periscope

Pan-European Response to the ImpactS of COVID-19
and future Pandemics and Epidemics

# The Commission for Pandemic Governance and Inequalities

Deliverable 9.3

# PERISCOPE

## Pan-European Response to the ImpactS of COVID-19 and future Pandemics and Epidemics

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# The Commission for Pandemic Governance and Inequalities

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# EXECUTIVE SUMMARY

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*This report is part of the EU-funded Horizon-2020 PERISCOPE project. It involved researchers at the London School of Economics (LSE), the Karolinska Institute (KI), the Federation of European Academies of Medicine (FEAM) and the Centre for European Policy Studies (CEPS).*

It features four reports reflecting on lessons learned about public health governance during the COVID-19 pandemic, in order to inform policy and practice recommendations. These reports have been developed through consultation with experts working across levels of governance. Our research spanned an extensive network of key figures involved in pandemic governance across Europe, including: global, EU and regional government officials (CEPS); medical professionals (FEAM); UK public health officials and leaders in the voluntary, community and social enterprise sector (VCSE) (LSE); and local officials and citizens in Sweden (KI).

The research methodology and analysis bring into focus the inequalities that have arisen as a result of COVID-19 governance. Our recommendations are aimed at reducing these inequalities in the present and preventing them in future pandemics. Our work generated collaborative, robust recommendations that span varying levels of governance. The overall report leads with recommendations for best practice governance frameworks, principles and approaches, as outlined below. Each case study then offers further evidence supporting these recommendations, as well as suggesting specific practical policies for preparedness and response.

- **Public Health Governance**: there is a need for democratic discussion about the role of scientific, legal and ethical responsibilities in pandemic governance at national and EU levels.
- **Data and Evidence**: pandemic preparedness requires data preparedness, including multi-disciplinary integration of open-access data and evidence across ministries, health bureaucracies and private entities.
- **Social Listening**: there is a need for an improved understanding of the role of qualitative social science approaches such as ‘social listening’ and co-production methods in mapping inequalities to inform pandemic policy.

- **Public Authority**: national governments need to focus on the health and provision of care for minoritised and disadvantaged people, in order to build trust and reduce inequalities.
- **Social Infrastructures**: flexible and sustained government funding is required to support an integrated ecosystem of VCSEs, public health and social care services. This approach would help to bridge macro and micro levels of governance to support pandemic response and preparedness. VCSEs should also be involved in high-level emergency government committees.
- **One Health**: a One Health framework should be foregrounded across levels of governance to address the interdependence of human, animal and environmental health during and beyond pandemics.

This report follows previous research in PERISCOPE work package 9 on best practice in multi-level governance (PERISCOPE, 2022). This showed that a broad and diverse evidence base is an essential in informing pandemic policy making. This is best produced and analysed by interdisciplinary collaboration among scientific research actors. The findings from this need to be channelled through strong communication mechanisms. Multi-disciplinarity and open data sharing are also core principles of the Periscope project more broadly (see Scotti et al., 2022). As this report shows, these offer a strong basis on which more equitable public health policy and resource distribution can be built.

Various Periscope studies have also offered crucial evidence to inform policymaking across the UK / EU throughout the pandemic. These studies have followed the evolution of public health policy priorities, assessing pandemic responses and their economic and epidemiological consequences. This includes for example; guidance on policies for containing the epidemic, including the effectiveness and costs of restrictive containment policies (Barrat et al., 2021; Cencetti et al., 2021; Woskie et al., 2021); assessment of vaccine measures alongside non-pharmaceutical interventions (NPIs) (Giordano et al., 2021; Gros et al., 2022; Iftekhar et al., 2021); and evaluations of the risks of securitised or militarised public health responses (Barceló et al., 2022; Parker et al., 2022). Overall, this research generally demonstrates the potential of early, 'moderate, adaptive NPIs' to: balance epidemiological and economic concerns; prevent excess deaths and the need for disruptive measures; respond to specific contextual concerns; and mitigate uneven economic outcomes (Gros et al., 2022; Iftekhar et al., 2021; Krueger et al., 2022; Woskie et al., 2021). Various Periscope studies also highlight the potential benefits of greater EU coordination and solidarity, including for sharing best practice, information

management and ensuring global vaccine access (Valdez et al, 2022; Priesemann et al., 2021; Steinert et al., 2022). Taken together, these policy insights from across the Periscope project have informed the Commission on Pandemic Governance and Inequalities, providing important grounding for COVID-19 policy recommendations and future pandemic preparedness.

# INTRODUCTION

# INTRODUCTION

*The LSE Commission on Pandemic Governance and Inequalities is a unique multi-disciplinary experiment in informing pandemic policy. It is an example of the kind of collaborative work, spanning the social, medical, public health and policy sciences, that is needed to prepare for the next pandemic.*

Researchers came together to reflect on government policies in the EU and UK during COVID-19. At the centre of our work was a focus on short- and longer-term inequalities related to the governance of the pandemic. We were interested in which policies had intensified or reduced structural disadvantages in society. By tracing the history of these processes at the local, national and international levels we have built recommendations for the present. Our proposals are vital for preparedness for the next pandemic and in order to create more equal societies now.

This report brings together the findings from partners working together across European contexts and disciplines. LSE, KI, FEAM and CEPS have currently been collaborating for two years on this work which is part of a larger three-year PERISCOPE project funded by the European Research Council (ERC), involving 31 institutions as partner institutions. We build on this broader stream of investigation and refer to the original PERISCOPE research throughout the report.

From September 2023 a smaller group prepared the methodology and questions for this report. Researchers included anthropologists, political scientists, public health policy experts and psychiatrists. From February to May 2023, we conducted workshops and interviews with experts who had been involved at multiple levels of governance during the COVID-19 pandemic. Our research engaged with key figures involved in pandemic governance across Europe: from global, EU and regional government (CEPS); the medical professions (FEAM); national government and the voluntary and community sector (LSE); and local officials and citizens (LSE, KI).

The methodological approach adopted by the LSE Commission reflected our focus on inequalities. Usually, policy inquiries follow a format similar to that in a courtroom: witnesses give evidence that is adjudicated on by experts. However, for this report, we treated all our participants as local experts on key public health relationships. We chose to involve ‘nodal’ people whose perspectives spanned a range of networks both inside

and outside of government. Many of them were also key mediators who turned policy into social action. For some of our investigations we also included members of the public who had experienced the pandemic response measures. We analysed the responses in relation to the positionality of the various experts in key institutions and social relationships that had delivered pandemic governance in each setting. The greatest weight was given to evidence from people at the lower levels of governance and/or those closely related to disadvantaged groups. This is because they would have faced the difficult task of making policies work on the ground. The strain they faced in attempting to bridge the gaps between state policies and social conditions reveals an especially valuable perspective on the impact of policies. Our methodology is highly unusual as often such mediators are treated as the objects of audit rather than as experts in policy effectiveness. Overall, we analysed public health governance through the framework of unequal social relationships and as involving the difficult relational work of translating policy into practice.

In this introduction we make our recommendations for governance frameworks, principles and approaches during global pandemics. Each case study that follows provides supporting evidence and more specific practical policies based on our research. From our collaborative work we offer overall recommendations in five areas: Public Health Governance; Data and Evidence; Public Authority; and One Health Frameworks. These themes were drawn from the overall research findings of the PERISCOPE three-year project. They were also identified as crucial in our group's previous research in 2021–2022 on 'Best Practice in Multi-level Governance During Pandemics' within the PERISCOPE project (PERISCOPE, 2022).

## Our approach to inequalities

Our approach is similar to that taken in the multi-disciplinary analysis of the high COVID-19 mortality rate in minority groups by the Ethnicity subgroup of the Scientific Advisory Group for Emergencies (SAGE) (led by Bear, Gov.UK, 2021a). The death rate was high for all ethnic groups in the second wave of the pandemic in the UK between October 2020 and January 2021, but was highest for British Bangladeshi (5x white populations) and Pakistani groups (3x white populations). These tragic numbers are linked to the amplifying effects of health inequities, especially high incidences of diabetes among these groups, coupled with social and policy inequalities. These groups also faced disadvantages in having less opportunity to work from home and living in over-crowded multi-generational households. They also suffered from stigma after the overnight imposition of restrictions in the north of England on the eve of Eid celebrations on 31 July 2020. This stigma took the form of suggestions that their homes would be a particular source of infection, at a time when families in the region were allowed to attend pubs and restaurants. Stigma is closely related to difficulties relating to health-seeking behaviour.

Other national policies such as furlough did not adequately support the small family businesses that provide the main source of income for British Bangladeshi and Pakistani groups. Families relying on these businesses had to keep them open even at periods of high transmission. Given all of the factors stacked against these groups, the ministerial decision not to impose national restrictions in October and November 2020 likely contributed to the high rates of death they experienced. In general, ministers throughout the pandemic introduced policies that would protect an 'average', middle-class citizen from a regional or national 'R' rate. But as the scientific evidence presented in this SAGE paper suggests, pandemic policy needs to be formulated for the whole population and also for specific social groups who face multiple disadvantages and are therefore more vulnerable to disease. A significant barrier to achieving this aim lay in the quantitative data that the central government used to track pandemic impacts. They were derived either from prospective modelling that predicted general R rate or constituted data on *post hoc* illness and mortality. If the government had targeted its efforts at places high on the multiple indices of deprivation and those which were known by local public health officers and general practitioners (GPs) to be areas of potential high impact and had it used this information along with qualitative evidence of unfolding events on the ground, then it would have been able to save more lives. In the latter part of the pandemic in the UK this bottom-up knowledge from local authorities and the local National Health Service (NHS) was integrated more into evolving policies in Public Health England (PHE) and the Department for Levelling Up, Housing and Communities (DLUHC). It is, however, important to note that the highest rates of death continued to be among British Bangladeshi groups even after vaccination in the third wave (ONS, 2022). This highlights the need for more targeted policies based on local knowledge and qualitative analysis.

### Public health governance

Policy moves between macro, meso and micro levels of governance, usually in a top-down direction. This means that it travels between very different kinds of institutions with specific histories. As policy unfolds within these various settings, the goal of any interventions may stay the same, but the content of the policy shifts as it interacts with social relationships. We were particularly interested in the role of national and lower-level public health officers and bureaucrats and the challenges they faced in integrating EU and national directives on COVID-19. We explored how these processes played out in space and time across the EU and UK. Our key question was: To what extent have mediations of policy exacerbated or ameliorated the unequal impacts of COVID-19? We also examined different kinds of health delivery structures and practices and assessed which ones had been most effective in overcoming inequalities. We then reflected with our participants on what our findings from this retrospective assessment suggested about future directions for design of public health bureaucracies and their relationships to each other.

Our findings demonstrated that the decentralisation of public health measures had mixed effects on inequality. On the one hand, it generated unequal outcomes across certain regions due to different eco-systems of public/private outsourcing of facilities and variability in funding resources between distinct areas. Multiple mixed messages from central government and from regional authorities also caused issues such as confusion about or even contestation of rules at the local level. On the other hand, the contextualisation of public health measures to specific socio-economic situations and social groups was very important in generating positive public health impacts. In addition, we found that new connecting relationships between the macro and micro levels of government, via lower-level public health and civil society organisations (CSOs), led to better-informed action. Similarly, the centralisation of power when deciding on cross-EU and cross-national measures sometimes led to a concentration of power among politicians and experts in a few dense networks, and they decided opaquely what was best for ‘our’ collective safety. In some settings, expert bodies were perceived as ‘too political’ and not able to recommend evidence-based measures to central government. In others, while leaders claimed to be following the science, the basis of their decisions was unclear even to their civil servants. It was also clear that inequalities cascaded quickly from macro to micro levels during the pandemic. For example, the crucial issue

of vaccine procurement had huge impacts on disease outcomes among the poorest in Europe and the Global South. Some countries prioritised central relationships to pharmaceutical companies rather than vaccine solidarity across nations. In addition, central governments' identification of some groups as 'vaccine-hesitant' or interventions during minority festivals led to a sudden intensified stigmatisation of these groups. Overall, during the pandemic, we traced a rising tension between top down and distributed power.

On the basis of our evidence, we recommend that, for ongoing and future pandemic policy-making:

- There should be a balance between the centralisation and decentralisation of health policy. Crucial in achieving this is the construction of social infrastructures or a good ecosystem of national and local VCSEs. These organisations provide a highly significant bridge between macro and micro levels of governance. They can best advise on the extent to which EU or national level policies and communications need to be altered at the more local level. They can also deliver well-informed and relevant health measures. They need to be centrally resourced and monitored and be context-specific.
- In addition, properly resourced local public health and care services are essential to recovery from this pandemic and preparedness for the next. These need to be centrally integrated too so that they are fully taken into account within central government provisioning. This is a form of pandemic preparedness that does not involve a dilemma related to trade-offs between expenditure on public health now versus expenditure on the possibility of a future pandemic. If VCSEs and local public health and care structures were funded sufficiently now, there would be better overall health outcomes outside of crisis times as well. We also recommend that the undemocratic centralisation of power in the hands of a few politicians and experts should be avoided as far as this is feasible.
- Scientific experts need to be independent of government. They should also be appointed through a transparent process now in preparation for future emergencies. The evidence bases for any decisions made by politicians should be made public, instead of being obscured from public scrutiny under secrecy rules.

