

Ethical concerns relating to current experiences and future expectations of Covid-19

June 2022





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Executive Summary

The public dialogue on ethical concerns relating to current experiences and future expectations of Covid-19 was commissioned by the University of Edinburgh on behalf of the UK Pandemic Ethics Accelerator (EA). The Accelerator is a consortium of the University of Oxford, UCL, the Nuffield Council on Bioethics and University of Edinburgh. It is funded by UK Research and Innovation (UKRI). Hopkins Van Mil (HVM), deliberative engagement specialists, were contracted to design and deliver the dialogue.

1. Dialogue aim

The aim of the dialogue was to follow up on the dialogue that HVM conducted on behalf of the Pandemic Ethics Accelerator in 2021, to explore identified issues in the changing context of eased restrictions and for the future.

The dialogue offered an opportunity for diverse citizens to come together to identify the main social and ethical issues and concerns around current experiences of Covid-19, as restrictions ease and change, and future pandemics. The dialogue findings will inform future work of the Accelerator partners and:

- The Accelerator partners' contribution to government inquiries
- Public and policy debate on post-Covid futures, public deliberation and public ethics.

2. Dialogue process

The dialogue was designed by HVM in collaboration with the Accelerator's Project Team and took place over four workshops held in May 2022 (Figure A).



Tasks in participants' own time in the online homework space

Figure A: Dialogue process

32 participants were purposefully recruited from across all four UK Home Nations, with a balanced participation from each country. The cohort were broadly representative of the population in terms of age, gender, life stage, social grade/ household income, geography and ethnicity, with a boosted sample for those particularly adversely affected by the impacts of Covid-19. As is typical for public dialogue, participants were incentivised to take part in the workshops and contribute to an online homework space.

3. Key findings

This dialogue builds on the findings of HVM's previous dialogue report and has equally revealed important ethical and social considerations, what we are calling the 'social contours' of Covid-19. The report demonstrates significant aspects of the ethical dimension of Covid-19 including the dynamic between individual and collective action and responsibility; the complexities of discussions around trust in relation to the government response to the pandemic; and the ethics of compassion. We hope these findings are valuable to the Accelerator's partners and wider policy stakeholders' considerations on Covid-19 inquiries; 'living with Covid' and responding to future pandemics. Findings reflect a balance between participant led discussion and researcher analysis of those discussions. The findings are drawn from a robust qualitative process typical of public dialogue. The findings are grouped under 1) research topics and 2) findings from each report section. These are set out below.

Research topics:

As a result of taking part in the dialogue participants have identified areas where further research could be undertaken on the experience of Covid-19 and which highlight key points for consideration on future pandemics. These are described in subsequent sections, but we highlight two here which are significant.

- 1. Developing tools for use in preparing for the next pandemic, including research into:
 - What support is needed across society to recover from the trauma of Covid-19, particularly for those who have suffered traumatic loss, and children and young people
 - What transparency in government decision making, policy making and communications should be like in a pandemic
 - How to prepare populations for a future pandemic including trusted sources of information, evidence and data
 - Who should deliver trusted communications on future pandemics and how.
- 2. Research into and policies for the rules, measures and restrictions, appropriate for future pandemics including:
 - How these should be agreed on in the future
 - Who would provide the most effective leadership on the rules, measures and restrictions
 - How to develop a subtle approach to implementation which does not cause more harm than good.

Findings from each report section

In writing this report we conclude that participants have welcomed the opportunity to take part in deliberative discussions on an issue which does, and will continue to, affect us all. They emphasise key points that they hope those making policies for future pandemics will take into account. These are summarised out below:

Mental health

- The anxiety around Covid-19 has not gone away, participants feel that uncertainty around how to apply personal responsibility, and keep those at higher risk in society safe, is a challenge which cannot be ignored.
- As a result poor mental health and the need for more resources for mental health support is highlighted.

Children and young people

- Concern is expressed that the impacts on children and young people have been extremely significant
- Participants fear that the consequences may be felt for years to come unless acknowledged and addressed.

Inequalities

- Covid-19 has exposed pre-existing inequalities.
- Now that they are more visible in society participants call for more action to address them so that social and economic divisions within communities do not widen further
- Participants feel this might be too idealistic, but it should nevertheless be a significant societal ambition.

Tensions and trade-offs

The dialogue has shown that in this transitional phase of the pandemic as restrictions are lifted there are significant tensions in society. In particular participants question the concept of 'freedom' as applied to Covid-19 rules being lifted. They call for an empowerment rather than oppositional language to be applied to ongoing deliberations on a future with pandemics.

The common good

As in the previous dialogue, solidarity, togetherness and the common good are seen by participants as very important in a future with pandemics. The ethics of a caring and compassionate society are highlighted by participants and as such they prioritise collective over individual needs in a pandemic.

Rules and measures

As restrictions lift, ease and change in this phase of the pandemic participants share a mix of relief and concern. They treat this issue too with great consideration being aware that everyone in society has had their own particular experience of the pandemic and therefore may react in many different ways to restrictions lifting. They call for thought and respect to be given to those, because they are at higher risk from the virus, who may not welcome this new phase.

A view from the home nations

Across the home nations, participants want to see greater clarity around the steps being taken or not taken by their governments in this phase of the Covid-19 pandemic. There is an expectation that guidance ought to be more obviously linked with responsible individual behaviour (e.g., around mask wearing and social distancing). Decision-making needs to continue to be justified, supported by more accessible and comprehensible evidence in the public domain. Some participants want the lifting of restrictions to be as clearly communicated as was their implementation. They express:

- A real desire for governments to act with transparency. In Northern Ireland, participants want less performance politics and more emphasis on government processes, as well as clear links between the actions taken by government and their public benefit.
- Their concern for the strength of public services, which receives mention in England and Northern Ireland especially. Services are thought to have been in a vulnerable state before the pandemic and are now perceived to be recovering too slowly. Participants want to see capacity increased as soon as possible, with resilience to future shocks built up in the longer term.
- Participants also want more collaborative governance within and between the home nations on pandemic responses. Collaboration is linked with consistency, which seems to help people make sense of the pandemic. This is thought to be in the interests of the public, rather than the political jockeying participants tend to perceive as the main reason for differences over decision-making.

Underpinning ethical values and principles

The dialogue reveals important underpinning ethical values and principles:

- The need for trust in our government and public institutions, a trust which has been lost in the current phase of the pandemic
- The importance of transparency and honesty in building this trust
- A desire for a greater unity and collaboration across the UK's nations
- Achieving a balanced rather than an oppositional approach to policy making
- The common good prioritised over individual needs and wants
- Living in new ways with a great respect for other people to provide a compass for our actions in the face of future pandemics
- Acknowledging and learning from the harms caused to prepare for the next pandemic

These values and principles, if upheld in society, will, in the eyes of participants, create a compassionate, equitable society which learns from its mistakes and builds fairness and trust into preparing for future pandemics.

Proposed solutions to living in a pandemic

Participants identify a number of factors which could improve how pandemics are managed in the future. These include:

- Having a more nuanced and subtle approach to protecting people at risk during a pandemic, tailoring lockdowns to absolutely essential risk management rather than a blanket approach
- Putting in place a plan for education in future pandemics so that the system can provide the education we expect for our children and young people
- Prioritise mental health and wellbeing including additional resource for mental health services across the country so they are more equipped to deal with the trauma of future pandemics
- A holistic approach to pandemic policy making which could include, for example greater investment in education on the science of a pandemic; the creation of an emergency fund which would be drawn on to fund emergency measures in the future; a multi-agency approach nationally and globally.

Participants also believe that citizens should have a greater involvement in policy and decision making for pandemics in the future. They call for measures which bridge the gap between publics and policy makers which might include:

- Developing contracts between the government and the people e.g. a 'transparency contract'.
- Calling on deliberative approaches: dialogue, assemblies and juries when, for example a decision might adversely affect one community more than another or where a balance is required between policy areas or restrictions.

Finally, we conclude by emphasising that participants desire a caring society, one where communities support each other. Where volunteering is encouraged and support for others is the norm.

1 Introduction and background

The public dialogue on current experiences and future expectations of Covid-19 was commissioned in March 2022 by the University of Edinburgh on behalf of the UK Pandemic Ethics Accelerator ('the Accelerator')¹. It was designed as a follow up on the dialogue that Hopkins Van Mil (HVM) was commissioned to conduct in 2021 by the Accelerator (commissioned by the Nuffield council on Bioethics for the Accelerator) to explore identified issues in the changing context of eased restrictions and the future. The work was managed by a Project Team drawn from the dialogue partners.

1.1 Public dialogue partners

The UK Pandemic Ethics Accelerator is an 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 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 conducts rapid synthesis of public and stakeholder values and attitudes, including public dialogue. As a result develops 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) brings people together to inform the future. We use deliberative qualitative approaches to create safe, inclusive, purposeful and intellectually stimulating environments to explore the big issues of our day. We support our clients and participants to listen, explore and challenge people's perspectives to find constructive ways forward.





¹ ukpandemicethics.org

1.2 Background to the dialogue

Socially acceptable and ethically robust policy needs to engage with the current scientific pandemic evidence, the wider societal context, and publics and stakeholders whose lives are being transformed by it. Public health ethics have always had to balance collective and individual concerns and trade-offs between different principles are required. Navigating routes through these requires transparency and dialogue to allow for the full range of different values, interests and perspectives in policy making and governance processes. In this way, dialogue and inclusive understandings can shape how evidence is generated, considered and acted upon and policy and interventions developed. This thinking has informed the work of the *Public values*, *transparency and governance* workstream of the Accelerator.

The Accelerator commissioned a rapid public deliberative dialogue to inform its ongoing work, engagement with stakeholder groups, and potential future engagement with the public. HVM conducted the dialogue, in close collaboration with the Accelerator team. This first report was published in September 2021².

1.3 Public dialogue in a time of change

The public dialogue fieldwork took place over three evenings and a Saturday in May 2022. Our discussions with dialogue participants began at a time when Covid-19 restriction measures had eased or been lifted in all of the UK's home nations to become guidance rather than a legal restriction. These changes to restrictions happened at different times in 2022 (see figure 1.1).

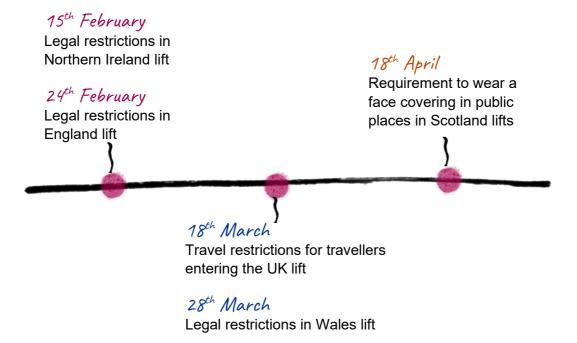


Figure 1.1: Restrictions lifting timeline

Hopkins Van Mil
We bring people together to inform the future

² Hopkins H, Kinsella K, Evans G, <u>Pandemic Ethics: A public dialogue on the ethical and societal considerations of Covid-19, Covid-19 recovery and future pandemics</u>, Hopkins Van Mil, September 2021

In April and May the Metropolitan Police confirmed it had issued fixed-penalty notices (FPNs) for events in Downing Street and across Whitehall spanning eight separate days, with 28 people receiving between two and five fines. The Prime Minister and Chancellor of the Exchequer both received a fine. The findings of the second permanent secretary's investigation into alleged gatherings on government premises during covid restrictions, known as the Sue Gray report³, were published on 25th May 2022.

Given this timing we see that participants' thoughts turned to concerns about the impact of restrictions lifting and changing. They considered the fact that changes happened at different times in different home nations. They also spent significant time reflecting on trust and transparency, particularly in relation to government decision making. Facilitators throughout the dialogue prompted participants to consider these factors, but also to think beyond them to a future with Covid and other pandemics, so that discussions did not exclusively focus on the ethical implications of this particular stage of Covid-19.

Policy makers during the pandemic have engaged the public most frequently through opinion polls⁴ and surveys⁵ conducted to measure citizens' beliefs about covid, to test compliance with social distancing requirements and to understand potential take-up of vaccinations. Some deliberative engagement⁶ 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 builds on the first dialogue, which was the first to focus explicitly on people's ethical considerations in relation to Covid-19, Covid recovery and future pandemics. In conducting this second dialogue we develop and build on the themes covered in the first. These include reflections on the complex trade-offs in collective versus individual priorities; the careful consideration given to compassion and solidarity and, of key importance, learning the lessons from the collective experience of Covid-19. We describe participants' views in this report, including where they have extended the thinking described in the first dialogue.

1.3 Dialogue aims and objectives

1.3.1 Dialogue aims

This follow up public dialogue offered the opportunity for a diverse group of 32 citizens to come together to identify the main social and ethical issues and concerns around the changing picture of restrictions in the UK and a future with pandemics to inform:

- The ongoing work of the Accelerator partners in this field
- Contributions to government inquiries
- Public and policy debate on post-Covid futures, public deliberation and public ethics.

