:15 (25 mins)	Speaker panel	TS records all presentations for playing at future sessions/ uploading to Recollective. RECORDER ON	Key questions comments and reflections made.

Time	Agenda	Process	Expected
		LF go round each group. Ask for one comment/ point first, then do a second round with the second point. Reflections from the panel on the comments/ points raised – highlighting the ethical questions/ dimensions the comments raise. RECORDER OFF	Outcomes
11:15- 11:20	Menti.com	Q2: What matters to you right now in relation to Covid-19? Q3: What will matter to society given future pandemics?	Closing off that section of the discussion.
11:20- 11:30	Break		
11:30- 11:35	Presentation	Lead Facilitator: reminder of all the stimulus seen/used so far including workshop presentations and Recollective stimulus. Visual prompts for the discussion that follows.	Giving people a reminder to inform their final discussions
11:35	Move to small g	roups	
11:35- 12:35		RECORDER ON We are going to spend the next hour pulling our thoughts together. When you think about Covid- 19, Covid recovery and future pandemics:	
11:35- 12:10 (35 mins)		 Q: What are the ethical and social considerations you believe are significant for society? Prompts to be used as useful/ necessary: What is significant for you? What is significant for society more broadly? What points do we want to make about personal v. collective responsibility? What, if anything, do we want to say about 	
12:10- 12:25 (15 mins)		 fairness? What, if anything, do we want to say about inequalities? What, if anything, that happened during the pandemic should stay in place e.g. flexible home working/ a focus on the environment? 	
12:25- 12:35 (10 mins)		 Q: Given all we have discussed what is an urgent priority for: Ongoing public engagement? Work by the Pandemic Ethics Accelerator and others including further research? Prompts to be used as helpful/necessary What more should be done to understand view points and perspectives on the social and ethical considerations around Covid-19? 	

Time	Agenda	Process	Expected Outcomes
		What should be done to inform policy on Covid-19?	Outcomes
		Facilitator to ask the group what the most important points have been in this discussion. Together create a summary sheet of 3 main points to be shared in the plenary. Volunteers to present — with reminders that we have 3 mins per group in the plenary. RECORDER OFF	
12:35	Move to main r		
12:35- 12:45	Group presentations	Each group presents their 3 main findings in turn.	Understanding of what each group has said/been thinking about.
12:45- 12:55	Reflections back	Sarah Cunningham-Burley and Ilina Singh give their thoughts on what they have heard including what the Ethics Accelerator will do as a result of the discussions in this public dialogue	Participants know they have been heard
12:55		www.menti.com MQ: One word of advice for the UK Pandemic Ethics Accelerator	
13:00	Close	With thanks for all their hard work in the workshops and on Recollective. The Accelerator may want to have workshops on Covid-19 and future pandemics in the future, so there may be an opportunity to meet again over the next year. The Accelerator will be in touch with you directly about this.	



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