- Most crucially, there needs to be discussion of what legal and ethical responsibilities are involved in pandemic governance. Rather than turning to autocratic structures as a default, we need constitutional or legal checks and balances against this. A democratic discussion about these should be held within each nation state and at the EU level.
- Macro-level organisations, such as the new European Health Emergency Response Authority (EU HERA), need to be prominent advocates against inequalities in this debate, for example in terms of global vaccine solidarity and pre-planned procurement supply chains.

### Evidence and data

There are global calls for the better use of scientific expertise and evidence in health policy-making, which also engages with the political realities which can influence the uptake of research for policy decisions (e.g. Parkhurst et al., 2018; Marmot, 2004; Oliver et al., 2014). The influence of research in policy relies on its alignment with political priorities, as well as effective communication between academic experts and decision-makers. Evidently, for complex, multi-dimensional health issues such as COVID-19, there is a need to engage with multiple bodies of evidence and dynamic approaches to research that can be understood in a political context. During the pandemic, evidence and data became fragmented due to silos between public authorities and the private sector. This meant that different levels and areas of governance could not be coordinated, nor could different departments easily share comparable evidence. In addition, established hierarchies of knowledge informed burdens of proof for different forms of knowledge within scientific advice. Modelling and epidemiology were given the most credence and qualitative social sciences the least.

Research detailed in PERISCOPE Work Package 9 on best practice in multi-level governance (PERISCOPE, 2022) suggests that a broad and diverse evidence base represents a best practice approach for informing pandemic policy-making, facilitated by interdisciplinary collaboration among scientific research actors and channelled through strong communication mechanisms. Multi-disciplinarity and open data sharing are core principles of the PERISCOPE project more broadly (see Scotti et al., 2022), which draws from epidemiological, clinical, political science, economics and social sciences. This

approach is necessary in responding to the complexity of global, regional, national and local level governance during a global health emergency.

During COVID-19, across contexts, decision-makers have sought to balance economic and epidemiological concerns, the former often taking precedence in political decision-making to the detriment of public health. Various PERISCOPE studies (Gros et al., 2022; Iftekhar et al., 2021; Krueger et al., 2022; Woskie et al., 2021) advocate for the potential of early, 'moderate, adaptive' non-pharmaceutical interventions (NPIs) to balance epidemiological and economic concerns, prevent excess deaths and the need for disruptive measures, respond to specific contextual concerns and mitigate uneven economic outcomes. These could include smart NPIs designed to target particular sectors. This was difficult during the pandemic due to lack of data and cross-disciplinary work at the highest levels of government.

Overall, using a cross-disciplinary, problem-focused team to tackle issues provided the most helpful and informed advice as, for example, in the UK SAGE. This was particularly important because quantitative data on disease outcomes were always 'catching up' with events such a high infection and mortality rates, whereas multi-disciplinary teams could use existing measures such as multiple indices of deprivation and triangulate them with knowledge about health inequalities to make recommendations. Co-production and social listening in real time produced helpful collaboration and informed policy at all levels of government. During the commission, there were also questions raised by participants about the democratisation of data and whom evidence was produced for. Publicly accessible data would support the work of people in the VCSE and community activist sectors, who otherwise, during Covid-19, needed to access and analyse disparate sources of available data to support their vital work.

We would, therefore, recommend that the following significant areas are addressed now:

- There could be a more problem-based use of cross-ministerial committees to collate data and evidence and build health and care policy.
- There also needs to be a plan for how various ministries can coordinate their efforts during health crises. To support such work there should be an exploration of data integration across care and health bureaucracies.

- The scientific advisors appointed for pandemic policy should be multi-disciplinary and all relevant disciplines should be represented on central advisory committees.

- There needs to be a campaign to improve the understanding among decision-makers of the value of qualitative social sciences and their ability to map inequalities in real time. In addition, we need to build the capacity for social listening and co-production of health policy. This means more than merely ensuring 'representation' of various VCSEs and community activists on committees. Instead, there needs to be a deep exploration at the local level of health and care issues.

- At various points in the pandemic, there were attempts to advise on adapting national restrictions into more targeted 'smart NPIs' that might have reduced both the financial and broader costs to social support, mental health and the economy. Yet there was not enough multi-disciplinary evidence and data to introduce these smart NPIs. Research could be conducted on the potential for smart NPIs in multi-disciplinary teams.

- There should also be reflection on, and the construction of, platforms for more open access to data and evidence to support the work of VCSEs.

- At the international level there needs to be concerted exploration of the legal measures and relationships required to create a link between private and public data.

### Public authority: Legitimacy and trust

During the pandemic, legitimacy and trust were built through the relational work of CSOs, for example in the use of Community Champions in the UK. These organisations often have broad social support, are flexible to various micro-groups' needs and can bring people together across various social groups. Trust is not a 'thing' that places and people have more or less of. It is a quality of relationships and reflects the degree to which people have experienced disadvantage and discrimination as a result of government policies.

It is also important to note that we now live in a 'post-COVID' world. The COVID-19 pandemic has fundamentally shaped how people respond to public authority and legitimacy. Although society appears to have normalised – and this is something that politicians have actively encouraged – our participants reflected on government action from the perspective of interventions during the pandemic. Across the board, participants were focused on the inequalities revealed and amplified. These concerns included the fact that some social groups faced life-threatening illnesses and died in greater numbers than others, including elderly and disabled people, minoritised and racialised people, and people with lower incomes. Our participants, who were variously positioned across contexts, were also acutely aware of the privileges that the upper and middle classes had in terms of housing, education and open spaces.

In addition, research participants recognised that mental health has declined due to extended social restrictions and the experience of mass uncertainty and fear. Various PERISCOPE researchers have also highlighted the mental health impacts of the pandemic at various stages, especially for socio-economically disadvantaged groups (Asper et al., 2022; Spiritus-Beerden et al., 2021; Winkler et al., 2021; PERISCOPE, 2022). Many participants also recognised the gendered burden of the labour of care whereby women, across the board, were disproportionately affected. They were all concerned with the need to invest and put in place policies to promote recovery from this experience. The most effective way of improving public authority and legitimacy in the next pandemic is to act now to reform health and care systems along the lines that would benefit citizens. They were also keen to ensure that the most far-reaching pandemic policies in future crises will not be punitive, but supportive of the ability of all members of society, whatever their background or work, to protect themselves. As highlighted during this research, there is a sense of a collective 'we' coming out of this crisis that can be helpfully focused on achieving a deeper transformation of state care and the realisation of the public good. This aim is deserving of sustained cross-disciplinary research, public investment and the development of effective care policies, which should be evaluated according to their outcomes in terms of alleviating inequities (Bear, 2015). As Renda asserts, there is, therefore, a 'moral and political imperative to approach COVID-19 recovery by triggering a deep economic transformation' (Renda, 2022: 5), with policies refocused towards well-being, sustainability and fairness:

- To increase government legitimacy, there is a need to focus on health and care provision for the disadvantaged.

- Trust needs to be constructed outside of pandemics through policies that assist minoritised and impoverished groups.
- Central governments also need to resource VCSEs to reduce biopsychosocial inequalities now in addition to creating a social infrastructure based on trust and preparedness.
- When the next pandemic arrives, policies should call on an ethical 'we' who are protecting the whole of society and they should focus on care for the disadvantaged so that people are able to follow regulations and remain protected.
- More punitive communications and measures (e.g. police interventions to enforce lockdowns) may work in the short term through fear, but in the mid- to longer term they will undermine the public authority of governments and elected officials.

### Social Infrastructures

It will already have become clear from the previous recommendations that the work of CSOs and community activists is central in our commission. Across all levels of government, the essential nature of this relational work was recognised. The UK's Community Champions scheme also provided us with a model of how best to provision and govern this sector. This was a successful scheme because it involved inclusive commissioning methods in which previously unknown organisations were supported to work with local government. It also included flexible monitoring practices negotiated with local authorities and local organisations, who otherwise often find it difficult to provide the evidence required by central government audit to back up their decision-making. Significantly, this scheme worked in all areas, but was most effective in areas that had a strong local eco-system of VCSE cooperation already. This was helped too by the work of national level CSOs that provided support and training to smaller micro-group organisations. It had at its heart not the 'delivery' of government health policies but a model of co-production. In this scheme, local organisations were treated as experts with useful knowledge and important ideas about how to provision neighbourhoods. Volunteers were also given the power, in forums with local public health officers, to challenge policies in real time and provide information on what was working, or not, on the ground.

Our recommendations in relation to social infrastructures are given below:

- Government policies should focus on the funding and provisioning of a national- and local-level social infrastructure of CSO and community groups.
- Importantly, again, this VCSE work needs central government funding. This funding should be provided for certain broad goals, but the solutions about how to deliver these should be left to lower-level and umbrella organisations more in touch with the barriers and potentials of social networks.
- At present many of the organisations that stepped up in national and international efforts are starved of funding. We suggest that perhaps national infrastructure banks should be set up and the European Investment Bank be enabled to fund social infrastructures as well as physical ones.
- The formation of service integration of health, care and social services is important at the local and national levels. This would help in the development of a more targeted suite of policies around the life cycles of communities and social networks.
- Along with these measures, local authorities should be legally required to supply a CSO infrastructure as a statutory right as well. This could, perhaps, be best achieved through the creation of a Ministry for Care. A Ministry for Care could join up health, social care and VCSE funding priorities and policies.
- In line with this, just recompense for unpaid care labour and fair wages for care workers should be a statutory right.
- When the next pandemic arrives, the rich, deep and well-funded social infrastructure these recommendations would create would be an invaluable resource. We argue, crucially, that CSOs should, in the future, be included in government committees at all levels of pandemic preparedness and response.

### Health frameworks: One Health and beyond

A One Health pandemic policy framework stresses the interdependence of humans, animals and the environment, and the need for an integrated approach to pandemic preparedness and response. The importance of a less anthropocentric policy view of the human-animal-environment nexus is particularly exposed in responding to zoonotic

diseases such as COVID-19. Over the past 50 years, zoonosis is thought to have caused annual disease outbreaks (Sironi et al., 2022), including severe acute respiratory syndrome (SARS), Middle East respiratory syndrome (MERS), swine flu, bird flu, Ebola, Zika, monkey pox and COVID-19. The risk of zoonotic viruses is exacerbated by ongoing intensive ecological extraction, industrial farming, wildlife trade, deforestation, global heating and climate change.

Despite these global public health and environmental crises, the interplay between human and animal health is often overlooked in pandemic policy-making. This was highlighted in the research led by the Karolinska Institute on the Swedish response to the COVID-19 pandemic (see also Osika & Pöllänen, 2023; Humboldt-Dachroeden, 2023). In this, they drew the following conclusions:

- We therefore recommend that national governments, international organisations and public authorities address health holistically in recognising the interconnectedness between human, animal and environmental health in pandemic preparedness and response. This includes the requirement for interdisciplinary collaboration to prevent and manage zoonoses.
- The One Health framework should be considered, debated and refined across sectors, contexts and levels of governance. There is a need to consider how to translate the One Health concept into policy practice. This would play a significant role in preventing and recovering from zoonotic diseases.

## Report summary

We now turn to the body of the report and our separate findings. Our overall arguments have been enriched by the comparisons from the international and country-based case studies that follow. Yet they also contain distinct disciplinary approaches and more specific recommendations as relevant to their material. They should be read as more than supporting documents to our arguments here. They are interventions that stand on their own in a cross-disciplinary and cross-contextual conversation. As such, you can read them as individual pieces in their own right, or read across them to draw your own conclusions. This is why we have preserved their distinct structures within our report.

For the first case study, the team at CEPS conducted workshops with high-level experts working across a range of international organisations, including EU officials, senior staff

in regional organisations, researchers and policy-makers representing regional authorities and CSOs. Research focused on deficiencies and strengths in global and regional pandemic governance from a macro-governance perspective. During the workshops, recommendations for global, regional and national-level public health governance, based on lessons learned during COVID-19, were discussed, with a focus on the role of: science and experts; international actors such as the World Health Organization (WHO); EU agencies such as the Health Emergency Preparedness and Response Authority (HERA); and crucially, CSOs. A focus on global vaccine access and solidarity was also included.