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We bring people together to inform the future

³ The Cabinet Office, 25th May 2022

⁴ E.g. Ipsos MORI's public and sectoral polls since March 2020

⁵ E.g. YouGov's tracker reports

⁶ 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)

1.3.1 Dialogue objectives

The objectives of the dialogue were agreed by the project team. They are to:

- Gain an understanding of people's experience of Covid-19 as restrictions are eased
- Explore differences in the home nations
- Build on the first dialogue's findings in relation to inequality, intergenerational issues, public health ethics and policy, trust, transparency and wellbeing
- Understand the ethical values and principles that underlie dialogue participants' views as they consider a desirable future society
- Produce a report suitable for sharing that will help inform current and future research.

1.4 What is public dialogue?

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

1.5 Recruiting dialogue participants

This was a somewhat larger, but nevertheless small-scale, public dialogue with 32 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 (see Appendix 1) 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, people experiencing racial inequalities, and people with disabilities were overrepresented in the sample.

Our preferred approach to recruitment is 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 in each of the home nations (figure 1.2).



Figure 1.2: Recruitment locations

To ensure we achieved a range of perspectives on Covid-19 we asked participants 'How worried or unworried are you by the transition out of Covid-19 restrictions?' ⁷. 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

⁷ Mirroring the question asked in the ONS survey: Coronavirus and the social impacts on Great Britain.

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 Recollective⁸. Five out of 32 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 delivered within a month of completing the design. 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 four 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 (figure 1.3).



Tasks in participants' own time in the online homework space

Figure 1.3: Dialogue design framework

Before attending the workshops, participants were emailed a participant workbook (Appendix 3) 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 restrictions lifting and changing and future pandemics they would like to 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:

⁸ 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.

- 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.

Table 1

Workshop 1: Experiences of Covid-19 now

Pre-workshop:

Participant workbook – guidance on joining the dialogue, sources of further information and workshop contents

Film - An introduction to the dialogue: Henrietta Hopkins, HVM; Sarah Cunningham-Burley and Hugh Whittall UK Pandemic Ethics Accelerator

Infographic – a Covid-19 timeline of key events from 19th July 2021 (the end of the first dialogue) to April 2022

During the workshop:

Presentation - John Coggon, Professor of Law in the Centre for Health, Law and Society, University of Bristol: As Covid-19 restrictions are changing and lifting Covid-19 what are the ongoing implications for society in relation to human rights/ freedoms. The legal and ethical context.

Workshop 2: A focus on the Home Nations

Pre-workshop:

Infographics from the Health Foundation's Covid-19 impact inquiry

Film – What do we mean by ethical? A recorded presentation from Jamie Webb, University of Edinburgh/ Early Career Researcher - UK Pandemic Ethics Accelerator

Data from government sites for England, Scotland Wales and Northern Ireland on the current Covid-19 statistics on, for example, cases, deaths, vaccinations and virus testing.

During the workshop:

Films from the Health Foundation's Covid-19 impact inquiry on <u>purpose</u> and <u>participants</u>

Presentations:

Scotland: Dr Margaret Douglas, Programme Co-Director, Masters of Public Health (full time), Usher Institute, University of Edinburgh Honorary Consultant in Public Health, Public Health Scotland

Wales: Dr Heather Payne, Child Health, Senior Medical Officer, Welsh Government

Northern Ireland: Duncan Morrow, Professor in Politics and Director of Community Engagement, Ulster University, Belfast (film)

England: Jasvir Singh, Co-Chair of the UK Government's Moral and Ethical Advisory Group (MEAG), Chair of City Sikhs and Vice-Chair of the Faiths Forum for London he is also a family law barrister (film).

Workshop 3: Expectations of future pandemic preparedness

Pre-workshop:

Film - lived experience of Long Covid

During the workshop:

- 1. The mental health impacts of Covid-19 and the implications for governance and policy for the future: Dr Alex McKeown, Research Fellow Neuroscience, Ethics & Society: Department of Psychiatry / Wellcome Centre for Ethics and Humanities and Deputy Director UK Pandemic Ethics Accelerator
- 2. Ethical Implications of Biosurveillance and Future Pandemic
 Preparedness: Emma Nance, Academic Fellow in General Practice, Centre for
 Population Health Sciences, Early Career Researcher UK Pandemic Ethics
 Accelerator

Workshop 4: Bringing our thoughts together

Pre-workshop:

Reviewing all the materials shared in the dialogue so far

Reviewing answers to questions asked during the dialogue

During the workshop:

- A summary of the presentations made during the dialogue
- A summary of views and topics for discussion shared by participants

The process plans used to frame discussions are set out at Appendix 2.

1.7 Analysis and reporting

The online dialogue workshops generated thirty-six 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. We have used more quotations in this report than might be typical

in public dialogue reporting. We have found participants' own words powerful, moving, and the best demonstration of how they have responded to an exploration of this critical time in the development of the pandemic. Quotation selection 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. What we are calling 'the social contours of Covid-19' follows, setting out important societal implications in the short and long-term for individuals, communities and countries. We continue with an examination of the tensions and trade-offs shared by participants. Chapter five focuses on views from the perspective of each of the home nations. Key values and principles raised during the dialogue, building on the first dialogue, are then presented with a focus on trust, trustworthiness and transparency for government and public institutions. The report concludes with an analysis of the thinking behind participant deliberations, summaries of next steps and final considerations.

2

Themes and topics raised by participants

2.1 Topics raised in advance of workshop one

In advance of the first workshop, participants were asked to raise topics they would like to see addressed in the dialogue in relation to Covid-19. These were shared with all participants and dialogue facilitators in an online workspace tailored for this dialogue⁹. All 32 participants contributed at least one topic they were interested in discussing; taken together, these reveal a diverse range of priorities among participants, though several common themes emerge. Comments run from a few words in length – 'mask wearing hand gel use' was the briefest – through to several sentences. Some participants framed their responses as questions they would like to see answered, while others shared their personal experience. From the outset, participants showed a clear interest in thinking about pandemic ethics across different temporalities: looking at the recent past to learn lessons from the COVID-19 pandemic, thinking about the appropriateness of different measures in the present day, asking how we can better prepare ourselves for a future shaped by this pandemic and others to come. Topics raised are summarised in the table below, organised thematically by the research team.

Table 2

Social & longer-term impacts of Covid-19



- impact on overall health from appointments and check-ups missed or cancelled because of the pandemic
- impact of lockdowns on child development and inequities in technological access
- social and mental health effects of the pandemic, including anxiety around renewed social interaction
- vulnerabilities to Long Covid and mitigating the risk
- positive lessons from the pandemic
- continuing impact on social and working lives, including sick leave, difficulties in recruitment and poorer treatment of staff by the public

"The social (or mental health) effects of COVID-19 and how individuals now feel post the pandemic stage."

⁹ HVM tailors <u>Recollective</u> for public dialogue use. It provides a space for participants to reflect/ review materials in between workshops

Pandemic preparedness



- living safely with COVID-19
- building resilience into the NHS
- vaccine development in response to new variants
- restoring faith in government to handle future pandemics
- preventing excessive financial gain from future pandemics

Governance



- did the Government govern effectively?
- rule-breaking and accountability in government
- remembering the successes of the pandemic response
- political value placed on the NHS

Rules, measures, shielding



- interest in maintaining isolation periods for positive cases and social distancing in some spaces, such as NHS waiting rooms
- mask wearing, now and in the future
- situation of people who are clinically extremely vulnerable (CEV), including the impact of easing restrictions on them

"Should mask
wearing be something
we encourage going
forward as part of
learning to live with
the pandemic?"

Financial considerations



- support for self-employed people during lockdowns
- continuing to support small businesses still in recovery

Mental health in lockdown



- effects of previous restrictions on mental health and well-being
- fear of future lockdowns and the impact on mental health

Vaccination



 negative influence of misinformation on the uptake of COVID-19 vaccinations, including demographic differences. "The fear that lockdown measures could return in the future, either related to COVID-19 or a new virus and the impact this would have on mental health?"

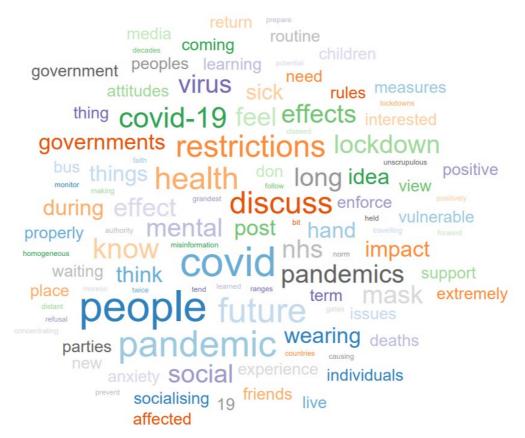


Figure 2.1: Participants words from the online space before workshop one

2.2 Topics raised in advance of workshop two

Between the first and second workshops, scheduled one week apart, participants were again asked to raise topics they would like to discuss. In line with the theme of workshop two, they were asked their perspective on how the government in their home nation is currently handling the pandemic. The task was carried out in the same format as workshop one, this time by 30 participants. Comments showed similar variation in length to the first set of comments, however many participants went into greater depth in their responses on this occasion. While some topics raised before the first workshop were repeated - pandemic preparedness, the mental health impacts of COVID-19, mask wearing – participants contributed a remarkably broad set of new topics to the discussion. Issues specific to – and differences between – the home nations were raised most frequently. Governance and the communication of public health information were also brought up repeatedly. Testing, vaccination and the current state of the NHS were each mentioned more than once, with new points also raised in relation to young people and financial considerations. Three participants expressed explicit concern that restrictions were being relaxed too quickly. One participant was interested in discussing 'the narrative of freedom vs non freedom.' Topics raised are once again summarised in the table below, organised thematically by the research team.

Table 3

Home nations



- inconsistencies between countries and counties and the issues this caused
- performance of Scottish Government
- Northern Ireland's policies, performance of its Health Minister and comparisons with Republic of Ireland
- Long Covid epidemiology across the home nations
- 'point scoring' between nations
- confusing governance in England

Governance



- decision-making in the pandemic
- misconduct in office, including contracting and rule-breaking
- a 'public review' on COVID-19

Public communication



- continuing to share data on infections and mortality
- clarity of public health guidance, press and public briefings

Testing



- importance of continuing to test
- confidence around case numbers

Vaccination



- booster vaccines
- non-mandatory vaccination

Relaxing restrictions



- current guidance on mask wearing
- speed of change, overconfidence

State of the NHS



- impact of COVID-19 on the NHS
- improving ambulance waiting times

"Have we removed restrictions too quickly? Would it not have been better to remove one restriction at a time and monitor the effect?"

"I'd say it's all been about point scoring to try and one up each other. Every time a new rule came out the other nations had to make sure the new rule was slightly better in some way."

Pandemic preparedness

- living with and moving on from COVID-19
- preparing for future pandemic, addressing inequalities

Financial considerations



- economic support policy to enable recovery
- how will we 'pay for covid' and cost of living

"How to go forward and provide enough protections without economic problems and of course ethical problems?"

Young people



- impact on young people's mental health
- compensation for students

Freedom



 Contesting the narrative of 'freedom vs non freedom'

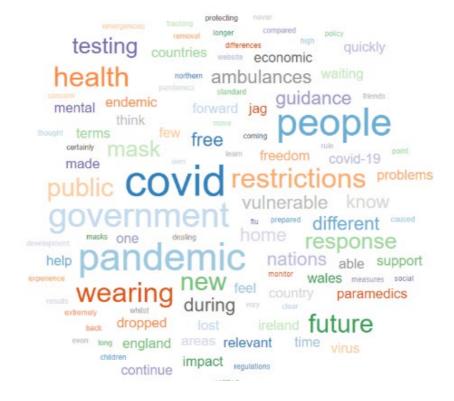


Figure 2.2: Participants words from the online space before workshop two.

2.3 Topics raised in advance of workshops three and four

Ahead of workshop three, participants were invited to raise any further topics they would like to discuss in the remainder of the dialogue. They were asked in particular about the ethical and social considerations of living with COVID-19 and future pandemics. Most (25) participants shared their comments prior to workshop three, with the remaining (5) participants offering input between workshops three and four. In line with the prompt accompanying this task, most participants clearly oriented their responses towards the future. Participants also engaged with topics in the context of ethical considerations more so than in previous similar tasks, with multiple participants weighing up the benefits and drawbacks of particular policies, or the relative importance of different priorities (see 'Tensions' in the table below). 'How do we get the balance right, so that the vulnerable are protected but not singled out in future outbreaks' is one example of this. Other participants introduced ethics into familiar topics, such as in the comment 'the ethics involved in the decision to stop social distancing in GP and NHS hospital waiting rooms.' Topics raised previously and once again returned to include long Covid, the pandemic's impact on mental health, and trust and accountability in government. All topics raised are summarised in the table below, organised thematically by the research team.