Where CEPS considered the crucial role of CSOs from the perspectives of regional officials and authorities, LSE's central focus was on the perspectives of CSO or 'VCSE' leaders from the outset of the commission. These leaders or key 'nodal' figures mediate between the communities they work and are embedded within, and the public health system in the UK. As such, these experts have a uniquely informed perspective on pandemic governance and inequalities within the VCSE sector in the UK and its successes in terms of up-holding 'social infrastructures', despite the difficulties presented by COVID-19. Their insights, knowledge and recommendations were then taken forward for discussion with public health officials and policy advisors at local authority and national government levels. Despite being variously positioned within the dense network related to pandemic governance in the UK, various affinities in the discussions focus the UK report around recommendations related to: supporting and resourcing crucial social infrastructures and 'mediating' figures; flexible and inclusive decentralised health governance and service integration; and the potential role of robust social evidence. The research team at LSE is made up of anthropologists and social scientists with extensive experience studying pandemics and informing health policy during COVID-19.

KI's case study focuses on civil society, expert and youth perceptions of the exceptional case of Swedish health governance during COVID-19, and emphasising the diversity of national-level responses to the pandemic (Kusumasari et al., 2022). Their study offers a particular focus on the One Health (OH) governance framework and the need to further refine policies addressing health holistically and in consideration of the animal-human-ecosystem nexus. OH aims to 'sustainably balance and optimise the health of people, animals and ecosystems' (OHHLEP, 2022: 11). It acknowledges that the health of humans, domestic and wild animals and plants, and the wider environment are interconnected and interdependent, with the aim of mobilising multiple sectors,

disciplines and communities at varying levels of society (Ibid.). Health cannot and should not be conceived only in relation to human beings, and the OH framework attempts to move away from an anthropocentric view of humans as the central element of existence (Sironi et al., 2022).

As researchers at KI highlight, infectious health threats like COVID-19 transcend species, and geographical, political, sectoral and legal boundaries, meaning that pandemic preparedness and responses should be similarly global, holistic and cross-disciplinary. What are the possibilities for governing effectively and equitably under interdependent, cross-border, 'transboundary' crises? The failures to collaborate and co-ordinate globally contributed to the tragic deaths of 7 million people worldwide (WHO, 2023b). This included failures to equitably distribute resources and protect marginalised people (The Lancet Commission, 2022). As KI's case study highlights, the response in Sweden, as in the UK and elsewhere, favoured the wealthier middle class who were able to work from home. This exacerbated existing structural inequalities related to overcrowded housing, language barriers, socio-economic status and age. In Sweden, the fragmented and underprepared health and social care system impacted elderly people in particular – those reliant on outsourced, decentralised and fragmented council care policies, which lacked coordination with regional healthcare systems. Delays in implementing containment measures in Sweden have been widely criticised, and this research suggests that timely prevention measures such as testing and travel guidance would have saved lives at the same time as safeguarding personal freedoms.

FEAM's research engaged health experts and decision-makers, two of the key groups engaged in the fight against COVID-19. Insights from workshops with experts from FEAM's Medical Academies network were then evaluated in consultation with policy-makers to contribute to recommendations for stronger, well-managed co-ordination between various stakeholders at subnational and supranational levels. This contribution, similarly to the other case studies, highlights the challenges of international and regional level coordination, as related to global inequalities, vaccine supply failures and geopolitical tensions, as well as best practice instruments for communication between countries for pandemic response and preparedness.

On the basis of these studies, we call in our conclusion for a movement across academia, civil society and medical professionals towards **an international declaration of pandemic rights**. We see this as complimentary to the negotiation of a pandemic treaty that the World Health Organization is currently engaged in and the ongoing work at the

UN General Assembly (UNGA). Our approach has a distinct emphasis on the harm that can result from top-down health policies that are not connected to a thriving civil society sector. This sector is essential not just for disseminating top-down policies better, but as an active decision-making partner in challenging the health practices of international and national medical organisations during pandemics. This is the role that the VCSE sector has played in this commission and in the report that follows.

CASE STUDY 1

# Multi-level Governance for Public Health

# CASE STUDY 1: Multi-level Governance for Public Health

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## Executive summary

*This case study aims to dive into the complex web of multi-level governance for public health and provide practical recommendations for policy-makers.*

Through two rounds of workshops with experts from different disciplines, we discussed their ideas about existing problems within the public health governance framework, as evident during COVID-19, and ideas for policy recommendations which address them. In this report, we focus on five topic areas: the role of science and experts; the role of international actors; global vaccine access and solidarity; the role of the Health Emergency Preparedness and Response (HERA), and the role of civil society organisations (CSOs). A key theme of this research is that in pandemic governance, there is a lack of structured responses; however, there are ample solutions and there is ambition to achieve them. We highlight some recommended governance principles and specific practical policy ideas to address these issues for future pandemics.

## Introduction

The institutional governance of public health is undergoing reconstruction following the COVID-19 pandemic. Complex multi-level public health governance involves actors ranging vertically from international organisations (notably the World Health Organization – WHO) to civil society, and also horizontally between public agencies and organisations. The massive threat posed by the COVID-19 pandemic clashed with this complex institutional health infrastructure, as evidenced by the early chaotic responses from various national governments. The pandemic shocked the institutional equilibrium, requiring and forcing components of the institutional framework to search for new positions. The responses to the pandemic revealed to the world both the strengths of the current system and the problems. This case study aims to discuss some of the problems and offer targeted recommendations in five topic areas, as outlined in the Executive summary:

- The role of science and experts
- The role of international actors
- Global vaccine access and solidarity
- The role of HERA
- The role of CSOs

After presenting the chosen methodology for this research, this case study on multi-level governance then considers the five topic areas. For each topic, we present the background before reporting on the discussions from the two workshops and some recommendations. Table 1 summarises the recommendations under each topic area.

**Table 1: Summary of recommendations by topic area**

| The role of science and experts | The role of international actors | Ensuring global vaccine supply and solidarity | Strengthening the role of HERA | The role of CSOs |
|---|---|---|---|---|
| Ensure advisory groups are multi-disciplinary | Promote inter-organisation collaboration | Acquire ownership of intellectual property rights through public investment | Extend the mandate of HERA | Formalise CSO involvement in decision-making processes |
| Review and improve existing advisory groups | | Explore vaccine joint procurement mechanism | Play a stronger role in Research and Development (R&D) | Build trusted CSO network at local level |
| Insulate advisors from political decisions | | | Define a collaboration scheme with other EU agencies | Establish open and resilient communication channels with civil society |
| Keep selection of experts formalised and transparent | | | | |

In the context of a discussion on multi-level governance, a very central question is whether the EU could enhance governance by either centralising or decentralising power. After collecting ideas from interviewees and also studying both the theoretical and empirical literature, the research team did not find a clear consensus on this issue.

The top-down approach generally saves time in reacting to crisis but may not allow for adaptation to local circumstances. The bottom-up approach allows information to be gained from the community but induces misalignments of measures and confusions. This de/centralisation debate should be broadened to consider feedback loops among authorities at different levels and in different communities. The discussion and recommendations oscillate between top-down and bottom-up perspectives, reflecting the complexity of multi-level governance in the EU. They also reflect an ambivalence between recommending more coordination at higher levels of governance and advocating for more local solutions. Coordination, thus, can often be broken down into better communication across levels of governance, and should not be understood as 'centralised planning' in the context of this case study. Feedback loops and the potential for formal and informal structures should be considered in future research.

## Methodology

In order to carry out this research with experts, we conducted two rounds of closed-door high-level discussions. The first workshop was held in-person in Brussels on 3 February 2023, and included four experts. Table 2 lists the background of the experts who took part. The workshop was semi-structured, allowing the experts to share their experience and opinions in an interactive way. Our researchers then summarised a list of recommendations which arose based on the discussion.

We organised the second workshop on 14 April 2023 in a virtual format, with four other experts. The experts received the list of recommendations, based on the discussion in the first workshop, before they attended. The main aim of this workshop was to hear the experts' views on the recommendations. Based on their comments, we selected and dug deeper into five topics according to their relevance, feasibility and novelty. For each topic, we provided some information before summarising the expert discussions during the two workshops. Together with additional desk research, we develop the recommendations with careful consideration of the limitations and obstacles.

The experts involved were selected by the research team according to several criteria. First, the two groups of experts needed to consist of experts from a range of disciplines. Second, the groups needed to have perspectives from different levels of the governance

framework, ranging from the EU level to the civil society level. Finally, they had to be regarded, to some extent, as authorities in their respective areas.

With such varying backgrounds, there was no requirement for the experts to reach consensus on the issues discussed and, in many cases, they were each concerned with different details of a recommendation. The workshops and the case study, rather, provided spaces for interactions among experts from different disciplines and this case study attempts to put forward the more generally accepted ideas of the invited experts.

This report aims to provide perspectives on recommendations, acknowledging that there is still a long journey from this report to actual actions by governments and international organisations.

**Table 2: Background of experts involved in the two workshops**

| Workshop 1 | Workshop 2 |
|---|---|
| Professor of infectious disease, one of the scientific advisors to a government | Professor of hygiene and tropical medicine, ex-official of an international organisation |
| Official in a European institution | Professor of social sciences and business |
| Director of an organisation representing regional authorities | Researcher of health and international trade |
| Director of a network of COVID-19 pandemic responses | Senior policy manager of a civil society organisation specialising in public health |
| Other attendees: researchers from the Centre for European Policy Studies | Other attendees: researchers from the Centre for European Policy Studies |

## Discussion

### 1. The role of science and experts

#### *1.1 Background*

During the pandemic, European countries took very different approaches in terms of how to incorporate scientific advice in formulating responses to the novel COVID-19 pathogen

that caught the Member States unprepared. The pandemic highlighted challenges for the role of science and experts in policy-making. It also demonstrated that there are still severe limitations in terms of the opportunities for scientists and politicians to collaborate smoothly and effectively on evidence-based policy-making during an ongoing public health crisis. While most countries already had scientific advisory groups or national research institutes in place, they did not withstand the stress test of the pandemic. The same is true at EU level; scientific advice mechanisms exist in various forms across different Directorate-Generals (DGs) in the Commission, but these structures were not activated systematically.

In Sweden, for example, the Public Health Agency (PHA) was largely responsible for setting the tone for policy-making during the first wave, with federal governments generally just implementing the PHA recommendations.[1] With lack of clear evidence, due to the novelty of the virus, and political ties, the PHA issued recommendations for weaker restrictions instead of applying a precautionary principle. Expert communities raised their concerns regarding this lenient approach from the beginning (Lundkvist et al., 2020; Le et al., 2022).[2] By October 2020, when the second wave arrived in Sweden, it had become evident that Sweden had fared worse than its Scandinavian neighbours in terms of death toll and infection rates (Ludvigsson, 2020). Public opinion turned, and authorities started to implement stricter policy measures. The Swedish case highlights not only the challenges of federated governance, but also the disagreement within the scientific community as to how advice should be communicated to citizens and whose scientific expertise should inform public policy. The pandemic has shown that action is needed to improve the functioning of scientific advisory groups during public health emergencies. The discussions focused on the changes that need to be made.

### *1.2 Expert discussions*

The experts reflected on the challenges of maintaining scientific integrity while advising politicians and trying to balance epidemiological considerations with socio-economic constraints. Border closure is an illustrative example of such a trade-off.

[1] PERISCOPE Deliverable 7.6 Country Report on Sweden, prepared by Ida Steinbeck Nilsson.
[2] Le et al., for example found: 'While travel restrictions benefit the community by preventing importation of some cases, these policies end up costing the global economy an estimated 400 billion USD and millions of jobs each month. The gravity of the situation highlights the need for balance between protecting the health of the public and mitigating the short and long-term economic damage related to infection control efforts.'

Epidemiologically, travel poses the risk of spreading the virus. On the other hand, border-closure interferes with trade and economic activities[i] and the principles of free movement. Meanwhile, scientists advising on policies speak from their own particular disciplinary background. It is thus important when forming a multi-disciplinary advisory board to gather opinions from different disciplines, ranging from infectious diseases to public health, economics, and social and behavioural sciences.

It is particularly difficult to assemble such multi-disciplinary advisory groups in the acute phase of a pandemic. As a result, they must be set up during 'peace time'. Even though there such groups were in place, they were not well-organised or properly 'activated' or consulted during the pandemic. A necessary step is to review these groups, and to understand how to make them better, more agile and more useful, and how to include representation from multiple levels of governance. For example, WHO has a roster of experts who can be contacted according to the type of emergency. This could be considered as a blueprint for the EU and EU Member States. However, it should be adapted to the specific context of multi-level governance in the EU, and include experts across disciplines as well as local expertise.

No matter whether a scientific advisory group was in existence before the pandemic or was created *ad hoc*, the experts were concerned with the democratic legitimacy of scientific advisors: they are not elected, thus their political power should be limited accordingly. A scientific advisor is, ideally, an independent expert, and as such, well positioned to tell inconvenient truths. The expert participants, found from their professional experiences, that public authorities, including public health authorities, were too bound by political constraints to speak so openly. Scientific experts should remain in a factual advisory position, while politicians, possessing democratic legitimacy, should consider various factors and are responsible and accountable for decisions, facing the trade-off between pandemic control and socio-economic concerns. This implies, on the one hand, that scientists should be protected from making political decisions and, on the other, that the general public, policy-makers, and scientists should be better equipped to understand decision-making processes, uncertainties, and necessary trade-offs. However, Sweden might be considered an outlier in this respect. In other places, like the UK, advice from experts was more binding for politicians. For the case of Belgium, one of the experts also reported on the challenges of advising the government, because the structure of their group had been decided on by politicians, therefore influencing which voices would be heard by policy-makers.

The real crux, however, is the selection of advisors for an advisory group. To safeguard the legitimacy of political decisions and to ensure accountability, selection procedures should be formalised. For example, clear procedures should be in place to outline how a multi-disciplinary advisory group documents its internal discussions, and how the group communicates with politicians on the one hand, and the public on the other. Public records can strengthen scientific integrity and democratic accountability.[3]

The usefulness of establishing an advisory group at EU level was also discussed. The first group of experts argued that there was a strong need for a formal, multi-disciplinary group at European level, that could coordinate approaches between Member States and collect best practices. The second discussion highlighted various **limitations** to this recommendation:

- Whom should this European group (e.g., the European Centre for Disease Prevention and Control (ECDC), European Medicines Agency (EMA), HERA) be advising? For example, HERA and ECDC have their own advisory groups and HERA is judged to be too political and close to the Commission.
- Fragmentation in advisory groups is so severe that there is resistance to establishing another group on paper. There is already extreme complexity at this governance level.
- Is cross-country advice useful considering pandemic response measures must take into account many socio-economic determinants that are context-specific?

## *1.3 Recommendations*

### 1.3.1 Ensure advisory groups are multi-disciplinary

Regarding public health matters, a scientific advisory group should be multi-disciplinary and bring together experts from social sciences, economics, environmental sciences, veterinary science, ethics, and also humanities. Such an advisory group could ensure that the measures, or any trade-offs, taken by politicians are based on relevant evidence and expert advice.

[3] For example, the UK government releases some information on the participants in the Scientific Advisory Group for Emergencies (SAGE) and related sub-groups. Participants are required to declare any interests and business affiliations that would be relevant. Minutes of meetings are also publicly available.

### 1.3.2 Review and improve existing scientific advisory groups

The political space is already relatively crowded with different advisory groups with various formats; therefore, authorities should avoid duplicating existing groups by setting up new ones. This is particularly true for the EU level, where a rich structure of agencies and groups related to public health exists already, like the ECDC, the COVID-19 advisory panel of the Commission, and the Health Security Committee. The first step is therefore to review the existing scientific advisory groups at national and at EU level, and to develop an action plan to improve the mechanisms of their activation and operation. This needs to be done during peace time. Secondly, these groups must be reformed to become more agile and connect actors across sectors, so that in a future health emergency (which might look very different to COVID-19) the group will add value to the response. As in WHO, Member States could consider building a roster of experts who would be contacted according to the type of emergency.

### 1.3.3 Insulate advisors from political decisions

Scientific advisors lack democratic legitimacy. While their scientific expertise is desirable and will improve the decisions made by democratic leaders, the final decision that weighs various factors, including socio-economic, environmental and epidemiological constraints, must remain in the hands of political leaders. At the same time, the general public, policy-makers, and scientists should be better equipped to understand decision-making processes and necessary trade-offs in pandemic response.

### 1.3.4 Keep selection of experts formalised and transparent

The democratic legitimacy of the multi-disciplinary scientific advisory groups lies in formalisation and transparency. Clear rules should be in place for the procedures used to establish membership and a clear delineation of the objective of the consultation between experts and politicians should be made transparent to the public. Protocols should be established on the communication of the experts with politicians on the one hand and the public on the other hand. Guidelines should determine how consultation activities are conducted, particularly during times of public emergency, when time is scarce and actions are taken *ad hoc*.

## 2. The role of international actors

### *2.1 Background*

The COVID-19 pandemic revealed many deficiencies of WHO (Gostin, 2020). After overseeing a comparatively quiet period with relatively small-scale and manageable outbreaks of influenza and other diseases, WHO was suddenly faced with the burden and attention of the global public when the COVID-19 pandemic hit in 2020. The first problem that emerged was WHO underfunding; currently, the WHO budget for 2022–2023 is US$6.72 billion (WHO, 2023e), whereas the budget for the US Centers for Disease Control and Prevention (CDC) is working on a budget of roughly US$9 billion in 2023 (CDC, 2023). Some argued that the WHO budget is too small considering the scale of threats and global expectations related to its capacity to respond. Lack of sufficient funding could hurt WHO's independence as the organisation might lean towards the benefits of big donors.

WHO has laid down many technical standards on, for example, water and hygiene, and, most importantly, the International Health Regulation (IHR). However, IHR has not been widely adopted or successfully enforced (Gostin et al., 2020). The pandemic triggered a review of IHR and certain recommendations have been proposed (Aavitsland et al., 2021).

WHO has produced numerous recommendations for countries since the pandemic began but countries often follow their own response strategies. WHO does not have the mandate to enforce any standards or discipline those countries which do not follow the recommendations (Velásquez, 2022). Two committees and one panel have been set up to consider reforms of WHO; these are led by international experts appointed by the WHO Director-General.[4] Yet, reforms from within WHO may still fall short of expectations if no mechanism is in place to enforce compliance. Meanwhile, WHO members have agreed to negotiate a legally-binding international convention to establish principles, priorities and targets for pandemic preparedness and response (PPR). The progress report will be delivered in 2023 with a view to adopting the instrument in 2024.

Meanwhile, the EU has stepped up its role in the area of public health. Apart from leading the joint-procurement of COVID-19 vaccines that successfully kept Member States

[4] They are the IHR Review Committee, the Independent Oversight and Advisory Committee for the WHO Health Emergencies Programme and the Independent Panel for PPR.

united, the EU has extended the mandates of the ECDC and the EMA and established the Health Emergency Preparedness and Response Authority (HERA) to coordinate the sourcing of essential medical supplies and responses to health emergencies in the EU. In 2022, the EU announced the EU Global Health Strategy in collaboration with WHO. Additionally, the EU has begun the application process to become a formal observer of WHO and aims to support WHO as the centre of the multi-level governance framework for global public health (European Parliament Think Tank, 2023).

### *2.2 Expert discussion*

Our invited experts expressed concerns over the independence of WHO. Independence of an international organisation is often and maybe unavoidably influenced by international political process but the technical arms of WHO should be given sufficient independence and also funding.

Some of the experts doubted the usefulness of WHO during the pandemic as its functions clash with those of some national authorities who prefer to conduct their own risk assessment and recommendation delivery process. Many guidelines issued by WHO were not followed. A major reason is that the epidemiological circumstances differ from one country to another while WHO usually only offers unified guidelines for all members. The positions of international organisations and agencies, including WHO and EU institutions, during a pandemic have not been well-defined and agreed upon. The extensions of the mandates of ECDC and EMA and also the establishment of HERA, together with the role played by national authorities, do not provide a clear delineation of duties, especially in relation to emergency responses. These EU agencies were also brought to the fore in place of politicians during the pandemic and the new mandates have not yet dealt with the adverse consequences of exposure.

The EU Global Health Strategy seems to be a promising idea. The existing structure of WHO is too rigid for significant change and the success of any initiatives to support change depends very much on strong leadership. The global community is also important in driving changes at international level. External pushes from the Global North, directed at international organisations, would be helpful.

## *2.3 Recommendations*

### 2.3.1 Promote inter-organisational collaboration

Any WHO reforms should not only be inward-looking. The COVID-19 pandemic demonstrated to the world that, in the area of public health, there are numerous actors and information is unevenly distributed globally. High-income countries tended to conduct their own risk assessment of the threat and implemented their own pandemic control policies. Recommendations from WHO were not strictly followed, and this situation sometimes created confusion; conflicting opinions between WHO and national authorities also provide a breeding ground for misinformation and political polarisation. Therefore, it is essential for any reforms to acknowledge this multi-actor galaxy and emphasise the need for coordination among actors.

The future of global public health seems, to a certain extent, dependent on this EU-WHO collaboration. First, the announcement of this collaboration gives some glimpse of hope that the top-down approach will work. No matter what, though, the rigid WHO certainly needs some external forces to push for changes so that it can overcome certain deficiencies revealed during the COVID-19 pandemic. Second, a closer relationship between the EU and WHO would also encourage the EU to better discipline their Member States in following the IHR. Finally, the success of such a collaboration could be a blueprint for other countries to follow and also draw funding to WHO.

The EU Global Health Strategy is a promising approach. The Strategy has laid down a great vision to 'position(s) the EU as a leader who is to drive international cooperation in health through the formation of equal-footing partnerships that are guided by shared values and common policy priorities' (European Parliament Think Tank, 2023: 5). If the EU, or Team Europe, were to lead and be the main contributor to this initiative, it would be natural to question the cost and benefit of this Strategy to EU citizens.[5] The answer would then be evaluated against the financial situation at that time and the extent to which EU citizens could see the potential for a healthier world beyond the EU.

Inter-organisational collaborations are exciting but can also fail easily. One major obstacle is the sustainability of the alignment of interests of the EU, EU Member States,

[5] Team Europe consists of the European Union, EU Member States, their implementing agencies and public development banks, as well as the European Investment Bank (EIB) and the European Bank for Reconstruction and Development (EBRD) (European Commission. n.d.d).

WHO and the Global South. This EU Global Health Strategy is promising on paper but requires incentives for every actor to sustain its long-term implementation. First, EU citizens may question the use of public funds for global public health and any economic downturn might easily disrupt the funding for countries outside the EU. Second, WHO may have its own views and approaches and may not welcome too much intervention that encroaches on its independence. Finally, the countries which make up the Global South may have their own public health provisions and requirements, which a top-down global health 'aid' strategy could overlook and undermine. Its approach would also be a matter for scrutiny. Oxfam questions if the Strategy is 'just a slogan' and urges the EU to empower the Global South to stop aid dependency (Oxfam, 2023). The Strategy might end up simply channelling funds to the Global South where they are spent on buying medicinal products produced in the EU, rendering the Global South more dependent on EU aid and products, and exacerbating existing global inequalities. Such an approach may help the Global South solve some more urgent needs but does not recognise or improve on the global capacity to respond to public health threats. The Strategy could be a turning point for global public health but only if the EU can sustain its willingness to contribute to the global public health condition and successfully mobilise resources efficiently and equitably, implementing actions through the WHO network. The relevance of WHO to global COVID-19 vaccine distribution will be explored in the next section.

## 3. Ensuring global vaccine supply and solidarity

### *3.1 Background*

Access to vaccines during a major global pandemic is crucial in stopping the disease from spreading. The development of COVID-19 vaccines and the expansion of vaccine production capacities were incredibly fast compared to previous experiences. The global distribution of the vaccine was, however, uneven and subject to many criticisms (Alaran et al., 2021). To speed up the progress of vaccine development, the US and the EU, among others, channelled funds to pharmaceutical companies to de-risk their research and development. In return, they were prioritised in the queue for vaccine delivery. Lower-income countries were given the access through COVAX, which was co-led by the Coalition for Epidemic Preparedness Innovations (CEPI), Gavi and WHO with UNICEF assisting in delivery (WHO, 2023f). The results of this approach relied on the

willingness of the Global North to donate, which made COVAX much less successful than initially foreseen (Usher, 2021). While national governments could always negotiate with pharmaceutical companies bilaterally, the Global South was disadvantaged in the process.

Ironically, it has been reported that in some high-income economies, COVID-19 vaccines have been left unused and sometime wasted (Walker, 2022). Surpluses have been building up and the European Commission had to renegotiate with vaccine providers to revise the delivery schedule so that Member States would not pay for vaccines that they no longer require (Krzysztoszek, 2023).

### *3.2 Expert discussion*

Our invited experts raised a few other issues concerning access to vaccines. The Global South was given less privileged access to vaccines because they lack the access to contracts with pharmaceutical companies. Global South countries have often been ignored at the pharmaceutical negotiating table, meaning that their needs are not being heard.

The exclusive ownership of the intellectual property rights for vaccines among vaccine developers might have limited the production capacity. The failure to activate the World Trade Organization (WTO) Trade-related aspects of Intellectual Property Rights (TRIPS) waivers led to widespread criticisms among the public.[6] The European Commission was the most vocal in opposing a TRIPS waiver (’t Hoen & Boulet, 2021) rendering President von der Leyen’s statement, about ensuring that a COVID-19 vaccine was a universal common good, empty (European Commission, 2020).