Table 4

Pandemic futures



- preparing for future pandemics, including government planning
- financing of future responses
- maintaining major services
- educating the public and organisations on pandemic preparedness
- rebuilding public trust to promote compliance with future measures
- risk of further global outbreaks as travel increases
- life post-Covid

"Improving preparedness for the next future shock so that civil society is better prepared to cope with the challenges."

Society



- individual and collective responsibility
- returning to normal
- technological progress and working from

Protecting public services



- immediate investment in the NHS
- %GDP spending commitments on public services

Public health



- obesity as a public health challenge
- disease diffusion models to measure the spread of COVID-19

Governance



- learning lessons from COVID-19 in government
- trust, accountability, lawbreaking

Vaccination



- booster vaccines
- sharing vaccines with the rest of the world

"Should we have given more vaccines to more in need countries when the majority of the UK had their first."

Relaxing restrictions



- ethics of end to isolation and social distancing
- legal implications of not isolating

Tensions



- balancing pandemic measures against wider healthcare and education priorities
- protecting the vulnerable without singling them out

Mental Health



long-term mental health impacts of COVID-19

"Managing this and future pandemics without setting back so much progress around health care and education."

Young people



 inconsistencies across schools on online education

Long Covid



 impact of Long Covid on long-term health, insurance, financial well-being

COVID-19 origins



discovering the origins of SARS-CoV-2

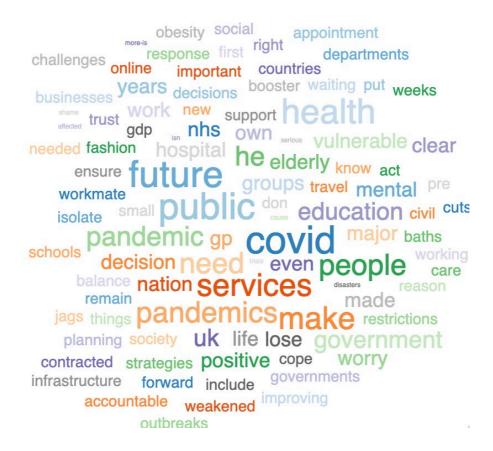


Figure 2.3: Participants words from the online space before workshops three and four

Hopkins Van Mil
We bring people together to inform the future

3

The social contours of Covid-19

In this chapter we explore the range of themes that emerge from the topics participants wished to discuss during the dialogue. We focus on the areas that participants emphasise and elaborate on beyond their first thoughts. Collectively the subjects discussed in this chapter provide an overview of the concerns that frame a Covid-19 dialogue. They set out a landscape for what is important and that form the social contours of Covid-19. These include mental health; impacts of the pandemic on children and young people; financial issues; and the collective memory of the height of the crisis. Participants describe the 'shock' of Covid-19 that they perceive now that most severe aspects of the crisis have passed. They welcome the opportunity to raise issues of significant concern. We begin with a summary of what participants see as the social contours of Covid-19. These can be summarised around three main areas:

- Measured relief at the lifting of restrictions
- Personal integrity
- Respect for, and thinking of, others

For some the easing of restrictions brings with it relief and joy. Here a participant from Northern Ireland speaks of her experience running a Bed & Breakfast,

It's fantastic just to see visitors coming. People are just so much more relaxed. I had some people from Teeside staying last couple of nights and they were just so full of the joy which obviously comes out of coming to Northern Ireland. It was for them a real treat. And it's just seeing people, it's almost like a heavy weight coming off their shoulders.

However, many participants remain worried about a future living with Covid-19, despite restrictions lifting and changing across the UK. Having respect for others in this fluctuating phase of the pandemic is a priority for participants. Some said that was easier to achieve when there were clear legal restrictions on, for example, travel, mask wearing and social distancing. The way we live now, with the onus on personal responsibility for doing the 'right' thing, is seen as more of a challenge in the minds of participants.

When we had legal restrictions in place it made it a lot easier for me to feel like I was doing the right thing about staying away from my parents. I'm 1 of 7 siblings, and we live all across the country, but when the restrictions were in place it was easier for us all to make those decisions not to see them, but when they started being lifted I still was quite cautious about fearing that I might pass something onto my parents and whereas the attitude of most of my siblings was, 'Well, it's not in law, therefore, we can do what we want.'

Some also said they now find it harder to take a stance on measures that they still feel are important when those around them are no longer social distancing or wearing masks. They describe a sense of pressure to conform with what the majority are doing even if they would personally feel more comfortable by keeping some practices, such as mask wearing on public transport, in place. Participants feel this is an ethical

dimension, what is right or wrong when the onus is on the individual to decide how to live with Covid-19? Such dilemmas are seen to cause people anxiety as is shown in the next section where we discuss an issue prioritised by many dialogue participants: mental health.

3.1 The mental health impacts of Covid-19

Participants stress that the fact that Covid-19 was a collective experience does not diminish the personal trauma associated with it. They demonstrate that mental health is a multi-faceted issue including everything from low level anxiety to very serious mental conditions and illness. This is made clear by many participants prior to taking part in the dialogue, including the following point,

I would like to discuss the social (or mental health) effects of Covid-19 and how individuals now feel post the pandemic stage including engaging with friends/ family who may not be vaccinated, anxiety issues, and travelling abroad.

During the dialogue participants describe their concern that very severe Covid-19 restrictions might be imposed again with words such as 'fear', 'stress', 'worry' and 'anxiety'. For many this hasn't diminished with restrictions being eased and, in some groups, participants welcome the opportunity to discuss this with others, to feel that they are not alone in having serious concerns about the diverse and long-term mental health impacts of Covid-19.

They call for recognition that it isn't possible, or desirable, to move on, to brush these anxieties under the carpet. They feel strongly that without an acknowledgement that there is a mental health problem in the UK, the government are letting society down. As one participant puts it:

The mental health aspect is the most important for me. The way that government talks as though they're doing so much to get it available is such lies... it makes them look even more out of touch with the public.

There's still an anxiety around (Covid-19). What if it happens again? It's taken a massive toll I think on everybody's mental health.

Having to change behaviours during Covid-19 is seen as a cause of anxiety by some participants. They describe aspects of their personality before Covid-19, for example, 'a hugger', but now must change how they behave in order not to inadvertently spread the virus or cause harm to those at high risk. Having to constantly check what you are doing and go against your natural instincts was seen as an issue for many and still rather 'strange'.

I have a lot of friends that were very anxious-, they were very strict on your, 'Stay 10 feet away from me.' And I was thinking that if one of us was a really big hugger and maybe one of my friends would be anxious about, 'Is she going to hug me?' And then feeling that they don't want to offend you. And that might cause someone to just say, 'I'm not really feeling well so can we just give it a miss?' It's so human to want to be near each other and you nearly have to change that, it's strange.

Participants describe a collective Post Traumatic Stress Disorder (PTSD) that they feel many people in society must now have as a result of the fears and anxieties arising from Covid-19. This includes for those who have lost loved ones in traumatic circumstances, such as being unable to visit them at the end of their life. Others describe situations of terrible grief.

I lost my father to Covid and miss him every single day. He caught it in hospital in December 2020 and it damaged his lungs beyond repair. We were allowed to care for him at home. It was nine weeks of watching him suffer so badly before he died.

Participants explain that the trauma includes losing family and friends who have died from Covid-19 and related illness, but goes far beyond the fear of being ill, catching the virus or giving it to others. Now that the phase of the pandemic has moved on it also extends to the impacts of:

- Being isolated for long periods of time, particularly those who live on their own and/ or who were advised to shield
- Not receiving treatment for serious illnesses unrelated to Covid-19
- Constantly being alert to the risks and dangers now that legal restrictions are not in place, particularly when you might cause harm to others.

As restrictions ease and change participants state that they expect to feel a greater sense of relief, but share that this hasn't been apparent to them so far because of these ongoing fears and anxieties.

You can't have mental health problems one day and suddenly the restrictions are gone, 'Oh, I don't have any mental health problems anymore.' That's not how it works. A lot of people are dealing with the emotional shrapnel from Covid-19 still.

Concern for those who had to shoulder a great deal of the burden in the height of the pandemic is an important thread for participant discussions. For example, those with jobs in the care or health sectors who worked right through the pandemic supporting others, but who may only now be suffering the consequences of that expressed in mental ill health.

3.2 The impacts of Covid-19 on children and young people

Linked to discussions around mental health, but not exclusively so, is the strongly held belief by participants that the impact of Covid-19 on children and young people has been and continues to be severe, with the consequences not fully understood yet. For some a key ethical concern is the impact on the younger members of society. Participants express disappointment and anger that children and young adults had to isolate during the pandemic, and they wonder if this was the right decision when consideration is given to the relative harms and benefits to young people. Key concerns for broad age groups are listed in figure 3.1.



raise of harms to older children and young people as a result of



Figure 3.1: Participants concerns on the impacts of Covid-19 on children and young people

Participants highlight the mental health impacts on children and young people, in relation to abiding by the restrictions, particularly social distancing, and the impact of lockdowns. The social, financial and academic impacts for many feel very harsh.

Their mental health has really been impacted I feel, more than most. Especially the ones who were about to take their exams two years ago. Like, none of them had their end of school proms. It was just hitting them from every angle. They couldn't go out. They couldn't socialise. Financially, the parents didn't have enough to keep the internet running.

An emphasis is placed on the unintended consequences of the universal application of successive lockdowns by participants. They feel that the very young, teenagers and university students will suffer adverse effects from this policy for years, even decades to come, unless appropriate interventions and support are put into place now. Parents in the group suggest there is a concern that the effects are not being taken seriously,

As a dad my concern has been to try and motivate my younger daughter through her GCSEs and now A-levels and the toll on them. For me, two years is not a high percentage of my life. For them it's a significant percentage and I think we underestimate the effect that that's had on them.

They worry about this in the short-term, for example, those children who had teacher assessed GSCEs are now sitting public exams for the first time. Many participants believe that they are doing so without support in place, support which recognises that they have not had a typical build up to their A' levels. For some the realisation that they would now be taking A' levels when their GCSEs had not taken place in the traditional way is a significant cause of alarm.

All of a sudden now they're faced with exams. They're back in their arena like nothing ever happened. There's been no coaching, like, 'You will do these exams.' And some of them are really stressed and really anxious.

These shocks are not limited to school age children. Some participants highlight that babies born in the pandemic have not experienced the social interaction that they would have without lockdown restrictions. Now restrictions have been lifted these children are, quite without preparation, meeting children their own age and the social skills required even at this young age are not in place. As one participant puts it,

It's such a shock, suddenly there's nursery, 'Look there are other children.', 'You have to share now, it's not just you.' It must be really hard.

Other participants agree, they refer to children whose speech and physical abilities have been delayed due to lack of social interaction and opportunities to learn from others.

Some participants also refer to the lack of opportunity for young people as we emerge from the restrictive phase of the pandemic. They refer to having to give young people notice from jobs that they have only recently started because of lockdowns. They speak of family members at the start of careers who were furloughed and then made redundant. They question whether these young people will recover, and will be able to forge a career given this difficult start in their adult lives.

I had students crying because they wanted to go home to their mums as I was having to give them the sack. My company couldn't support them, and I was, 'this is an absolute joke'. It's on my mind. How did they get through it? What will happen to them now?

3.3 Economic considerations

The economic and financial impacts of Covid-19 are an important part of the ethics of a pandemic. Participants consider that policies to protect and boost the economy are central to Covid recovery and are not being effectively discussed or implemented. They raise concerns about the ethics of living in economic uncertainty as a society,

Is there anyone working on the ways of how we will 'pay for Covid'? Mental health dropped, there's been a Russian invasion of Ukraine, everything is getting shockingly expensive. It is scary to think about the future. Is there any economic safety plan?

Other key economic considerations in relation to the Covid-19 landscape include:

- Supporting small businesses to rebuild after the income loss in the pandemic
- Providing tailored support for specific industries who were badly affected by lockdowns including the performing arts and hospitality
- Not forgetting the self-employed, many of whom were not eligible for any meaningful support during the pandemic
- Ensuring individuals and families have enough money to live on given the costof-living crisis on top of reduced incomes because of Covid-19
- Supporting people who lost their job during the pandemic and have now gone into debt.

Participants feel that a lack of action on the economy now will hinder the overall recovery from Covid-19 and create and exacerbate inequalities. Many suggest that policies proposed by the government are not being enacted in the way they had expected them to be.

The levelling up agenda should be a way of addressing economic problems but it needs resources the government seem unwilling to commit. You only have to look at the inadequate way they are failing to deal with the cost-of-living crisis to see they don't really care about alleviating poverty and tackling inequalities.