Meanwhile, one expert commented that the Global North did not actually respond to the needs of the Global South. For example, during the COVID-19 pandemic, there were voices from some countries in Africa asking for malaria vaccines instead of COVID-19 vaccines, but COVID-19 vaccines continued to be prioritised as they were perceived as something that would protect the Global North against threats from the Global South.

[6] TRIPS waiver is a provision written in the WTO Agreement that permits WTO member states to waive obligations for public health emergency. See Corporate Europe Observatory (2022).

## *3.3 Recommendations*

### 3.3.1 Acquire ownership of intellectual property rights through public investment

To accelerate vaccine production, many advocated sharing of intellectual property (IP) rights so that production could be expanded quickly. Yet, pharmaceutical companies are very reluctant to share the fruits of their research. The TRIPS waiver could have been activated but even the COVID-19 pandemic, in spite of its severity, failed to attract sufficient support for the wavier to order vaccine companies to share their technologies (Leicht, 2021). To avoid a similar situation in the future, governments and international organisations should consider acquiring part of the IP rights of some emergent innovative technologies using public money, before a potential threat emerges, and further developing them in public-private partnerships.

Lack of production capacity can be another clear reason for vaccine shortages. This is very likely why high-income countries would prefer bilateral arrangements to ensure vaccine supply for themselves. International organisations should support the development of vaccine manufacturing facilities in different regions so that more countries will be equipped with basic knowledge and machinery for vaccine production and therefore better able to respond to a future shock swiftly. This would also lessen the worries around scarcity that drive preferential bilateral contracting in some countries.

### 3.3.2 Explore a vaccine joint procurement mechanism

Access to vaccines is an issue of access to contracts and negotiations. Joint procurement has the potential to solve this problem. The experience of the EU in procuring COVID-19 vaccines could point us in the correct direction. In mid-2020, the EU announced that it was signing Advanced Purchase Agreements with vaccine developers through which the EU procured vaccines on behalf of all Member States. Eventually, the EU succeeded in distributing vaccines evenly across Member States where every Member State was given equal priority. While there have been criticisms concerning the transparency of this joint procurement arrangement, as the details of the public contracts with pharmaceutical companies are redacted (Arroyo, 2023; Beke et al., 2023), from the negotiation and contracting stage to the evaluation stage, the joint procurement successfully avoided a vaccine scramble among EU Member States that would have fundamentally damaged the internal solidarity of the region.

Would it be possible to mimic this joint procurement but for a broader range of countries involving both the Global North and South? COVID-19 Vaccines Global Access (COVAX) aims to ensure equitable global access to COVID-19 vaccines by channelling donations of vaccines from high-income countries to low- and middle-income countries but does not provide the recipients with easier access to contracts with vaccine developers. WHO should establish a permanent vaccine purchase and delivery mechanism for the entire world based upon the lessons learned from COVAX. Such a coalition would benefit from the bargaining power of a large population and the participation of negotiators from different backgrounds would enhance transparency and credibility. Allowing access to contracts would elicit preferences for often-excluded countries, and therefore aid would be better directed towards actual need, deliveries would be more timely and vaccine waste would be minimised.

Distribution of vaccines could be driven by several factors while acknowledging that no one life is less valuable than another. In terms of distribution, the epidemiology of a disease should be one of the most relevant factors and thus vaccines should be channelled to where the disease is more prevalent but not to where countries are able to buy them. Vaccines should not be left in storage and then wasted. Second, receiving countries should have the facility to store and administer vaccines. Third, public investment into vaccine development by willing and able countries should not be discouraged by a global joint-procurement mechanism. Those countries investing in development using their own funds should still be able bilaterally to engage in purchase contracts with companies, but any preferential conditions should not be excessive such that they jeopardise delivery to other countries in more urgent need.

The main obstacle relates to the fact that some high-income economies would only want bilateral contracts with pharmaceutical companies in order to ensure more favourable delivery schedules. Yet, no one can predict the epidemiological development of the next global pandemic, which might affect one region more than another; high-income countries might be more willing to prioritise the Global South when they are less affected. In any case, it is important to institutionalise a mechanism that would function satisfactorily and equitably; this will require careful design and also international consensus.

Another major obstacle comes in the form of the big pharmaceutical companies, which state that joint procurement of vaccines should only be used if it can improve access to vaccines (Vaccines Europe, 2020). This position could well be driven by profit.

Establishing public ownership of IP rights is a possible way to solve this issue. Governments should invest in some emergent technologies, facilitate public-private partnerships, and thus obtain a share of IP rights; this would be very useful in expanding global access to medicines.

## 4. Strengthening the role of HERA

### *4.1 Background*

The early stage of the COVID-19 pandemic unveiled the EU's lack of competence in public health and the fragmented responses of its Member States. It particularly highlighted the need for a structured, coordinated response at EU level. Against this backdrop, the EU established its HERA on 16 September 2021. HERA was not granted European agency status, like ECDC or EMA, but instead was set up as an internal service within the European Commission. HERA is in charge of 'i) strengthening health security coordination within the Union during preparedness and crisis response times, and bringing together Member States, the industry and the relevant stakeholders in a common effort; ii) addressing vulnerabilities and strategic dependencies within the Union related to the development, production, procurement, stockpiling and distribution of medical countermeasures; and iii) contributing to reinforcing the global health emergency preparedness and response architecture'.[7]

Since its establishment, several areas in HERA's governance and operation have already been subject to lively public debates. *Mission-wise*, HERA's mandate lacks a clear focus on public interest and global health. *Governance-wise*, it does not have a mechanism to ensure accountability, transparency, and autonomy, particularly when it comes to its interactions with other EU institutions, Member States, industry, civil society, and the scientific community. *Operation-wise*, HERA risks overlapping in its activities with other EU agencies such as ECDC and EMA. *Budget-wise*, HERA's operation mainly relies on existing Union programmes such as Horizon Europe, EU4Health and the Union Civil Protection Mechanism (rescEU). HERA's activities are hence restrained by the scope and mechanism of these funding programmes, endowing it with limited autonomy to manage its activities. Finally, HERA's role in the EU's *global health* agenda is not

[7] Commission Decision on establishing the Health Emergency Preparedness and Response Authority, 16 September 2021, C (2021) 6712 final.

clearly defined, and potentially underbudgeted. It is uncertain whether HERA is in charge of leading or only providing support for the EU's action in terms of its international cooperation in global health security (Renda et al., 2023).

### *4.2 Expert discussion*

The experts pointed to certain limitations linked to the set-up of HERA which were revealed during its first year of operation.

First, HERA has not fully demonstrated its role in ensuring the Union's open strategic autonomy for medical countermeasures. An emerging venue of discussion when it comes to the effectiveness and relevance of HERA is antimicrobial resistance (AMR). This area has attracted increasing attention, particularly because AMR has been recognised as a global public threat and a potential shortage of antibiotics could arise in the EU. Meanwhile, the EU faces increasing logistical challenges because it has been relying more and more on imports of medicines and pharmaceutical ingredients from a limited number of third countries. To relieve this growing dependence, the EU should either increase its domestic production of medicines and ingredients ('reshoring') or diversify its suppliers (Bayerlein, 2023). Additionally, to date, HERA has not optimised its leading role in securing the availability of antibiotics and supporting the development of new medicines to address this 'silent pandemic'. Mandated to ensure EU's strategic autonomy in medical goods, HERA needs to play a stronger role.

The experts considered that one of the underlying problems leading to HERA's ineffective stockpiling and management of medical countermeasure availability is its suboptimal interaction with the pharmaceutical industry, especially outside emergency situations when the power of HERA is limited. HERA has no authority to access information from pharmaceutical companies on stockpiles or their supply chains for medical countermeasures (e.g. the amount of certain raw materials that have been bought, the source or production location of a material). This information can be considered sensitive because it contains industry secrets. It is, however, critical to enabling HERA to correctly address supply-chain bottlenecks, ensuring the EU's strategic autonomy for medical countermeasures, as set out in HERA's mission (DG HERA, 2022). Apart from data, HERA is also missing a monitoring tool to foresee and prevent supply-chain bottlenecks, both during the preparedness stage and times of emergency. This showcases a systemic limitation of HERA, namely its lack of legal basis to investigate the commercial supply chain.

Second, HERA's role in promoting research and development (R&D) for medical countermeasures critical for health emergencies is not yet concrete. An area where HERA should play a stronger role is in shaping the EU's financial framework to develop novel medicinal products in the face of emerging AMR threats (e.g. by incentivising the pharmaceutical industry to do more research in the area). The Commission published its proposal for the revision of pharmaceutical legislation on 23 April 2023 (European Commission, 2023a). The proposal introduces Transferable Exclusivity Vouchers (TEVs)[8] as a financial incentive for pharmaceutical companies to advance their research and development of new antibiotics. TEVs represent a 'pull' policy that public authorities can use to incentivise the development of medicinal products which are based on a societal need but of little commercial interest. This tool is expected to fix the market failure.[9]

HERA, responsible for managing R&D funding for medicinal products (AMR in this case), is in a position to identify alternative approaches to incentivising R&D in this area. The workshop experts argued that if HERA was an independent authority, it would have more power to act on the recommendations made by the European Health and Digital Executive Agency (HaDEA) (Publications Office of the European Union, 2023). Instead of relying on TEVs, a more independent and well-funded HERA could channel public funding for private or not-for-profit developers to develop new medicinal products through different preclinical and clinical phases and promote prudent use of existing antimicrobials.

Third, HERA's relations with other EU agencies need to be clarified. The experts particularly pointed to the interplay between HERA and EMA. While HERA is responsible for identifying and addressing supply-chain bottlenecks for medical countermeasures,[10] EMA is in charge of monitoring medicine shortages (defined as a 'major event' in terms of EMA's operation).[11] These two tasks are strongly interrelated: EMA's recognition of a medicine shortage can trigger HERA's process for procurement and stockpiling of

[8] TEVs are vouchers awarded to innovators of new medicines, allowing them to extend the data protection period for any of their patented medicines in the market for 12 months. Holders of a TEV can use it for any of their own medicinal products or sell it to another marketing authorisation holder.
[9] Supported by the pharmaceutical industry, TEVs, however, face criticisms from diverse stakeholders as they would transfer the cost of the vouchers to Member States' health systems and delay the entrance of alternative medicinal products into the market, hence reducing overall benefits for patients (Lietzmann & Moulac, 2023).
[10] Commission's Communication COM(2021) 576 of 16/09/2021 introducing HERA.
[11] Regulation (EU) 2022/123 of the European Parliament and of the Council of 25/01/2022 on a reinforced role for EMA.

medical products, while HERA's supervision of supply-chain vulnerabilities can reveal weaknesses, e.g. dependence on one major medicine supplier which might lead to future medicine shortages. To this end, HERA and EMA must strengthen their coordination. However, the Decision establishing HERA and the Regulation reinforcing EMA do not clearly point to this coordination. The recently signed working agreement between HERA and EMA refers to such coordination but does not yet define specific actions to be taken by the two bodies.[12]

## *4.3 Recommendations*

### 4.3.1 Extend the mandate of HERA

The EU should consider extending HERA's mandate to enable it to have access to information, held by the industry, on the supply chain for medical countermeasures, during both normal and emergency times. Proposed by a HERA-commissioned study, the Commission should also consider extending HERA's mandate to grant it access to information on commercial supply chains for critical medicines in its revision of the Pharmaceutical Legislation (DG HERA, 2022). The proposed Data Act on harmonised rules on fair access to and use of data would also partly address the issue discussed above. For example, Chapter V enables public authorities to access companies' data for free during times of public emergency, or purchase the data under exceptional circumstances, such as during recovery from a public emergency (Eur-Lex, 2022a). In addition, HERA can also support the establishment of a monitoring system for supply chains, which can be linked to the WHO Global Pandemic Supply Chain and Logistics Network proposed in Article 6 of the Conceptual Zero Draft of the Pandemic Accord (WHO, 2023g).

### 4.3.2 Play a stronger role in R&D

HERA should play a stronger role in R&D policy. It should conduct in-depth analysis to consider different approaches to boosting research into unmet medical needs (such as AMR) including through the provision of financial incentives to private and non-private actors. Such a funding approach should not only allow for new medicines to be

[12] Working agreement between HERA and EMA: European Commission (2023b).

developed, but also to ensure efficient public spending on medicines and early and affordable access to them for patients.

#### 4.3.3 Define a collaboration scheme with other EU agencies

Third, HERA needs a clearer coordination framework with EU public health agencies such as EMA. The coordination activities between the two bodies (meetings of experts, sharing of data and information, etc.) should define a collaboration mechanism that allows for quick detection of supply-chain bottlenecks and rapid mitigation actions.

Finally, the formation of HERA represents a step in the right direction, considering that it has just completed its first year of operation. Although there are several areas for further improvement, HERA has managed to respond to the on-going COVID-19 pandemic while building some of the foundation needed for its long-term preparedness. Its working agreements with ECDC and EMA represent a promising avenue for further advancing its collaboration with these two agencies. The new HERA-owned budget – HERA INVEST, while still relatively small compared to HERA's annual total budget,[13] is a signal that there may be an opportunity for HERA to secure its own budget in the future. The recent adoption of the Regulation on serious cross-border threats to health and the EU Global Health Strategy – two other milestones of the European Health Union – would also open new windows for HERA to play a role therein.

## 5. The role of civil society organisations

### *5.1 Background*

The COVID-19 pandemic has, among other things, emphasised that CSOs are key actors in the European multi-level governance framework when it comes to dealing with unexpected, unpredictable and complex events. As defined in European law, CSOs are organisations that act as mediators between public authorities and citizens and serve the general interest (Eur-Lex, n.d.). CSOs have emerged as key enablers of the fight against the virus, specifically by contributing to the protection of vulnerable and marginalised groups and thus limiting the ways in which the pandemic widened inequalities within and between countries. Indeed, a report by the European Economic

[13] HERA INVEST is a funding mechanism of 100 million EUR, managed by HERA, to support R&D for medical countermeasures against priority cross-border health threats (European Commission, 2022).

and Social Committee (EESC) indicated that during the pandemic, CSOs often acted and provided assistance on behalf of or in addition to government authorities – willingly or not – notably by providing essential health and social care services and information (Tageo et al., 2021). Additional research has also shown how CSO engagement during COVID-19 led to positive results for pandemic management (see for instance Bhargava, 2021; Baum et al., 2021; Cai et al., 2021). In that sense, CSOs contributed to mitigating the health emergency while also fighting against inequalities arising from it.

The findings of such a positive influence of civil society actions on pandemic responses seem to be in line with a longstanding stream of research which highlights how CSOs traditionally play a key role in disaster management thanks to their expertise, resources, and local implementation capacity (Aldrich, 2012; Shaw & Izumi, 2014). More broadly, the roles of social networks and social capital in disaster response have been intensively studied by social scientists, who emphasise how these supportive webs of trust and reciprocity can enhance the response to extreme events (Aldrich & Meyer, 2015).

Yet, the involvement of CSOs in the COVID-19 pandemic management did not come about without hurdles. Previous research on CSOs in natural disasters highlights that the positive impacts of civil society actions during these types of event are not guaranteed but can be stimulated by certain policies and instruments administered in a timely and inclusive manner. Part of the discussion in the workshops focused on these issues; we then extracted practical recommendations for the involvement of CSOs in pandemic governance, notably regarding capacity building, communication and preparedness.

### *5.2 Expert discussion*

During COVID-19, CSOs played a key role in the pandemic response and recovery, thanks both to their relationships with communities and their expertise. Existing networks of civil society facilitated informal cooperation quite quickly, and many of the initial responses to urgently tackling the crisis were informally designed and implemented. Contact with communities on the ground has been identified as being a key factor in helping to enhance pandemic mitigation, as they possess a better and immediate understanding of what is needed in practice, as well as the ability to trace where gaps are in response capacities. Nurturing these links are thus of paramount importance, especially considering the distance between decision-makers and people working on the ground.

Yet, in many cases, at some point, these bottom-up practices or measures reached a ceiling because they did not possess the necessary power or authority for further impact and were not endowed with structural support. Involving a representative set of organisations in decision-making processes is thus important – but while local authorities can consult different stakeholders when making their decisions, civil society would often not have the direct authority to implement measures. To overcome this barrier, we need to establish CSO inclusion in decision-making processes during peace time so that informal networks are rightly empowered and the involvement of CSOs in pandemic governance is formalised.

Processes of deliberative democracy in emergency times were also discussed. On the one hand, organising fora-like citizen panels during pandemics would slow down the response to the health emergency, while the flexibility and speed of decisions should be prioritised in these times. On the other hand, 'going slower in crisis can mean going faster overall', and more citizen involvement can also help to soften any backlash against containment measures and prevent disinformation. Research indicates that performance differences in pandemic responses were highly correlated with trust in institutions and the resilience of political systems, and hence the political aspect of citizen participation should not be underestimated.

In that sense, the role of CSOs in communication is key. Local implementation of pandemic mitigation measures cannot work without community awareness and context-adjusted communication. Local authorities have a role to play in this, and so do community-based organisations and civil society, notably in helping people to understand how trade-offs between scientific advice and socio-economic considerations are reached.

Finally, the role of civil society at international level was also discussed, especially given that there was a concerning void in global politics in terms of the representation of civil society in the early stage of the pandemic. The pandemic response at the international level was characterised as a 'mess' and the need for the role of CSOs to be heightened, in the future, by offering them a voice, was highlighted.

### *5.3 Recommendations*

The key message emerging from the expert discussion is thus that the attention and actions of policy-makers need to shift from emergency mode into preparedness in order

to efficiently involve CSOs in pandemic governance and benefit from their expertise and networks. The governance framework that would most likely adapt to conducting such initiatives appears to be the one that is centrally coordinated, with strong leadership able to take decisions rapidly, but that still preserves local autonomy through strong local networks and authorities. Establishing and making such a framework work is, among other things, reliant on the meaningful involvement of civil society at multiple levels of governance.

### 5.3.1 Formalise the involvement of CSOs in decision-making processes

CSOs should occupy a seat at the table from the initial pandemic response steps. Their role and the structure of their involvement should be formalised *ex-ante*, to ensure that their contribution can be valuable and immediate, and thus be beneficial for pandemic mitigation. This would contribute to pandemic management by drawing on CSOs' expertise, but also mitigate inequalities and soften the public backlash against non-medical countermeasures by ensuring that the voice of civil society is included in the process.

### 5.3.2 Build trusted networks of CSOs at the local level

Strong relationships with existing CSOs should be built during 'peace' times, in order to facilitate better collaboration during emergencies. Local authorities should invest resources – financial, but also time – to identify relevant organisations and networks and engage with them. This engagement should be beneficial for both parties, taking into account the needs and demands of CSOs while contributing to the authorities' strategic actions. Most importantly, trust needs to be at the centre of these relationships.

### 5.3.3 Establish open and resilient communication channels with civil society

When it comes to dealing with public health emergencies, communication is key. Having open communication channels with CSOs working on the ground at local level would help identify gaps, response capacities and appropriate adaptations; it would also institutionalise best practices, as well as providing an opportunity for local authorities to better communicate with the public, which would, in turn, foster solidarity and compliance, thus contributing to better pandemic management.

## Conclusion

The COVID-19 pandemic is unprecedented and exposed the limitations and possibilities in the current multi-level governance framework to cope with a deadly threat. Different actors in the governance framework sought new initiatives, networks and roles, being ambitious and full of hope. Many of these attempts, however, failed to fulfil their promises and ambition was met with disappointment. Experts were often not heard and sometimes exposed to public discontent. HERA has been criticised for a lack of independence and authority. CSOs were helpful but encountered bottlenecks due to a lack of support from the authorities. COVAX was designed to facilitate global vaccine solidarity but was left at the mercy of the Global North. Disappointments should now be turned into lessons for the future. This case study on multi-level governance for pandemic responses aims to collect views from experts and propose viable policy recommendations. This post-pandemic era is not a time to slacken our efforts but offers a key moment to be ambitious and build preparedness for future health emergencies. Funding, attention, and continued evaluation should match the ambitions expressed by different actors in the governance framework. After all, the world is not short of solutions or ambitions but requires a more structured response framework and, most importantly, determination to carry out reforms and sustain the changes.

## CASE STUDY 2

# COVID-19 and Social Infrastructures in the UK

# CASE STUDY 2: COVID-19 and Social Infrastructures in the UK: Recommendations for Equitable Pandemic Governance

Authors: Professor Laura Bear and Dr Charlotte Hawkins, LSE

## Executive summary

*Our UK-based case study demonstrates that well-resourced and integrated social infrastructures are central for pandemic governance.*

By social infrastructures we mean the networks of formal and informal care that support families and communities. The commission recommends that these are built up and sustained outside of health emergencies. This can best be achieved by:

### Resourcing social infrastructures:

1. **Adequate and sustained flows of government funding are required for the UK voluntary, community and social enterprise (VCSE) sector**. This could include experimentation with a wider range of funding models, such as training and support for cooperative models. Grants for VCSEs could become a statutory responsibility of local authorities. Alternatively, different structures and supports should be put in place, such as a national infrastructure bank or central government funds to build social infrastructures. This would enable the central commissioning of diverse local initiatives with a common general goal to support short- and long-term change in the ecologies of care in the UK.
2. **Flexible, equitable and inclusive funding and commissioning** are needed at the local authority level with community-based organisations at the centre of the process. This approach is essential to ensure that funding processes are not exacerbating or causing inequalities.
3. There is a need to recognise, reward and resource key mediators within and across the health sector who create access to care services and mitigate inequalities, particularly for minoritised groups.
4. **VCSEs need to be given an advocacy and strategic role in the National Health Service (NHS) system as health provision experts.**

5. **Regional inequalities in the VCSE sector and social infrastructures need to be investigated by a special task force assigned to the work from across ministries**. Mapping and ameliorating these inequalities in social infrastructures is particularly important in expanding the provision of integrated care and in the resolution of regional and community health inequalities.

**Decentralising and integrating service provision:**

6. **Decentralised health governance**, in the form of more distributed and horizontal forms of pandemic preparedness and response, is needed. This would involve the inclusion of key VCSE organisations at all levels of pandemic response, particularly emergency planning committees.
7. **Service integration is crucial to equitable pandemic preparedness and service accessibility in the UK**. This includes the integration of health and social services at the local and national levels, with the formation of a cross-ministerial care planning team and local authority representatives who look at provision holistically. In the longer term, there should be a ministry for care that takes account of the whole life-course provision for child, elder, health and organisational support.
8. **New approaches to data integration are vital to achieving service integration**. Central coordination and linkage between the national and local scale in terms of data would support the new integrated care experiment. There is a need to strategically link complex data sets across sectors, to consolidate information regarding social issues related to health inequalities and design programmes responsive to them. The UK Health Security Agency (UKHSA) could be responsible for coordinating this, and ensuring data are open access.
9. **A key area for integrated data would be to combine data sets on housing and health outcomes** in line with the indices of multiple deprivation area maps. Poor housing conditions contribute to higher rates of mortality from COVID-19 and other illnesses, and there is a need to recognise housing as a right and as a fundamental component of healthcare and health equity. We recommend a cross-ministerial task force that addresses this holistically rather than housing being siloed in the Department for Levelling Up, Housing and Communities (DLUHC).

**Expanding the use of social science analysis and evidence in decision-making:**

10. **There is an urgent need to conduct research which traces the processes which produce inequality**. Mapping of communities and relationships in local authority areas can help to overcome complex inequalities and issues faced by 'unseen' communities. This mapping must go beyond the current population categories deployed to understand race in the UK.
11. **Social analysis and evidence provide a crucial addition to population-level public health, social psychology and behavioural science perspectives.**
12. **Social media platforms such as WhatsApp can be used productively for sharing and gathering public health evidence** through 'social listening' during pandemic situations if their usage is embedded within responsive policy relationships and supportive environments for engagement.
13. **There is a need to build an explicit legal and ethical framework for elected officials during pandemic situations.** This would map institutional structures and responsibilities to the public and their care. Social scientists and legal experts could assist in the design of this legal and ethical framework and also play a role within pandemic governance structures by highlighting to civil servants and politicians the ethical frameworks and consequences that are implicit in their actions. This would create more effective, dialogic pandemic governance as it would not be built according to the single political ideologies of a few powerful figures.
14. **It is important to build civil service structures to support the work of external academic experts outside of emergency situations**, and across disciplines and decision structures. A transparent recruitment and appointment process for experts is advised before the next pandemic.

Our findings are based on a commission method that illustrated the value of social science approaches. We consulted people who acted as key mediators in central and local government and VCSEs during the pandemic. Many of these nodal individuals were people we had long-term research and/or professional relationships with and we understood their structural position in delivering pandemic policy. We treated them all as experts in their own area, rather than nominating some people as commissioners and others as 'witnesses'. In interpreting the data, we gave greatest weight to the opinions of local-level providers of services since they have to combine policies on the ground and

build bridges to the everyday realities of marginalised communities. We also took our findings with local-level organisations to central government policy-makers, asking them to reflect on the information from their perspectives. We recommend that this method be used more widely in evaluating COVID-19 pandemic policies. Through it we can understand the complex social processes of governance and their implications for social inequalities in the past, present and future.

### A policy experiment: Building social infrastructures

In the UK, the crisis of the COVID-19 pandemic generated experiments in health policy. Our case study follows the innovations in relationships between central and local government and VCSEs. Through these connections: vital health information flowed into local areas; policies were contested by minoritised groups; local and central government confronted long-term health inequalities; and new ties of cooperation were created. Social infrastructures were built to support pandemic governance and provision disadvantaged groups.