3.4 Societal inequalities

It is clear to participants that the pandemic exacerbated existing inequalities and made them more visible to society. They believe that in revealing systems under stress Covid-19 brought to the fore issues which might have been more hidden prior to 2020. As a result, they want more to be done about these inequalities now that they have been exposed, including prioritising action to address inequalities.

So, I suppose, the question is, now that they're more visible than they've ever been, how do we take advantage of that? Rather than move past it and brush over it. How do you address the inequalities, now that they're prevalent and they're hard to ignore? How do we strike while the iron is hot on that, I suppose?

Participants summarise those who may have been disproportionately adversely affected by the pandemic, because of an existing inequality as being:

- Those in precarious employment
- Home carers
- People working in social care
- People living in care homes
- Low-income families
- People and communities experiencing racial inequalities

Participants from Black communities spoke of existing inequalities driving mistrust, around whether Covid-19 exists at all. They report that people they know are extremely wary of the vaccine which they feel could be being used for extremely harmful reasons in relation to their community. As one participant explained,

Honestly, a lot of people were like, they sort of look at me as if to say, 'Are you on another planet? It's all a scam, it's this, it's that, I don't believe in it, you're not having the vaccine?', 'But you don't know what they're putting in that.'

They feel that inequality in society has led to a place where there is a divide between people and communities which now needs to be resolved.

A specific point raised in this and the previous public dialogue was the fact that education provision was very unequal during the pandemic. Some families were well-equipped with spare laptops and space for their children to engage with home schooling. Many others were not as fortunate. Participants reflect on the disparity this created during the pandemic with children missing out on learning at key stages of their lives because their families cannot afford and do not have the technology (laptops or broadband) to learn online. Participants describe situations in which children were learning on a shared parental phone, wholly inadequate for the task. They are concerned that these disparities will have an impact on these children into adulthood and permanently damage their life chances.

3.5 A global challenge

Participants are not only concerned about national inequalities. They also feel that this is a global challenge which requires global equity. They want to know that:

- 1. Learning from the pandemic will be shared between countries so as to be more prepared in the future
- 2. That the UK should not only protect itself, there is an ethical duty to consider the needs of other countries in a pandemic

In terms of international relations in a pandemic, and in a post pandemic recovery period, boasting of a country's achievements in handling Covid-19 is not relevant. What is important is to ensure that the knowledge gained about how viruses are spread and what protects populations from them best is shared.

I'm trying to think. I think, maybe, from an ethical point of view, taking the politics out of it, like the whole one-upmanship of everything. That aspect of it needs to be removed, it needs to be, not even just from the British countries, I just mean in general. We need to learn from each other, rather than trying to be better than each other.

This brings to the fore a question that participants consider is important in this context, 'What is the duty of a government, is it to look after its own population or is to act in the global interest?' For many participants the answer is clear, that working internationally is in the interests of the UK population as well and should be an important aspect of pandemic policy. They stress this particularly in relation to learning from different country experiences of the pandemic, what went well and what could have been done better or differently.

I would like to know that if a country has a great idea, that we would bring that on board as well. Because lots of different heads are better than one head.

However, they fear that this ambition may be unrealistic and even idealistic in the current global political context. As a minimum, many feel that as a wealthy nation the UK should be doing a lot more to support and communicate with other countries which have fared less well in the pandemic. Not least because if the UK doesn't do this there is a risk of the increased spread of new Covid-19 variants. Many participants felt there is a duty on the UK to support countries to get the vaccine and establish a systematic vaccination programme. They feel disappointed that the UK might be hoarding vaccines that might expire before they can be used when these could have been made available in those countries with a very low vaccination rate, participants mention countries in South America such as Peru, and Africa such as Nigeria, Ethiopia and the Democratic Republic of Congo.

I'm just thinking the developed countries should help the developing countries, like Africa, Peru or those countries to improve their healthcare infrastructure because even we are doing well in the UK, if those countries are not getting enough help, they will develop new variants. So, the pandemic needs to be able to globally, not just focus on our own country.

3.6 The collective memory

Participants want to ensure that society doesn't forget what happened during the pandemic now that it is moving into a different phase. In particular they want to ensure that those who have died are remembered. They know they will be remembered by their friends and family and want to ensure that we do not forget that the pandemic had very serious consequences for many. In remembering the dead and those who have been very severely affected they want an acknowledgement that mistakes were made. For example, they point to how long it took for lockdowns to be implemented both in March 2020 and December 2021. They wonder if more people could have been saved if the decision making at these times had been swifter. They wonder if in remembering and acknowledging our collective losses now governments will be more accountable in future pandemics.

I think it's important that we don't forget the people that did die and the weaknesses in our health sector and even political. And that some of the mistakes that they made actually did contribute to a lot of those people's deaths.

In the Covid-19 inquiries to come participants want it to be understood how deeply people have felt the hurt and harms from areas of the handling of the pandemic that have not been successful.

Just thinking about those who've been deeply affected by the COVID-19 pandemic, those who have lost relatives and friends have been badly affected themselves. Their message has to be taken on board. They do feel deep aggrieved, and I can understand that.

We have seen that the social contours of Covid range from individual to societal concerns. Each of these involves tensions and trade-offs which we explore in detail in the next chapter.

4 Tensions and trade-offs

By reviewing stimulus material and in workshop discussions with the Accelerator team participants developed their ethical considerations of trade-offs in this shifting phase of the pandemic. They frequently describe ethics as having to make choices, sometimes between two good things by balancing potential good and harm. They list a number of significant tensions and trade-offs in the pandemic such as:



Figure 4.1: A summary of some key trade-offs and tensions witnessed by participants

For some participants tensions such as these have clear demarcation lines between benefits and harms. For one participant with a chronic health condition the choice is clear,

My thought is that 'What use are freedoms if you're dead?' and so I prioritise staying free from infection above all else.

4.1 The concept of freedom

'Freedom' was a word used by many in the dialogue to describe a post-lockdown situation. However, this highlights a very significant tension. They feel that the

approach taken by many during the pandemic, including the government, is too oppositional. They observe, for example, that even as restrictions lift and change the needs of young people appear to be put in opposition to the needs of older people and those who might be at higher risk of Covid-19. In essence that freedom is being put in opposition to not being free. These participants feel that narrative and the language around Covid19 should change from one of 'other', 'opposition', 'this versus that', 'restrictions' and 'imprisonment' to equitably balancing people's needs across society, empowering people to be aware of others and support their needs.

A question I'd want to explore is how can we change the narrative from it being about freedom versus not freedom, to just how can we just realistically deal with this situation in a way that empowers people? How do you change it from feeling like not imprisoned to feeling like this is just a situation that we have to deal with and it's our responsibility to care for our fellow person? It's not imprisonment, it's caring for your fellow person, in my opinion.

Many participants believe that this tension in using the word freedom in relation to Covid-19 has bred more fear about the virus than was helpful. They want society to be given the resources to be able to make appropriate choices to protect themselves and others. They feel there is an ethical imperative to encourage people to think differently about Covid-19 and the protections needed to mitigate risk.

Think of it in a different way and to just not fuel people's fear basically and I think it's important to consider the language that's used and how you can actually empower people and assuage their fears and make them feel like they are armed with resources, and actually make choices that are not so frightening.

Many participants agree that society needs to find a balance between public health needs and all other societal needs. They feel that polarising language prevents us all from trying to find this balance and even from identifying what we mean by freedom. For these people it is about finding the common good, not each of us individually seeking our freedom.

4.2 Seeking the common good

Common, public and collective good are important to participants. This builds on what was discussed in the first public dialogue with their focus on solidarity. Participants in our most recent deliberation frequently discussed concepts such as, 'togetherness' and 'community' and 'working together for the common good'. Again, it comes down to finding a balance:

How do you balance the individual needs/ concerns of everyone to make the best decision for all?

In the dialogue participants noted and were impressed by the concern everyone expressed for protecting others and the wellbeing of people across society. In seeking the common good many share their belief that individual responsibilities need to be fulfilled at every level of society from people in communities, to public institutions and national governments.

Vaccinations and mask wearing frequently came up in this context. Participants discussed the extent to which it is an ethical decision whether to get vaccinated or to wear a mask. They considered the implications for those who choose not to do these things and the impact this has on the rest of society. They raise concern about how to strive for the common good when there is so much divided opinion about the right course of action. Linked to this they raise the role of social media which gives a platform for those who may not have the appropriate knowledge, evidence or experience on which to form their opinions.

People who have degrees in epidemiology from YouTube are in no position to make decisions which have negative health effects on the wider community and have been medically proven to do so. I think your personal choices that you make, when it comes down to affecting the wider community, with a communicable disease, you lose that right.

This sense of solidarity remains for many very important throughout these discussions. As one participant explained,

I just feel together, we are so strong, alone we're weak. And that's whether it's local or national. When we were all together on the same page, we really did have strength, there was this feeling of what you got in the war, I suppose, that we were all in a bad situation but we were making the best of it together. So, yes, together strong, alone weak.

However, whilst striving for this sense of togetherness many feel it may not be achievable. They witnessed a shift as we moved out of restrictions away from being in something together to people wanting their own individual needs met, without as much consideration for others. This quotation below sums up the views of many who feel disappointed in the lack of recognition for others in some people's decision making.

I think that after a comparatively short period of time in the first lockdown we lost that sense, we lost that community, we lost the togetherness and then the dichotomy of the common good and personal freedoms started to assert itself in the anti-vax campaign and all of that stuff, which kind of missed the point because in pursuing personal freedoms a lot of people seem to disregard the fact that they were members of the collective and they were members of society, and they have a responsibility to that society because they're in it.

Participants across all the groups prioritise the common good over individual needs. They believe this should be achievable in any decent modern democracy, but it is sometimes hard to achieve. Barriers include:

- Not having a government requirement to isolate if you have Covid-19
- Feeling pressurised, either because of loss of income or because the employer requires it, to go into work if you have Covid-19 - particularly those in lower income jobs and those whose jobs can't be done from home
- Receiving a clear and evidence-based picture of what to do to protect others
- Not knowing what information is true.

4.3 Rules and measures

To end this chapter we will look at participants' views on Covid-19 rules and measures as restrictions ease and change. For some participants this comes with a sense of cautious relief.

I think it's really, really good now. Don't get me wrong, I found the pandemic very, very hard and very scary and things. But at this present time, I think it's just a sense of relief and it needed to happen at some point.

This is combined with a desire to work out what 'living with Covid' means and when it would be appropriate to have social distancing or wear a mask. There is an acknowledgement that Covid-19 hasn't gone away, and some measures may still be necessary in some instances.

For others there is a sense of anxiety that the onus on the individual to make choices about what is appropriate. They fear that now measures are not mandatory that the virus might resurge and force society back into the most restrictive measures.

I think it's still with us, and it's likely to peak once the restrictions are removed. I don't know how things are in other areas, because I'm in North Wales, but we've still got where there's an option to wear masks, but it looks like when you do go out there are very few people wearing masks, and that's a concern. Its going to get worse again.

Many participants share that they find the picture of rules changing at different times in each of the home nations complex and therefore hard to follow. We discuss this in detail in the next chapter. Here we focus on how participants perceive these rules and measures as society learns to live with Covid-19 and future pandemics. People question whether personal choice should be the arbiter of whether measures are applied. They ask - should:

- mask wearing continue to be compulsory in confined public spaces?
- vaccines be mandatory?
- some restrictions have been eased more gradually?
- the State still pay for testing particularly for those on lower incomes and at most risk?
- people be required to isolate if they have Covid-19?

It concerns participants that you could have Covid-19 and yet still go to work or mix with others. These concerns are not necessarily expressed in relation to the individual but rather that those at higher risk from Covid-19 are unnecessarily exposed to it, and that it could cause a surge in infections which puts too much strain on the NHS. Equally many participants feel uncomfortable and disconcerted by the move from a lockdown situation to personal decision making. They feel it has happened too fast in some countries giving people little time to adjust. They also wonder if the decisions being made are not following the science, as was promised to them in government briefings at the height of the crisis. There is a recognition that people are different and may require different time spans before they feel comfortable with restrictions easing and lifting.

It's all about just piecing your life back together. And everybody's at different stages with that. I think I've learnt tonight listening to other people that we're all at completely different stages with that. Where some people are ready to get back on with their life, others are sitting saying, 'Do you know not quite yet but maybe in a few months' time I might be ready to do that.'

In the back of some participants' minds as they discussed the easing of rules and measures is that some people consistently broke the rules anyway. They believe those people are unlikely to take any personal responsibility for protecting themselves or others now that restrictions are lifting.

There were so many parties going on, well, not parties, raves. There were thousands and thousands of people at these raves, and this was in the thick of the pandemic, but they're not bothered because they either don't believe it exists and it's a load of codswallop, or they're out for themselves, enjoying themselves, they're living their lives. I truly think we'll get the same response now. They aren't going to care.

5 View from the home nations

5.1 Home Nations: Cross-Country Perspectives

Participants entered the first round of dialogue workshops with national differences in restrictions as one of the subjects at the forefront of their minds. They had questions about the why and the how of decision-making at different levels of government, as well as thoughts about the impact this fragmentation can have on a sense of collective endeavour. Participants shared strongly held views that the different routes taken by the home nations through the pandemic were political choices, rather than about public health.

Who makes the decision about the balance between what restrictions are in one place and another? When you go more regional, so, like, Wales do their own and England do their own, it's so confusing. I think in the very first part of the COVID pandemic, everyone was on the same page and it did feel like a national, universal effort. But now everyone's making decisions in their own region, aren't they? And that's changing from region to region.

I think the majority of the decisions, especially between the countries, I'd say 90% of it was political...

At the start of the dialogue, participants shared their frustrations about the confusion that disjointed measures wrought on their own lives, exacerbating already difficult circumstances brought about by the pandemic. This feeling is particularly acute for participants who live either on the border of regions with different rules or somewhere seen as a desirable destination for others to escape to. For some participants, the implementation of measures that impeded some people more than others contradicted the notion that an effective response to the pandemic needs to unite, not divide, people.

The whole local government lockdowns were just a nightmare in my opinion, they couldn't facilitate saying, 'This person has to be in lockdown, but this person can't.' It's also the fact that you're pitting other people against each other, like from different places.

5.2 England

Concerns about trust, transparency and responsibility dominated the dialogue between participants in England. This is perhaps unsurprising given the timing of the workshop, held in the middle of May 2022, which coincided with widely reported revelations about rule-breaking parties in Westminster.¹⁰ Erosion of trust was

¹⁰ BBC News online, Partygate: A timeline of the lockdown gatherings, 19 May 2022.

associated with 'various major players' and several participants cited an apparent lack of due diligence around the contracting of personal protective equipment (PPE) supply as a clear indication of governmental misconduct.

We didn't necessarily have to agree with what the government were doing but we had to have trust in they were doing it for the right reasons

In England, participants also discussed having to navigate decisions in the context of increasing personal responsibility for the handling of the pandemic. Trust, in government and each other, is seen as important for flipping between this, on the one hand, and strict governance, such as during the first lockdown, on the other. There is a sense that if trust in government erodes, this might impede responsible decision-making on an individual basis.

The government didn't take personal responsibility of themselves, like individuals within it. So, how do they expect us to do that with all that in the background?

When compared with Scotland and Wales, participants paid relatively little attention to the measures taken by the other home nations and fewer arguments were made for or against undertaking a consistent approach across the UK. However, one participant looked to Wales as an example of how the pandemic response could have been handled better.

5.2.1 Perceptions of good leadership and governance

In England, participants found little of merit in the Government's handling of the pandemic. In the context of widespread disapproval, a few participants did suggest that criticism of any government ought to consider that the challenges presented by the pandemic were unprecedented. The vaccine programme and coping with the high demand for PPE were also cited as successful interventions by the Government. One participant who was critical of the actions of national government described the support she received from her constituency MP in more positive terms.

5.2.2 Perceptions of bad leadership and governance

Otherwise, participants in England expressed overwhelming dissatisfaction with the Government. The pandemic was 'handled appallingly', in the words of one participant, by a government that 'kept moving the goalpost', in the words of another. The tierbased system, leading to the fragmentation of rules within and between regions, came in for specific criticism. Generally, rules were described as 'haphazard' and 'inconsistent', creating confusion among the public.

I feel that the restrictions in England went through haphazard processes during the lockdowns and I do believe that they were lifted in such a way that many people were confused as to actually what's happening, what was not allowed, what was allowed, why and how.

Some participants make clear that their displeasure with Prime Minister Boris Johnson predates the pandemic, but they also feel that this has been exacerbated by his handling of it. Johnson is seen to be emblematic of the Government's perceived failure to express remorse or act responsibly. It was suggested that the Government had sewn division in the public, encouraging a 'blame-game' to emerge rather than take responsibility for their mistakes. Participants repeatedly cited Dominic Cummings trip to Barnard Castle, as well as the inquiry into bullying by the Home Secretary Priti Patel and opaque PPE contracting as reasons for questioning the Government's credibility, accountability and due diligence.

I probably wouldn't have ever trusted Boris Johnson before the pandemic, but after everything that happened, I don't think I could ever, ever trust him.

There is a sense that widespread lack of trust in the Government's handling of the pandemic has damaged a social contract that would have previously encouraged people to follow the rules. This is expressed by participants concerned that people in England might be less likely to comply with future measures as a result of the Government's perceived failure to take rules seriously during the pandemic.

If we don't trust the government then how are we supposed to believe that other people are going to trust them and the unity is destroyed at that point and then people are just fending for themselves rather than working as a team, sort of thing. I noticed that when I've been to other countries, other than England specifically, the people from that country follow the rules so much better than the people here. The people here are just like if they introduced face masks again, I'm pretty sure half the people wouldn't bother putting them on

5.2.3 What Needs to Change

Reflecting widespread disapproval of the way the pandemic has been handled, participants in England propose a variety of changes they would like to see happen. These relate to measures and messaging, the state of public services and the political context. In the immediate term, consistent information is seen as important for ensuring members of the public are on the same page about the state of the pandemic. In the longer term, strengthening public services is a priority, with waiting times for elective procedures in the NHS offered as evidence of a problem that predates but has been exacerbated by the pandemic. One participant wished to emphasise the public's role in guiding the direction the country takes, suggesting that change could be enacted via the ballot box.

There's a massive backlog with elective operations. Obviously a lot got postponed through COVID which was unavoidable, but there was already a huge backlog beforehand. If we'd been in a stronger position then it probably wouldn't have been so bad now.

5.3 Northern Treland

Dialogue participants in Northern Ireland are broadly positive about the country's initial pandemic response. It is felt that pre-existing divisions were put to one side and political parties worked together to mitigate the impact of the pandemic at its outset. Northern Ireland's population (fewer than two million) was described as a 'small community', equivalent to a big city, and this was seen as beneficial for engineering a collective response to the pandemic. However, many participants feel the united approach disintegrated into familiar factionalism and political bating when examples of lockdown disobedience by political figures came to light. The lack of a functioning government in Northern Ireland overshadows participants' interpretations of the pandemic response. This could explain why we heard fewer arguments here, compared with Scotland and Wales, for and against consistency across the UK. Arguments were made, however, in favour of an all-Ireland approach.

Covid wasn't a thing that cared about whether you were orange or whether you were green. And I think that got lost when it became an opportunity for point scoring and the actual needs of the community and the people of Northern Ireland got left behind as the politicians went back to obtaining their power from division.

5.3.1 Perceptions of good leadership and governance

In their dialogue conversations, participants in Northern Ireland drew specific attention to two public figures who were believed to have demonstrated good leadership during the pandemic, Chief Medical Officer Michael McBride and Minister of Health Robin Swann. They are both seen to have risen above politics for the broader benefit of the country. Though, over time, Swann was considered to have fallen into line with his political party, the Ulster Unionist Party, at the expense of acting independently or relying on his own judgement.

I just get that sense, do you know, that he [Swann] was genuine and sincere, and he wanted to do the best for everyone in Northern Ireland, for everyone's health, whether they're vulnerable, or whether they're young children.

Overall, participants envisage good governance as being honest about what went well and where mistakes were made. Participants used words such as 'transparency', 'genuine', 'measured' and 'mature' to describe the characteristics they would like to see in politics and politicians. However, many were keen to stress the importance of politicians 'working together', as opposed to having allegiances to individual people or parties. This is reflected in participants' hopes for future governance, which include greater focus on government processes and less emphasis on public performances. Following the pandemic, there is an appetite for the economy and the NHS to be 'strengthened' in order to absorb future shocks to the system.

Don't want performative governance. I want a government who clearly lays out their decision-making processes, lays out what data they're using, what policies they're

using, what their process is that makes them arrive at a decision. Essentially, that's what I want, I want transparency, I want public access to the government processes, insofar as is possible.

5.3.2 Perceptions of bad Leadership and Governance

As in England, participants in Northern Ireland identified political figures who appeared to ignore or exempt themselves from wider restrictions in place during the pandemic. The funeral of Bobby Storey in June 2020 was cited by one participant as causing confusion and eroding trust in the government's ability to implement rules fairly. When public figures were viewed to have flouted COVID-19 restrictions, leading to political point-scoring, participants saw this as dashing hopes for harmonious governance in the face of crisis at the start of the pandemic.

Some of the ministers themselves broke the Covid rules. They're trusting us to follow them, and they don't follow them themselves, so is it that serious?

Northern Ireland itself is seen by some participants to hold huge potential, uniquely situated between the United Kingdom and the European Union, with a well-educated, highly skilled and loyal labour force. However, participants expressed frustration that a lack of competent governance is smothering wider potential. The absence of a functioning government was described by one participant as:

A blanket on any green shoots, they're not getting the light because they haven't got a cohesive, functioning government, which would be the access route to any inward investment, and which would normally encourage inward investment but be the gateway to actually bring it to fruition. So, until that's in place, we're going nowhere.

5.3.3. What Needs to Change

The need for a comprehensive plan for Northern Ireland to 'get back to normal' is clear in many participants' minds. However, the repeated use of the word 'strengthen' suggests that it is not sufficient to simply return to providing services at their prepandemic levels. There is a desire for the economy, health sector and education system to foster resilience against potential future crises. In line with this, participants believe public services ought to return to being fully operational as early as possible. Many expressed frustration that some services remain difficult to access or only available virtually, with specific reference to GP surgeries and city council planning departments. The reasons why such services are not able to operate as openly or effectively as retail and leisure industries was unclear to participants. To be hopeful about the future, participants want to see a more transparent plan for recovery, led by a government capable of demonstrating it can act to strengthen public services and the economy.

I would really need to see transparency on how the government are going to tackle all these problems. I mean, it's a wide range of problems, from healthcare, to schools, to businesses, to people themselves, and I would like, in an ideal world, to see a plan put in place. I would like both sides of the coin to work together, to be able to come

together and agree, and make sure that they form a government so that they can show us a positive and bright future for Northern Ireland coming out of COVID-19.

Participants want to see the political parties working for the common good in Northern Ireland, and for the benefit of the community rather than their own interests. Young people in particular are distanced from party-political or religious divisions and seen to embrace the wider community. There is a desire for a cooperative and pragmatic approach to the future, focused on clear objectives, the means to get there and deadlines to achieve them by.

If they could get together an all-party subcommittee ... somebody there that is tasked with achieving certain well defined objectives, in a particular way, properly funded in terms of resource, budget, and all the rest of it. Say, 'Okay, you have now got this period of time to get this job done, go.'

5.4 Home Nations: Scotland

Dialogue participants living in Scotland draw clear distinctions between the Scottish response to COVID-19 and those of the home nations. Local communities are framed as particularly resilient in the face of crisis and Scotland is seen as a preferable place to be, with England being singled out as less ideal. Participants who had spent time in both countries during the pandemic interpret Scotland's rules as having been 'safer' and better adhered to by the public.

It's been fairly strong here, I would say, the community spirit. I think it was always there. I've lived here for about 5 and a half years. It's been reinforced by the Covid pandemic.

I was thinking, 'Where out of all the places I've been would I rather be in?' And to be honest, I was quite happy that I chose to be in Scotland at the time, out of the whole nations I think I would pick Scotland or Wales where I lived for 40 years or even Northern Ireland, over England.

Participants in Scotland gave examples of measures which were not consistent with those in place in England, citing this as a major source of confusion. Some felt a responsibility to keep up to date with the different rules in each country, either due to work or travel. One participant, who worked in a restaurant in Scotland, frequently had to explain Scotland's different rules on table sizes to customers from England. However, this inconvenience is balanced alongside a widely held view that Scotland opter for stricter, safer and more sensible measures than England.

I often get so confused, because the England and Scotland rules are very different and I have to keep track of the news and the policy changes again, but I always had a feeling that I feel that Scotland's rules are more strict than England ...

sometimes I feel it's not that convenient, but I do feel living in Scotland is safer than when I lived in London. I feel I think I trust the Scottish government. More.

5.4.1 Perceptions of good leadership and governance

As in Northern Ireland, many participants feel broadly positive about the Scottish Government's handling of the pandemic in its early stages. First Minister Nicola Sturgeon and the wider government received favourable comparisons with Prime Minister Boris Johnson and Westminster. Scotland's National Clinical Director, Jason Leitch, was also singled out for praise. Participants believe the Scottish response stood out for prioritising public health over other concerns, and feel daily press briefings were clear and necessary, and perhaps ought to have continued.

Many participants perceive Sturgeon and the Scottish Government as being more trustworthy than their counterparts in Westminster. In this context, participants see trust as being tied to clear, consistent messaging and an obvious focus on public safety.