These innovations began at the local level with the work of VCSE mobilisers in the first period of national restrictions from March 2020 to May 2020, as local authorities closed their services, national charities suspended operations and the government focused on containment structures which were built tirelessly by these groups (Bear et al., 2020b; Fernandes-Jesus et al., 2021). These efforts were most effective in local authority areas where there was already an existing strong infrastructure of VCSE provision and relationships with local authorities (PERISCOPE, 2022). This placed a heavy burden of pandemic-time delivery of services on organisations that, for many years, had not been well-supported by central or local government funding. From 2010 onwards they had faced central government austerity budget cuts to the voluntary sector and rationed, competitive funding from local authorities.

Once the first national restrictions were lifted from 4 July 2020, local public health teams and NHS agencies had to invent ways to safeguard their local populations from COVID-19. There were no precedents for this, and many regional and local government organisations had little knowledge of how to reach out to different social groups.

In addition, there were broken links between central and local government, as the regional offices of the Ministry of Housing, Communities and Local Government (MHCLG) had closed during the same period. These had once been a source of regional

expertise and the offices had liaised with the VCSE sector as well as businesses. It was also difficult to coordinate the activities of local public health officers and regional clinical commissioning groups (CCGs), so different arms and levels of health provisioning were increasingly separated.

At the same time, the disproportionate mortality from COVID-19 among minoritised groups and low-paid workers became an issue of public concern. The Office for National Statistics (ONS) published a report in May 2020 that showed links between occupation and mortality, with men in 'the lowest skilled occupations' having the highest rates of mortality (ONS, 2020a). In June 2020, the ONS released further information evidencing the fact that for all ages, the COVID-19 death rate for Black men was 3.3 times greater than that for White men of the same age, and the rate for Black women was 2.4 times greater than for White women (ONS, 2020b). The Public Health England (PHE) 'Beyond the Data' report led by Professor Kevin Fenton also highlighted the unequal impact of COVID-19 according to ethnicity (Public Health England, 2020). Advocacy around these issues increased after the murder of George Floyd and the global outcry in the Black Lives Matter movement from June 2020. Attention among scientific advisors in the Scientific Advisory Group for Emergencies (SAGE), the NHS, government officers for science, civil servants, local authorities, voluntary groups and community mobilisers turned to how to prevent further illness and loss of life. But the way forward was not clear, especially given the tense political environment caused by high-level breaches of regulations; focus on restarting the economy and negative depictions of protestors against racism.

A potential solution emerged from local public health teams. The London Borough of Newham led the way with the creation of its Community Champion networks. These were made up of volunteers who combined an advocacy and health information role within local networks. Their activities included challenging local public health policy, providing feedback on responses to it, and spreading vital information and practices within their communities (Newham Council, 2022). Newham Council held regular online meetings with other local authorities who were repurposing the health champions concept for the pandemic. In Leicester, which was subject to regional restrictions after national restrictions had been ended in July, the local authority turned to experiments in community consultation. At the same time SPI-B, the independente behavioural science advisory group under the Scientific Advisory Group for Emergencies (SAGE), became aware of these efforts, authoring two relevant papers that travelled through government.

One of these was on local restrictions based in part on anthropological research (SPI-B, 2020a). This emphasised the importance of co-production and community consultation to ensure local restrictions were acceptable to the public, non-stigmatising and effective. A second paper on Community Champions and peer-education suggested ways forward in health protection (SPI-B, 2020b). It was informed by Newham's COVID-19 Community Champions programme, as well as research conducted with local public health officials, which drew on anthropological methods and international comparisons. This paper suggested that cooperative relationships needed to be actively built with volunteers being rewarded through training and payments. This advice understood 'community' not as a discrete, fixed ethnic or social group, but as a fluid series of relationships that could cross-cut occupation, ethnicity, religion and racialised categories. This paper was read by civil servants at the then Ministry of Housing, Communities and Local Government (MHCLG) who began to design a national Community Champions scheme. They then started a centrally funded experiment in delivering community-led health policy with the new scheme. This was rolled out in two stages in January 2021 and February 2022. It drew in local VCSEs, who linked with micro-organisations to deliver information and services. The first wave of funding also supported two national-level VCSEs to provide knowledge, assistance and support for micro projects. At the same time, local VCSEs and community mobilisers continued with their independent activities. All across the UK, central government and local authorities relied on these networks to deliver advice and information, and support communities. These were reported by local authorities as contributing to an increase in vaccine uptake among excluded and marginalised groups from February 2021 (Kamal and Bear, 2022).

This response to COVID-19 was based on the practical understanding of relationships that existed within VCSEs and how these might be broken or built on. These relationships included those within and between communities, and among various institutions and social groups. The VCSE members and volunteers painstakingly mobilised these relationships and created new connections. These organisations also carried out the most relational work and took on the labour of linking isolated groups to healthcare, welfare or vaccinations. Significantly, the most effective central and local responses were those that could build flexible and supportive relationships with such organisations and the people they served.

These experiments depended on new forms of cooperation between different arms of central government, local government and academics in SAGE. Overall, national- and

local-level public health officials became important voices in debates about how to respond to the pandemic.

> *Public health officers came to the fore in a fascinating way. They were the people on the ground … who understood their communities, and could talk with authority about what was going on.*
>
> *- Senior civil servant*

Public health officers were significant within the MHCLG's Resilience and Emergencies Division (RED) teams led by the Ministry of Defence for No. 10. They supplied information about on-the-ground situations in regular weekly meetings with PHE and contributed analysis in SAGE task groups. Alongside this, special task groups developed within SAGE and across government departments, such as PHE, MHCLG, the NHS and SAGE committees. The typically siloed practices of health protection, social cohesion, health monitoring and academic inquiry were thus joined together. Unusually, social science analysis and ethnographic, qualitative evidence were used as part of policy advice and evaluation. Task-based ethnographic work informed innovative policies such as housing rough sleepers and ensuring access to the dying and humane funerals (Bear et al., 2020a). Efforts to integrate responses to poor housing, ventilation and COVID-19 morbidity and mortality effects led to similar unusual collaborations (Gov.UK, 2020a), as did the work of the Ethnicity subgroup of SAGE on the social causes of disproportionate death among minoritised groups (Ibid.). Towards the end of 2021, an advisory subgroup on Enduring Prevalence joined together public health teams, academics and health and safety experts to uncover explanations for persistently high levels of COVID-19 infection in particular geographical areas. Most of these efforts directly addressed issues of inequality and racism. They also balanced an economic and behavioural science framing of policy initiatives at the centre of government with more place-based, public health and qualitative social science approaches.

The legacies of these efforts have continued beyond March 2022, when the government's 'Living with COVID' policy normalised COVID-19 as a cause of illness and mortality and placed it under regular department management (Parnaby, 2022). The most significant legacy is that the issue of health inequalities remains central to the public health agenda in the UK.

*It had been harder before the pandemic to … communicate what we really meant by inequalities; it suddenly … became common language and people were understanding the gravity of what could happen.*

*- Local public health officer*

*The pandemic created all sorts of data that shone a light. As soon as you get mortality data that looks as stark as some of those early datasets on ethnic disparities, you say what is going on here? ... And so a lot of awareness was created among senior civil servants …*

*- Senior civil servant*

*My experience of COVID is that it's transformed permission to talk about really difficult things, at least in the council … you can walk into a room and say, this health inequality is structurally racist. This health inequality is institutionally driven. This is the system's fault, not the community's fault …*

*- Local community public health officer*

The Office for Health Improvement and Disparities, established in October 2021 under the Department of Health and Social Care, has a goal to lessen inequalities in health by addressing issues of work, housing and healthcare together (Gov.UK, 2021b). Its staff include prominent experts in public health inequalities such as Professor Kevin Fenton, PHE's London regional director. At the local authority level, public health officers have started to collaborate with other local authority departments to produce place-based improvement plans that focus on service access, inequalities between local areas and health. Where local authority resources have made it possible, Community Champions networks have been retained beyond central government funding and are at the core of a health inequalities approach. In addition, some local authorities have built new strong links with VCSEs. The 'playbook' in central and local government for future pandemics now includes the use of Community Champions and a community consultation/co-production approach. The NHS, following the model of integrated coordination between the NHS, local authorities, VCSEs and local social services, has created a new structure of Integrated Care Systems (ICSs) (NHS England, 2022). ICSs take a place-based approach to inequality and join up previously siloed forms of health care and social care.

All of this adds up to a greater understanding of health inequalities and the value of cooperation with VCSEs in overcoming these.

There has also been a greater recognition of the value of social science analysis and evidence. The Government Office for Science now has a Head of Social Science. Senior civil servants trained in social sciences have joined together in a committee to enable a greater contribution of these disciplines to crisis preparedness.

> *Across government because of the COVID response there is a recognition of the importance of social science in policy-making … it has made a huge impact on the recognition that we need robust, rigorous research on society and behaviour to make sure that we get the right policy.*
>
> *- Civil servant*

> *I think one of the things that was just so phenomenal was bringing together people with expertise across multiple disciplines and giving them all a problem to come up with an answer in a very short turnaround time. And the collaborative spirit of being able to engage on … similar questions but from very different perspectives.*
>
> *- Civil servant*

> *You've got to be interdisciplinary in your approach, you can't just look at it from a microbiological perspective or an engineering perspective, you have to think how those different components work together.*
>
> *- Civil servant*

Yet, on the other hand, two crucial elements of the policy experiment have not survived the normalisation of COVID-19. The first of these is the end of non-siloed ministerial cooperation in task groups focused on a single policy problem. The second loss is that funding for VCSEs and the work of key community/government mediators is again competitively rationed. Alongside this, local authority funding is in crisis. The NHS too is unable to overcome staff shortfalls, exhaustion and the long backlog for medical treatment from the pandemic. As one local public health official stated:

> *We're still fighting the immediate, huge crisis issues that are a matter of potentially life or death, or a matter of … homelessness or severe*

> *sickness that, you know, means a child is under-cared for. Food poverty alone means we are on the brink of a crisis.*
>
> *- Local public health officer*

This has a destabilising impact on the relationships with VCSEs that proved to be so vital for health and service provision during the pandemic:

> *We are trying to fix an immediate, severe issue with our right hand while thinking about the next generation with our left without any money or time or resources in addition to the very little that we have. So then you put a huge amount on to the voluntary, community and faith sector to pick up the pieces. And what is that doing for our already difficult trust relationship?*
>
> *- Local public health officer*

The case study that follows explores the lessons that can be learned for future pandemics from these policy experiments. But its overall message is that we cannot wait until the next global emergency to support social infrastructures and diversify policy design and evidence. The foundations laid down during the COVID-19 pandemic need to be built on now. So many volunteers, social enterprises, voluntary organisations, charities and local authority teams have worked long and hard to build these. If we don't act, we are likely to undermine our future responses to global health crises and the equitable provision of health and social care in the present.

## Commission methodology

Our findings are based on a commission method that illustrates the value of qualitative social science approaches. Rather than using commissioners or a representative citizen jury to adjudicate on evidence, we followed COVID-19 policy through the networks it was realised in. Our analysis was helped by the fact that one of us had been part of these networks (Bear). We also had long-term research relationships with the institutional sites and people enacting the policies. This deeper knowledge enabled us to locate what people said in the present in relation to the unfolding of policy initiatives out of specific governance arrangements, uncertainties and events. We were not aiming for judicial impartiality or a balancing of arguments. Instead, we located people's statements in a known history of policy and a social field of its enactment. We gave greatest weight to

the evidence contributed by local-level providers of services, VCSEs and community groups. This is because, although they have the least power in COVID-19 policy networks, they experienced the strains of building formal and informal social infrastructures. They also saw most clearly the impacts of COVID-19 and long-term inequalities on minoritised and disadvantaged groups.

Earlier PERISCOPE and London School of Economics (LSE) research has highlighted the need for 'immersive social listening' for public health consultation (Bear et al., 2021), as opposed to more extractive models of public health consultation or 'citizen juries' (Street et al., 2014). Current consultation practices are generally 'sanitised', tick-box versions of health knowledge (Kashefi and Mort, 2004). Innovative approaches to policy research building from longer-term ethnographic relationships and collaborative methodologies allow for more meaningful engagement. This report therefore highlights the possibilities of social research in terms of both method and content. It aims to counter the sole use of metrics-driven quantifiable indicators in commissioning.

Our UK study involved consultations from February to May 2023 with community and voluntary sector leaders, policy-makers and scientific advisors. This began with a one-day workshop with people who work directly on the provision of services in local authorities, voluntary sector groups, the NHS and community organisations. This led to a set of policy recommendations for a more equitable and people-centred pandemic response in the future, by addressing the inequalities exposed and exacerbated by governance during the pandemic. The recommendations highlighted by these experts were then discussed during one-to-one interviews with high-level experts and decision-makers.