The Scottish government were trusted a lot more than the Westminster ones were, definitely. I think that was really down to Nicola Sturgeon, if I'm being honest with you. Especially at the start, the first three or four months, it was very clear, very direct, very to the point. She answered questions quite openly and honestly, whereas Boris Johnson when he did get questions, he just fumbled across a line and messed his words up, and that loses faith.

I always trusted the Scottish government more than the Westminster government ... In Scotland it seemed truer in looking after the people and keeping the people safe seemed to be the priority.

5.4.2 Perceptions of bad leadership and governance

Participants' praise of the Scottish Government, however, mostly concerned its initial response. It is widely felt that the Scottish Government's handling of the pandemic deteriorated significantly after the first few months. The same features that come in for praise – Sturgeon's leadership, government messaging and decisions on rulemaking – become subject to criticism as participants take a longer view of the pandemic. Increasingly unfavourable decision-making is associated with growing influence from Westminster. There is a sense that decisions such as the Eat out to Help Out scheme and around the Christmas period in 2020 gradually deprioritised public health in favour of other concerns.

I do feel the Scottish government, for the first maybe 2 or 3 months of the pandemic got things pretty much spot on, but as soon as June, July came about, it just all went completely out the window.

As soon as she [Sturgeon] went along with the Westminster, Eat Out To Help Out, she started to lose people then, and at Christmas as well, I know in working in

hospitality we were really, really busy that first Christmas of 2020. It was absolutely astounding and then she came out on the 17th of December and said we're going to close down on Christmas night, and it's like, but if the situations that bad on the 17th of December, why on Earth are we not closing down on the 17th of December?

This downward turn is acutely associated with a decline in trust when the Scottish Government is perceived to concede ground to Westminster. There is also a view that, in the context of the pandemic, shifting responsibility for decision-making onto individual people and businesses amounts to poor governance. Having been praised for the communication of measures being implemented to mitigate the spread of COVID-19, the Scottish Government is seen to have been silent as it lifted these restrictions. This is a concern for several participants, who feel that it indicates a lack of transparency.

We were asking the government directly, 'Should we be asking people to wear masks?' They were saying, 'Well, it's up to you,' and I was thinking, 'You can't leave that up to individual restaurants to manage,' because the public aren't going to listen to the likes of me, that needs to come from government.

5.4.3 What Needs to Change

Looking to the future, participants in Scotland want to see the Government pay more attention to how members of the public will be affected by rules and measures as they are introduced. There is also an expectation that evidence behind such measures ought to be accessible and communicated in everyday language, with televised briefings continuing to be popular. One participant advocates for a nationwide, centralized approach to pandemics, while another expresses a related desire for consistency in rulemaking.

I just feel you need to take the whole public with you, and then actually understand what it's like from everybody's walk of life and how these places are going to function under these new rules and new terms.

5.5 Wales

In Wales, participants identify inconsistencies between the measures that were in place in England and Wales, offering nuanced interpretations of their impact. The delayed reopening of nightclubs in Wales was offered by one participant as an example of a policy in which the Welsh Government acted smartly in diverging from decision-making in England. However, other participants feel it does not make sense to have restrictions in place in Wales but not in England when members of the public can travel across the border freely. One participant suggested the First Minister in Wales ought to have eased restrictions faster to match policy changes in England.

I do wonder about the consistency across like, because I border Wales, England. When we had certain restrictions in Wales, people would just avoid Wales and go over to England.

5.5.1 Perceptions of good leadership and governance

Many participants praised the Welsh Government's pandemic response. Participants view the situation in Wales particularly favourably in comparison with England. The Welsh Government is seen as pragmatic, among other things, for basing its decision-making on regular reviews of the evidence and for not being lured into making promises too far in advance, such as for a 'Freedom Day'.

I'm proud, to be fair, from obviously the Welsh perspective, it was so different to the English. Obviously, we're 3 million population here, compared to England's, what, 60 million. But, it was more transparent and honest and we did things, I think, way better.

I think where we did it right, where the Welsh government did it right, was, right, it's 3-weekly or 2-weekly reviews, or whatever it was, and then it was like, right, and we will only promise you something within that, that we will change, within that time period.

Wales's First Minister, Mark Drakeford, is thought to have demonstrated especially effective leadership during the pandemic. Although his decision-making is frequently framed as unpopular by participants, it is also viewed to have been necessary. Participants associate him with 'integrity', 'stability' and 'feeling secure', as well as being 'firm' on tough decisions. The practice of making unpopular but essential decisions appears to engender greater trust in his leadership for some participants.

I am not a political person. I don't have the first idea about politics but I actually trusted Mark Drakeford because he held us in a lockdown and we knew what we were doing. We knew what our restrictions were, how long they were going to be.

In Wales there is a solid opinion that Mark Drakeford kept the people informed - and although he held Wales in prolonged lockdowns with additional restrictions around boundaries and exercising should be done within a 5 miles area of home which made him unpopular - this in effect also gave the people stability rather than swinging in and out of lockdowns - which can then shatter the trust that people have.

Participants partly connect the backlash aimed towards Drakeford with the fact that rules were not consistent between England and Wales. One participant describes the resentment shown towards him as sewing division in their own community, splitting people on their views about restrictions.

5.5.2 Perceptions of bad leadership and governance

In line with this sense of resentment about lockdown continuing, a few participants think the First Minister and the Welsh Government were too slow to ease restrictions. One participant, however, feels that the UK Government's handling of the pandemic has left a worse impression than that of the Welsh Government, pointing to recent local election results as an indication of this.

5.5.3 What Needs to Change

Looking to learn lessons from this pandemic, one participant in Wales believes that any new measures need to be clarified and more adequately justified. It is felt that measures need to be communicated effectively for the public to have a clear understanding of the changes they ought to make to their behaviour. Persistent confusion about the usefulness of masks among the public is cited as evidence that public health messaging must be improved.

We've been through two years of a pandemic and lots of people-, masks are a great example, lots of people really don't know if masks help or not. So it seems like we should know that. That should be firmly in our minds as yes or a no.

Across the home nations, participants interpret inconsistent measures as a failure to reach political consensus, rather than as an indication of different public health strategies. Even in Northern Ireland, where the specific political context came to the fore, and less attention was paid to other nations, participants aligned differences over approach with political division.

Participants in Scotland and Wales frequently allude to the policies in place in England and the influence of these on their own governments' approaches. In England, participants appear to be less cognisant of the actions taken by the other home nations but equally clear about the need for consistent advice. In Scotland and Wales, devolved decision-making is perceived to have come with benefits, including distance from an unreliable government in Westminster and generally stricter, or safer measures. However, this does not override the feeling that a lack of consistency across the UK was not in the public interest during the pandemic. There is a strong sense among participants that health in the context of a pandemic is not a regional or political concern. There is an appetite for governments to work together, dispose with point-scoring and, in the words of one participant, 'sing off the same hymn sheet'.

The trouble was, I think there was a fair amount of jockeying for position and profile and saying, 'We're much better at dealing with this than you are.' Which is frankly a bit infantile when you're dealing with a global pandemic.

So instead of our national governments showing off their wares or concealing their inabilities, that an all-islands approach in the context of where we are geographically would have made more sense, and still would make more sense and should be legislated for in the future.

6 Underpinning ethical values and principles

In this dialogue, as in the last, deliberations have revealed important underpinning ethical values and principles. The previous dialogue highlighted a range of important factors which build up to a fair, resilient equitable society able to withstand the manifold shocks which take place in a pandemic. Participants in this dialogue have demonstrated their agreement with these values and principles and have built on them. We share the analysis of these as the foundation stones of their thinking (figure 6.1):

The need for trust in our government and public institutions

The importance of transparency and honesty in building this trust

A desire for a greater unity and collaboration across the UK's nations

Achieving a balanced rather than an oppositional approach to policy making

The common good prioritised over individual needs and wants

Living in new ways with a greater respect for other people to provide the compass for our actions in the face of future pandemics

Acknowledging and learning from the harms caused to prepare for the next pandemic

To create a compassionate, equitable society which learns from its mistakes and builds fairness and trust into preparing for future pandemics

Figure 6.1: Underpinning ethical values and principles

In this chapter we explore the themes that emerge from this analysis: trust; and transparency; shoring up the NHS we need for the future; and pandemic preparedness.

6.1 Trust

Trust was a significant tranche of participant deliberations. Trust in government; in our public and scientific institutions and reflections on what builds and what erodes trust.

Hopkins Van Mil
We bring people together to inform the future

As already noted, the fieldwork for a dialogue took place in the eye of the Westminster partygate storm¹¹ and following the Owen Paterson scandal¹² which took place the previous year. Participants used the term 'corruption' in relation to the awarding of public sector contracts and Personal Protective Equipment (PPE) supplies for example. This contributed to a focus in participants' minds on trust in government which we turn to first.

6.1.1 Trust in government

There are variations in perceptions of trustworthiness across the home nations which are described in the previous chapter. However, many participants describe a complete loss of trust in UK government decision making. This is typified in this participant quotation,

One thing that jumps out at me from these responses is that people distrust that the decisions made by government were in the best interests of national health, rather than in the interests of individual characters and political players.

Participants used very powerful and frequently angry words to describe why they perceive trust in the UK government to have been so strongly undermined, particularly in the latter stages of the pandemic crisis and as restrictions have been lifted (figure 6.2)

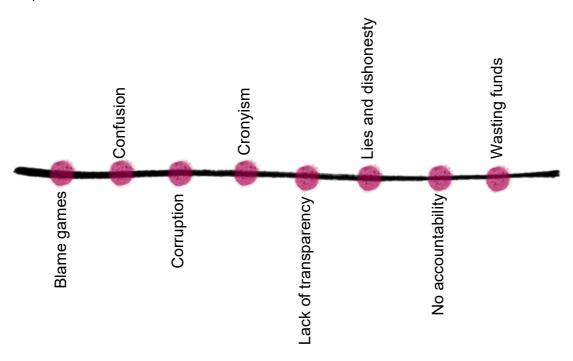


Figure 6.2: Words used to describe reasons for mistrust in government

Participants acknowledge that governments will make mistakes, particularly in a new crisis situation such as this. However, they believe that people have suffered more than was necessary, in part because government trust has been lost. It is clear that a perceived lack of honesty from the government has had an impact on how successfully participants feel the pandemic has been handled.

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¹¹ BBC News online, Partygate: A timeline of the lockdown gatherings, 19 May 2022

¹² BBC News, What did Owen Paterson do? November 2021

A lot of people, the majority of people, have the same thoughts, the lack of trust within the government. They've just left a lot of people are suffering, a lot of vulnerable people have suffered, lost their lives, they're suffering still now, and it's just not right, we're human beings at the end of the day and it's just not right how they're going about things and at the end of the day it's the lack of trust, they just need to be honest with us, that's it they need to be honest.

Some firmly blame the government for the loss of people close to them.

I believe my father would still be alive if the government had not been in control

The question then becomes is the loss of trust so profound that people will not follow government restrictions should they be necessary in future pandemics? Will people rely on their own decisions which could cause further divisions in society? Participants are concerned that this is the case. And they fear that this will cause more anxiety for everyone - but in particular those at higher risk of harm in any pandemic.

At the time of writing this report a Conservative Party leadership election has been called. Participants wonder if a change of those at the top of the current government, or a general election, would be a positive step towards building trust. Many believe this is the case.

The approach of the Westminster government has been absolutely disastrous and disgraceful. And how anyone can have any faith in a system like that is utterly beyond me. So, we have to deal with that. It's a vast impediment to going forward because Johnson simply doesn't believe in the NHS and helping the vulnerable in society. We need a clean slate, new people making these decisions.

6.1.2 Trust in public institutions

A situation of varying trust in public institutions is described by participants. They share that trust remains extremely high in the scientific community advising government and trying to understand the shifts in the virus and its mutations. They continue to have high levels of trust in those who work in the NHS, and in those involved in developing and rolling out the vaccination programme. Some also mention local councillors as being trustworthy. The reasons for these individuals and institutions being trusted and trustworthy are that they:

- Are rooting their work in the evidence
- Have been working under extremely testing circumstances and still delivering what society needs
- Show empathy for others in society
- For the most part, followed the rules and when they didn't they stepped aside.

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Participants separate their feelings for these public institutions from the strength of feeling they have around the government being trusted. They state that it is not the fault of these public institutions if the government chooses to ignore, mis-represent or mis-use the advice given.

A few participants speak of the police, particularly the Metropolitan Police, as not having demonstrated that they can be trusted. They refer to, for example, the vigil after the murder of Sarah Everard¹³.

I think one of the public institutions that has gone down in my estimations is the police. I think it was the Sarah Everard vigil, the way they were so heavy-handed policing that, combined with the complete opposite of the unwillingness to investigate the parties, the Dominic Cummings episode. They've seemed to have picked and chosen what to investigate and what not, depending on political pressures.

Whilst trust in those working for the NHS remains high, participants say that the NHS system as a whole is losing trust, particularly in its ability to recover from the prioritisation of Covid-19 in the pandemic. Participants have found it increasingly hard to make a GP appointment, particularly at the surgery, even though restrictions are lifting. They speak of not receiving treatment for serious and life-threatening conditions in a timely fashion. They are concerned that this will spiral into an entirely broken health system which will be unable to cope with any future pandemics.

I'd like to know how we actually recover our NHS because it isn't recovered at all, and you can't trust it to be there when you need it. There is no primary care where I am. You can't go and see a doctor you have to be triaged by a nurse and they have an eConsult now and they've continued with that for whatever reason even though restrictions have been lifted.

Participants want to make sure that trust in the NHS system can be rebuilt, that the NHS can function well in the future, even if there is a new pandemic around the corner. They want the NHS to protected: more staff, more funding and more distance between the NHS and politicians, who as we have seen are not trusted to manage the system.

I feel like this has highlighted that the NHS really needs taking out of politician's hands. They're clearly not capable of running the NHS and it's highlighted when a pandemic comes along and they just lost control of it throwing money at face masks that never exists, throwing money at Track and Trace that didn't really do anything at all.

6.1.3 Regaining trust

We see four key elements of participants thinking on how trust in government in particular might be rebuilt:

- Transparency in all decision and policy making processes
- Clear communication
- Swift action when things go wrong
- Demonstrating that a key motivation for government decision making is a fair and equitable society.

Transparency

¹³ BBC News online, <u>Sarah Everard: Met police breached rights of vigil organisers</u>, March 2022

Opaque decision making is a key element of loss of trust. Therefore transparency, for many participants, is the key to regaining trust and bringing people along with you at each stage of managing a pandemic.

The trust is never going to be there without a clear transparent way to live with Covid.

Participants point to a lack of clarity in the rationale for decision making which they feel is a substantial barrier to policies being trusted. In various ways participants said that citizens don't necessarily have to agree with what the government is doing, but they do have to trust that they are being done for the right reasons.

Communication

For this reason a stress is put by participants on clear and consistent communication and messaging being essential in a crisis situation. They don't believe they have seen that, particularly in this phase of restrictions changing to different timescales across the UK. This includes:

- Presenting data which draws on scientific evidence
- Demonstrating where scientific evidence has come from and how clear cut it is, e.g. where there is, or is not, consensus on the science
- Ensuring that data has not been manipulated for political ends
- Involving citizens before decisions are made, or throughout the process of decision making
- Highlighting trusted sources of information so that people don't fall back on social media as their main resource.

Swift action

In addition taking swift action when things go wrong would also be appreciated by participants. This includes removing members of the government who break the law, or who go against the spirt of the compassionate, collaborative society participants want to create as a result of the Covid-19 experience.

Fairness and equity

Participants stress fairness. As we have seen participants feel that Covid-19 has exposed inequalities in society. They believe that a trusted government would be seen to prioritising fairness and equity, particularly in the face of the unequal impacts of the pandemic and a cost of living crisis.

Ensuring that no-one's left behind, omitted, feels aggrieved in our public systems and how they are managed.

6.2 Learning the lessons from Covid-19

Participants raise learning the lessons from Covid-19 as an ethical consideration. They believe that, given the level of suffering experienced by everyone during the pandemic, society has a moral duty to commit to understanding what has happened in order to prepare more effectively for the inevitable next pandemic. Participants want to consider how society learns the lessons to:

- Create the kind of society we want as a result of the learning one that is robust, compassionate and fair
- Help society to live with Covid-19 and future pandemics
- How to balance restrictions with people's wellbeing
- Never forget the danger that a virus can pose
- Rebalance social inequalities
- Understand what good governance and leadership should be like in the future
- Understand that we can't live as we did before, that adjustments need to be made to 'live with' Covid-19 and future pandemics.

Participants believe that learning the lessons should occur at an individual as well as a societal level. They speak of people having learned more about personal hygiene in the pandemic and they hope those habits and behaviours continue – although they suspect they will not. Civility and kindness were also raised as an important aspect of our pandemic behaviour which participants would like to see continue.

I think during the pandemic people seemed to be a little more civil to each other. I think a general rollout of civility in society, people were mindful of others' abilities, personal space, and that was something which was quite unusual. People generally seemed nicer, because I think it was a nationwide severe public health issue, which no one has seen anything like this in this country.

In terms of societal learning, participants want to know that we are learning about the impacts of very restrictive lockdowns on, to give two examples, our mental health and on our children's education. They would like to know that a thorough assessment is made of the timing of lockdowns in the pandemic cycle. If lockdowns as a tool are properly examined they hope that in future pandemics this very severe measure can be used in a more subtle and balanced way, rather than as one blunt instrument.

Other elements of the evaluation of the handling of the pandemic should include how to achieve:

- Effective and accountable public procurement e.g. of PPE and sanitisation equipment, including ensuring that appropriate supplies are in place when needed
- Efficient rolling out of vaccination programmes including who should be prioritised for vaccination and why
- A better system of track and trace that people can trust and won't discriminate
- Any benefits that might have accrued from living in a digital age during a pandemic.

Participants also feel it is important to learn lessons about balancing a range of competing and important policy priorities. For example, non-Covid health needs, education, the cost of living and geo-political situations such as post-Brexit trade deals, negotiations with the European Union and defence issues in the light of the Russian invasion of Ukraine.

The point participants stress is the need to find good from this very challenging situation. They feel this will be achieved by openly and transparently exploring what happened during the Covid-19 pandemic and how to do better in the future.

? Proposed solutions

Throughout the dialogue participants reflected on what they might like to see in a future living with pandemics, one which had learned the lessons from Covid-19. This chapter focuses on these proposed solutions. It is structured around:

- Education in a pandemic
- Prioritisation of mental health and wellbeing
- A holistic approach to pandemic policy making
- Bridging the gap between publics and policy makers
- A caring society communities supporting each other

7.1 Education in a pandemic

Participants call for a more nuanced and subtle approach to protecting those at high risk from harm in a pandemic. Many suggest that universal lockdowns should rarely be used and when they are that they shouldn't be at the cost of providing an effective system of education.

Perhaps we need to tailor the response to recognise that there are vulnerable people and those are the people who need to be protected. Whereas actually perhaps education can continue in a bit more of a normal fashion.

It is understood that personal restrictions will be necessary in a pandemic, but these should be imposed proportionately and be followed by everyone throughout society. Participants propose that a plan is put in place now which has two aims:

- 1. To put in place support for those who have missed elements of their education whether in school, higher education or early employment
- 2. To ensure that in future pandemics society knows how the education system will be managed more effectively with provision maintained at the levels we expect as a society for our children and young people.

I know from having 2 children that education has suffered. I would like to see a plan being implemented for education that's been lost. For future, does that mean that the fact that when they go to university will this all have a knock-on effect? Will universities drop down what they need to get into those types of courses? Will jobs ask for less qualifications? I don't know. I do believe that children have been left behind. I would want to see a plan in place for those that have been forgot.

Some participants also suggested that compensation should now be given to university-age young people who missed key elements of their degree due to the pandemic.

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7.2 Prioritisation of mental health and wellbeing

As we have seen, concern for the impacts on mental health across society is high amongst participants. As a result they call for a 'mental health revolution'. This comes in two forms:

- Additional funding and resource for mental health services across the country so that they are equipped to provide support for all those people that need it as a result of the pandemic trauma
- 2. A mental health action plan which gives significant weight to mental ill-health prevention which might include:
 - Providing resources in public spaces including libraries, schools and hospitals so that people can prioritise their own mental health and wellbeing, including signposting support organisations
 - Public briefings, such as the briefings we had during the pandemic, focused on mental health issues and how to achieve positive outcomes
 - Raising public awareness of the treatments available for mental health
 - Buddying schemes for those who are shielding or on their own for significant other reasons
 - Tailored support for those individuals and communities that feel they shouldn't rely on external bodies for mental health support.

Finance for mental health. Are they going to put money into that? I'm thinking, is there going to be this huge mental health revolution now? Because it's a major thing in society. It's quite sad and tragic, really, the amount of ill people. Now there is more widespread knowledge of the problem action is needed.

7.3 A holistic approach to pandemic policy making

What is clear in participants' minds is the fact that the trajectory a pandemic takes can influence and be influenced by much more than just health policy. There is a sense that investment in education will help to mitigate the effects of a future pandemic, specifically by fostering good mental health and enabling science to 'become common currency' among young people. It is hoped that the latter will help to limit the spread of misinformation and increase the uptake of vaccines in the future. Participants also advocate for legislating in advance in order to better prepare for the next pandemic, proposing that this might extend to policy areas including social media and misinformation.

I think we almost have devolved science to a small niche of people. I think it needs to become common currency so that when the chief scientist stands up, or chief medical officer, we can actually understand it a bit better and be thinking, 'Yes I see. He makes a point.' That probably would be a good counter tool to all the anti-vaxxers and conspiracy theories that were floating around which did real harm.

Participants also emphasise financial consequences of the COVID-19 pandemic and this influences their thinking about preparing for future pandemics. Spending both on recovery from this pandemic and on preparation for future pandemics are popular.

Several participants propose the creation of an emergency fund in order to limit the economic impact of a future pandemic. They are open-minded about how this might be financed, with windfall corporation taxes, philanthropic investment, and taxes on income all mentioned.

Why could we, obviously as a working person, not pay a section, a portion of our tax to an emergency fund that could gather within years so that it could actually be spent on protecting the likes of businesses, the likes of our NHS? Just preparedness for these things. Obviously a strategy in place for this in many years to come. It mightn't happen, I'd say it probably will happen, but if it was there in place we wouldn't have to foot the bill.

Participants also refer to the need for a long term economic policy which takes in to account the probability of future pandemics. They feel that future society should not make knee-jerk economic decisions but have planned in how, for example, to run and fund a furlough scheme, how to support small businesses to be resilient in a crisis, how to prevent the fall-out from a pandemic combined with a war from becoming a life-harming cost of living crisis.

And we need to stop being so immediate and just so like, 'Just shut the economy down for 3 months and we'll deal with it later,' I mean that's just nuts, it's absolutely crazy, we can't just keep closing things down when things like this come along, we need to think about the economy, kids, the future.

I would like to see the development of a comprehensive economic support policy which genuinely seeks to restore stability.

For some participants the range of policy areas involved, and the funding needed indicates a holistic approach to policy making. They suggest that a government department dedicated to pandemics which has responsibility for handling the pandemic across all policy areas might be a useful way forward. Equally an independent standing advisory body which shares ideas and evidence to ensure in future pandemics people are not impacted more than necessary.

I like the idea of a board or something maybe that they could all sit and battle ideas off each other and then find out what would work all round where education's not getting impacted too much, businesses aren't getting impacted too much but health is still at the top of the umbrella type thing.

Some participants propose a multi-agency approach which is more joined up than they believe inter-departmental working to have been in the pandemic is essential for managing future pandemics. They call for this to have a global as well as national dimension:

I think that it's a global issue. The virus doesn't mind what country it's in. It doesn't even know. So, yes, it is a global thing. It should be a global approach.

7.4 Bridging the gap between publics and policy makers

During the dialogue we heard a call for what in essence is a 'transparency contract'. That any elected government should set out how they will share information and evidence with the population. In their turn citizens must have the opportunity to define what information and evidence they expect and need in order to manage their lives in pandemic situations.

There's a much bigger issue at a societal level of saying, 'What's this transparency all about during a pandemic? What can we expect as ordinary citizens? Or what's our approach to that?'

Such a contract would hold elected officials to account and lead to greater public involvement in decision making. For example public dialogue models could be used to define the terms of this transparency contract with ethical principles in mind.

We see that there is an appetite for novel approaches to public participation at a national level. Participants are less certain about what this might look like and how to measure its effectiveness. The notion of forums, replicated throughout the country and based on the format of the dialogue workshops, is one proposal. This is envisaged as a 'bottom-up approach' to policy making that would enable information from the 'grass roots' to be synthesised and presented to government. Another idea put forward is for a 'people's jury' to be present at events such as the Covid-19 daily briefings. Although members of the public were able to submit questions in advance of these briefings, it is thought that being able to provide 'immediate feedback' on policy and messaging might draw attention to issues more quickly.

I was putting forward the idea that the forum in which we are all involved presently could be replicated across the country. It seems to be an excellent model for not just sampling on a poll basis but for collecting discussed opinion and I suppose a mechanism for channelling the idea of a collective collegiality from a bottom up approach, in other words a grass roots level.

Still, participants are sceptical about the capacity of government to 'meaningfully accept' information generated by the public. It is also reiterated that policy making still 'has to be guided by subject experts.' Bearing this in mind, one participant suggests that the public's perspective may be most useful in assessing 'where the balance should be', for instance between restrictions and measures. The idea of initiating a forum for public deliberation over issues like this is popular. Some participants suggest that it is especially important for the public to be able to influence measures that factor in regional differences or that disproportionately affect one population over another. This appears to be based on a premise that those most directly affected by restrictions ought to be closely involved in the decisions that affect their lives.

The way things are happening in one place may not necessarily be necessary or good for another place, because of local conditions and local controls, and all the rest of it. So, it would be another element of input to decision-making at a national basis if

there was some mechanism for people to be able to express those opinions and have them processed quickly.

The ambition for local views and public participation to influence policy on restrictions does, however, sit in tension with the generally held view that devolved decision-making causes confusion in a pandemic. The contradiction between an expectation for measures to remain locally relevant and a desire for national cohesion may be a significant challenge for policy making on future pandemics.

One thing that I think central government made the error in, local governments and the devolved powers making their own decisions. I think because it was so fragmentary, there was a lack of clarity.

7.5 A caring society - communities supporting each other

The Covid-19 pandemic provides inspiration and lessons for thinking about the role citizens can play in delivering positive change in local communities and across the country. Participants are excited by what is seen as 'a huge volunteering effort' in support of the pandemic response. The vaccine roll-out is identified as an example upon which future attempts to coordinate local volunteers ought to be modelled. Meanwhile, mutual aid schemes, which proliferated during the pandemic and enabled supportive networks to form among communities, are thought to be able to meet ongoing needs.

I think let's use this opportunity to say, 'If you do want to help wider society. Here are the avenues that you can exploit in the future.'

Importantly, participants believe local, voluntary efforts will benefit significantly from external support and planning. Multiple participants would like to see the formation of an organisation or register through which members of the public could sign up to volunteer in advance. One participant suggests looking at Germany's civil protection organisation, Technisches Hilfswerk¹⁴, as a model that could be replicated. Another participant suggests being able to identify and coordinate volunteers in advance might enable them to carry out routine tasks such as vaccination, reducing the burden placed on healthcare staff in a future pandemic.

I've got Crohn's disease and I actually inject myself 4 times a day, so I'm trained up on it, I know how to do it. So they could use people like me rather than cancer specialists and stuff to actually go and administer what is a quite easy vaccination just to pop into the arm. Instead of that they close down loads of departments in the NHS for years or several months in order to roll out a vaccine. And I feel like we missed something there, if there was a group that we could all go and register with. And maybe you have to go and update your details once a month or whatever. I'm sure a lot of people would do it. I know for one I would.

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¹⁴ Bundesanstalt <u>Technisches Hilfswerk</u>, accessed 1st July 2022

8 Conclusions and final reflections

As a result of taking part in the dialogue participants have identified areas where further research could be undertaken on the experience of Covid-19 and which highlight key points for consideration on future pandemics. These are described within the previous sections, but we highlight two here which are significant.

- 3. Developing tools for use in preparing for the next pandemic, including research into:
 - What support is needed across society to recover from the trauma of Covid-19, particularly for those who have suffered traumatic loss, and children and young people
 - What transparency in government decision making, policy making and communications should be like in a pandemic
 - How to prepare populations for a future pandemic including trusted sources of information, evidence and data
 - Who should deliver trusted communications on future pandemics and how.
- 4. Research into and policies for the rules, measures and restrictions, appropriate for future pandemics including:
 - How these should be agreed on in the future
 - Who would provide the most effective leadership on the rules, measures and restrictions
 - How to develop a subtle approach to implementation which does not cause more harm than good.

In writing this report we conclude that participants have welcomed the opportunity to take part in deliberative discussions on an issue which does, and will continue to, affect us all. They emphasise key points that they hope those making policies for future pandemics will take into account. These are summarised out below:

Mental health

- The anxiety around Covid-19 has not gone away, participants feel that uncertainty around how to apply personal responsibility, and keep those at higher risk in society safe, is a challenge which cannot be ignored.
- As a result poor mental health and the need for more resources for mental health support is highlighted.

Children and young people

- Concern is expressed that the impacts on children and young people have been extremely significant
- Participants fear that the consequences may be felt for years to come unless acknowledged and addressed.

Inequalities

- Covid-19 has exposed pre-existing inequalities.
- Now that they are more visible in society participants call for more action to address them so that social and economic divisions within communities do not widen further

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• Participants feel this might be too idealistic, but it should nevertheless be a significant societal ambition.

Tensions and trade-offs

The dialogue has shown that in this transitional phase of the pandemic as restrictions are lifted there are significant tensions in society. In particular participants question the concept of 'freedom' as applied to Covid-19 rules being lifted. They call for an empowerment rather than oppositional language to be applied to ongoing deliberations on a future with pandemics.

The common good

As in the previous dialogue, solidarity, togetherness and the common good are seen by participants as very important in a future with pandemics. The ethics of a caring and compassionate society are highlighted by participants and as such they prioritise collective over individual needs in a pandemic.

Rules and measures

As restrictions lift, ease and change in this phase of the pandemic participants share a mix of relief and concern. They treat this issue too with great consideration being aware that everyone in society has had their own particular experience of the pandemic and therefore may react in many different ways to restrictions lifting. They call for thought and respect to be given to those, because they are at higher risk from the virus, who may not welcome this new phase.

A view from the home nations

Across the home nations, participants want to see greater clarity around the steps being taken or not taken by their governments in this phase of the Covid-19 pandemic. There is an expectation that guidance ought to be more obviously linked with responsible individual behaviour (e.g., around mask wearing and social distancing). Decision-making needs to continue to be justified, supported by more accessible and comprehensible evidence in the public domain. Some participants want the lifting of restrictions to be as clearly communicated as was their implementation. They express:

- A real desire for governments to act with transparency. In Northern Ireland, participants want less performance politics and more emphasis on government processes, as well as clear links between the actions taken by government and their public benefit.
- Their concern for the strength of public services, which receives mention in England and Northern Ireland especially. Services are thought to have been in a vulnerable state before the pandemic and are now perceived to be recovering too slowly. Participants want to see capacity increased as soon as possible, with resilience to future shocks built up in the longer term.
- Participants also want more collaborative governance within and between the home nations on pandemic responses. Collaboration is linked with consistency, which seems to help people make sense of the pandemic. This is thought to be in the interests of the public, rather than the political jockeying participants tend to perceive as the main reason for differences over decision-making.

Underpinning ethical values and principles

The dialogue reveals important underpinning ethical values and principles:

- The need for trust in our government and public institutions, a trust which has been lost in the current phase of the pandemic
- The importance of transparency and honesty in building this trust
- A desire for a greater unity and collaboration across the UK's nations
- Achieving a balanced rather than an oppositional approach to policy making
- The common good prioritised over individual needs and wants
- Living in new ways with a great respect for other people to provide a compass for our actions in the face of future pandemics
- Acknowledging and learning from the harms caused to prepare for the next pandemic

These values and principles, if upheld in society, will, in the eyes of participants, create a compassionate, equitable society which learns form its mistakes and builds fairness and trust into preparing for future pandemics.

Proposed solutions to living in a pandemic

Participants identify a number of factors which could improve how pandemics are managed in the future. These include:

- Having a more nuanced and subtle approach to protecting people at risk during a pandemic, tailoring lockdowns to absolutely essential risk management rather than a blanket approach
- Putting in place a plan for education in future pandemics so that the system can provide the education we expect for our children and young people
- Prioritise mental health and wellbeing including additional resource for mental health services across the country so they are more equipped to deal with the trauma of future pandemics
- A holistic approach to pandemic policy making which could include, for example greater investment in education on the science of a pandemic; the creation of an emergency fund which would be drawn on to fund emergency measures in the future; a multi-agency approach nationally and globally.

Participants also believe that citizens should have a greater involvement in policy and decision making for pandemics in the future. They call for measures which bridge the gap between publics and policy makers which might include:

- Developing contracts between the government and the people e.g. a 'transparency contract'.
- Calling on deliberative approaches: dialogue, assemblies and juries when, for example a decision might adversely affect one community more than another or where a balance is required between policy areas or restrictions.

Finally, we conclude by emphasising that participants desire a caring society, one where communities support each other. Where volunteering is encouraged and support for others is the norm.

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. We particularly welcome their honesty, frankness and compassion in sharing their experiences of this phase of the pandemic.

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 John Coggon, Professor of Law in the Centre for Health, Law and Society, University of Bristol/ UK Pandemic Ethics Accelerator; Margaret Douglas, Hon. Consultant in Public Health; Heather Payne, Child Health, Senior Medical Officer, Welsh Government; Duncan Morrow, Professor in Politics and Director of Community Engagement, Ulster University; Jasvir Singh, Co-Chair of the UK Government's Moral and Ethical Advisory Group, Chair of City Sikhs and Vice-Chair of the Faiths Forum for London; Alex McKeown, Research Fellow – Neuroscience Ethics & Society: Department of Psychiatry/ Wellcome Centre for Ethics and Humanities and Deputy Director UK Pandemic Ethics Accelerator; Emma Nance, Academic Fellow in General Practice, Centre for Population Health sciences, Early Career Research, 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: Sarah Cunningham-Burley, Hugh Whittall, Jamie Webb, Kiran Manku and Catherine Joynson. 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.

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Appendix 1

UK Pandemic Ethics Accelerator – Covid-19 as restrictions are eased : Recruitment specification

Client: UK Pandemic Ethics Accelerator – Edinburgh University and the Nuffield Council on Bioethics

Study theme: An online public dialogue on ethical concerns relating to the transition out of restrictive methods for managing Covid-19

Engagement contractor: Hopkins Van Mil: Creating Connections Ltd

Aim & objectives:

The aims of this study are to:

- To engage a broad demographic of society, weighted for those who have been and might continue to be more disadvantaged by Covid-19 and Covid-19 restrictions, and the easing of those restrictions;
- To inform and shape potential future engagement activities on these three themes
- To inform and shape future policy programmes on these issues.

The methodology will be an online public dialogue using Zoom. The recruitment will create one group of 28 people who will meet four times and have access to an online space to review materials outside workshop discussions. The purpose of this document is to give the framework through which the fieldwork team will develop the detailed schedule and screener for recruitment. These will be approved by the Project Team via HVM before being used in the field for recruitment.

The study will involve recruiting 28 participants from the UK, broadly representative of the population in terms of age, gender, life stage, social grade/ household income, geography and ethnicity. We will be gaining informed consent from participants in terms which comply with the DPA 1998 and will allow identifiable data to be transferred and stored securely by the commissioning body for future research and/or dialogue purposes. HVM is registered as a data controller with the Information Commissioner's Office no: Z2969274.

Recruitment summary:

- The public dialogue will involve recruiting 32 participants
- Participants are required to attend all four workshops which will be online
- They will also contribute to an online space in between workshops
- Respondents will be asked to review some very short written/ visual material before participation.

Incentive: £250 for attendance at all four workshops and some online responses in between workshops

Support will be provided for participants who need either equipment or data to take part, they will not be excluded for not having access to a laptop or ipad

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Dates and times for workshops:

| Activity | Dates |
|-----------------------|---|
| Optional tech try out | Monday 9 th May 4-5pm |
| Workshop 1 | Monday 9 th May 6-8pm |
| Workshop 2 | Thursday 12 th May 6-8pm |
| Workshop 3 | Monday 16 th May 6-8pm |
| Workshop 4 | Saturday 21 st May 10am to 1pm |

Screener to include:

| Criteria | Target |
|---|---|
| Gender | 50% identifying as male / female |
| Age | Good age distribution across age groups from every adult life stage from 18 upwards. |
| Ethnicity | A boosted sample of 6 participants from Black, Asian, minority ethnic (BAME) backgrounds in line 2011 census data (13%) but boosted by 3 people. |
| Disabilities | A boosted sample of 6 participants above current ONS figures |
| Life stage | A broad range of life stages from students, young |
| | professionals, raising young children to empty nesters and those who are retired |
| Current working status and type | A range of people who are employed (part-time/ fulltime/ self-employed) and unemployed, plus those who are retired. |
| Social Grade | Mix of AB (7 participants) C1C2 (11 participants) DE (10 participants) |
| Geographic location | The group should be drawn from a UK sample. We suggest focusing on communities which have score higher in the indices of multiple deprivation we need 7 participants each from England, Wales, Scotland and Northern Ireland. Each group of 7 should include those from rural, urban and coastal regions. |
| Experience of market research/ dialogue | Should not have taken part in a focus group/ Citizens' Jury/ Citizens' Assembly or public dialogue in the last twelve months |

| Perspectives on the issue of Covid-19 | To achieve a range of perspectives (rather than as an exclusion criteria): |
|---------------------------------------|--|
| | How worried or unworried are you by the transition out of Covid-19 restrictions? |
| | From 1 = not worried at all |
| | To 5 = extremely worried |

Important note: please do not recruit friendship pairs or use snowballing techniques.