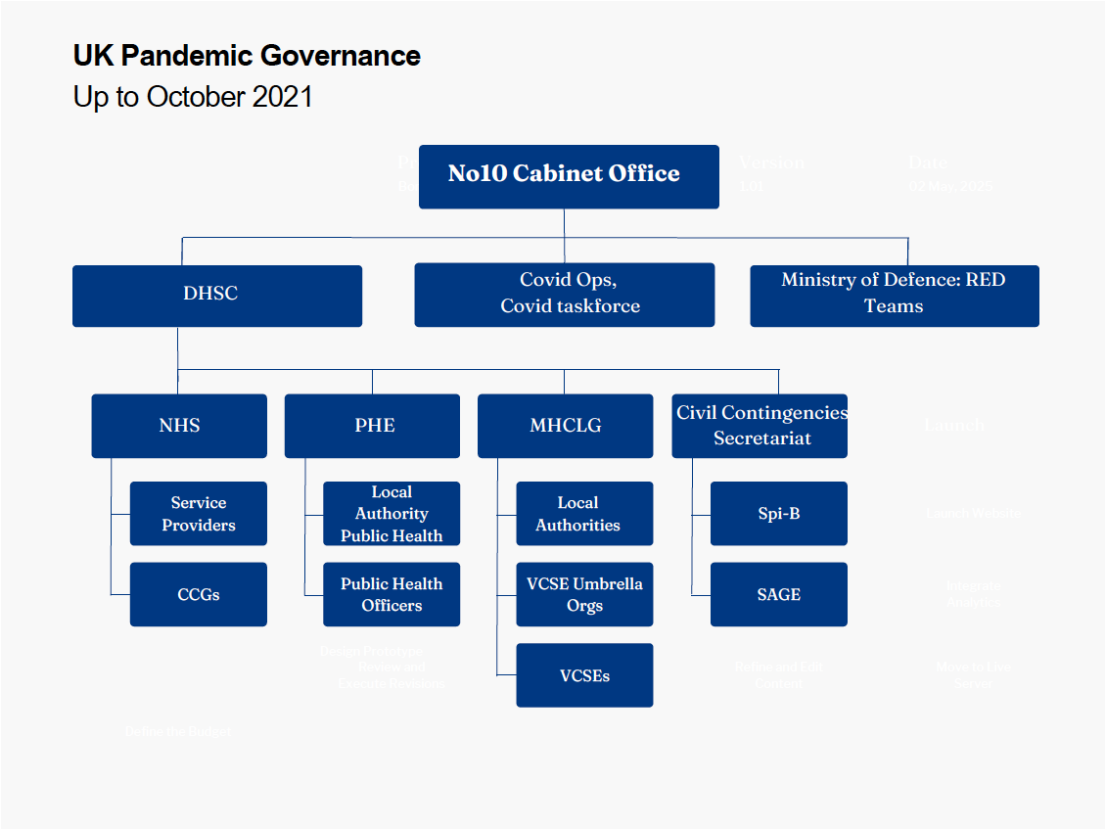
Our conversations at all levels were facilitated by an open-ended, collaborative approach, designed to enable reflection on the difficult experiences related to crisis policy-making and action, COVID-related illness, death and loss. In each commission setting, the researchers and participants addressed the harm of racialised, classed, gendered and other inequalities. We also looked for positive examples of relational working, solidarity and mutual support.

The experts we consulted were part of the following organisations and networks (also illustrated in Figure 1, below):

- UK Cabinet Office. UK decision-making body chaired by the Prime Minister and other senior cabinet ministers, including HM Treasury, the Department for

Levelling Up, Housing and Communities and the Department of Health and Social Care.

- Scientific Advisory Groups. For example, SAGE and SPI-B, involving experts from government, academia and industry.
- Department for Levelling Up, Housing and Communities (DLUHC). Ministerial department responsible for housing, communities and local government with access to funds across the UK. Previously MHCLG.
- Department of Health and Social Care (DHSC). Ministerial department leading national health and social care.
- Public Health England (PHE). Provided advice to support public health and works with the NHS and local authorities to implement policies until October 2021.
- The Office for Health Improvement and Disparities. Government unit to improve public health policy across England, founded in October 2021.
- National Health System (NHS). Publicly funded healthcare system in the UK. Allocated UK government funding via the UK Treasury, and the Department of Health. The NHS is responsible for allocating funding for Integrated Care systems (ICSs), formally Clinical Commissioning Groups (CCGs), statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.
- Integrated Care Systems (ICSs). Place-based partnerships for delivering integrated services involving the NHS, local authorities, service users, carers, and community and voluntary organisations.
- Local authorities. Responsible for social care, public health and other vital services.
- Voluntary and community sector umbrella organisations, which disperse funds and information to a network of community-based, grassroots and voluntary organisations.
- VCSE organisations. Voluntary and community organisations, charities, social enterprises, mutual aid groups, co-operatives, and grassroots organisations.



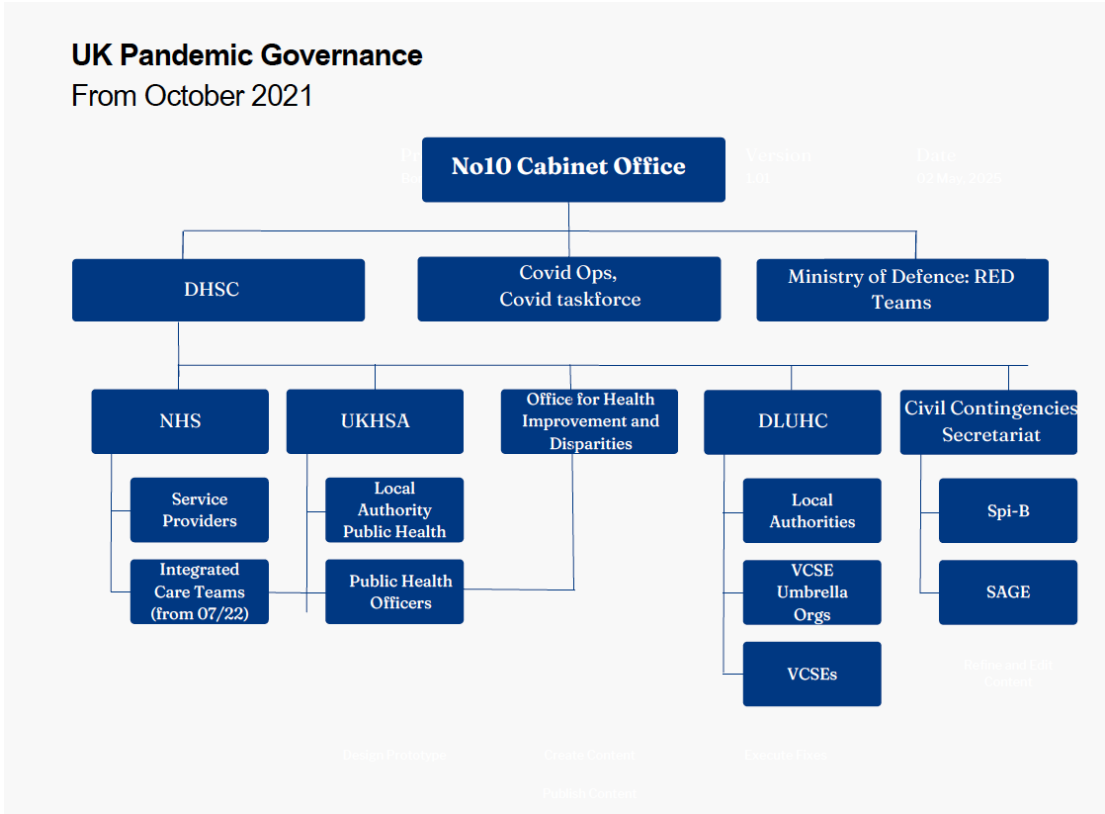




**Figure 1: Pandemic governance network before and after October 2021, as relevant to this report.**

Based on this evidence, the case study is structured around three key policy areas: resourcing social infrastructure; decentralising and integrating services and expanding the use of social science analysis and evidence in decision-making. We found there were some surprising affinities in perspectives across levels of governance, suggesting that the problems and potentials we have identified are crucial parts of policy networks. Yet, following our methodology, we lead with the evidence provided by the key 'nodal figures' bridging the public health system and the communities they engage with.

## 1. Resourcing social infrastructures

### 1.1 Voluntary, community and social enterprise sector funding

> *Core funding of the voluntary sector, that has to be a priority, and that is something to directly argue for from central government … it's not rocket science to say, you need central statutory funding for the voluntary sector. And it's worth making that point loud and clear.*
>
> *- VCSE officer*

> *There is a wealth of local networks now within each local authority. And I think that [the] Community Champions approach shows that we can tap into those networks when we need to. The challenge here is how to keep those networks alive and going once the crisis has ended.*
>
> *- Civil servant*

The value offered by the VCSE sector during the COVID-19 pandemic was recognised by research participants across all the networks of governance. In particular, participants highlighted the effective and rapid formation of coalitions mobilised in the crisis of the pandemic, which provided essential support for those who needed it. In acute phases of the crisis, during national and local restrictions, networks which included supermarkets, churches and mosques, came together to provide food. Informal organisations played a key role, setting themselves up as responders to distribute food parcels to those identified as being in need. Community transport initiatives helped to provide food and access to health services. Where statutory services were slower to respond, people and

organisations embedded in their local neighbourhoods worked together to provide vital, life-sustaining support.

Local authority representatives consistently recognised the deep significance of VCSEs for the delivery of services at the local level during COVID-19. For example, a participating London public health officer described the importance of two-way conversations with VCSEs about how the health system could better support minoritised people during the pandemic. This two-way dialogue was central to the Community Champions programme, which in some areas involved volunteers in the design and delivery of programmes, reversing typical top-down public health processes. This programme highlighted to local authorities 'that there was a huge amount of capacity … in the communities already to do good work themselves'. Central government civil servants agreed on the vital importance of this.

It was recognised that funding was needed to sustain the momentum built during the pandemic. Despite a temporary increase in available funding for the VCSEs during the initial years of the pandemic (2020–21) (Gov.UK, 2020b), after the later 'fiscal tightening' (Blundell et al., 2022) and cost of living crises, VCSE research participants noted a retrenchment as resources were further squeezed during subsequent cost of living crises.

> *The challenge that I'm seeing in the difference between COVID and cost of living response … we don't have any money … resources are really retrenching; we're seeing retrenchment in mutual aid … people are scared at an individual and an organisational level about their costs.*
>
> *- Local community public health officer*

In fact, people across levels of governance noted how funding shortages limit the prioritisation of VCSEs in local authority budgets. As a central government civil servant also explained: 'the challenge here is how to keep those networks alive and going once the crisis has ended'. They require careful, long-term resourcing for crisis prevention, rather than continual crisis management; as one public health officer put it, 'the whole system is still firefighting'.

Restricted funding has implications for longer-term processes. Between 2010 and 2019, local authority spending power fell by 16%. More importantly, the disparities between the

budgets of different local authorities have widened. Now, local authorities only receive 23% of their funding from government grants, 50% from local council tax and 27% from retained business rates (Institute for Government, 2020), figures that vary according to the underlying economy of each area. All these factors have combined with the high cost of private borrowing for capital schemes and local authority budgets are in constant crisis. This has been exacerbated by rising inflation and changes in the value of UK Treasury bonds, which provide the baseline against which local authorities can be charged interest for borrowing.

The barriers to funding for local authorities and VCSEs are not just financial, however, as the mechanisms through which government funding is distributed are competitive and restrictive. Local authorities receive funding for statutory services such as social care according to 'the formula' that is set and agreed as part of a political process at the DLUHC (formerly MHCLG):

> *The formula is incredibly difficult to negotiate in the first place and has enormous inertia to it, because to change the formula requires negotiation with 300 or so local authorities, and there will be winners and losers.*
>
> *- Government civil servant*

Local authorities can compete for additional funds in competitive bids for particular projects. The Community Champions project worked according to a combination of these methods. Eligible local authorities were chosen using a bespoke formula that was designed to include not just the index of multiple deprivation but also other inequality measures such as percentage of disabled people in the region. Local authorities were then chosen on the basis of a competitive grant bid. Although guidance was given on how to submit bids, such processes may favour more advantaged local authorities. These local authorities are more likely to have the capacity and networks to make community projects work quickly or they may already have an existing relationship with central government civil servants.

There is a further barrier to long-term funding for the voluntary sector. Central government civil servants do not want to create 'dependence' by providing long-term funding. This can mean that organisations are vulnerable because the political cycle and ministerial changes can alter government priorities. Additionally, they do not want to

'crowd out' innovation and furthermore, participating civil servants argued that if they change VCSEs into a direct arm of government then this may alter their capacity to serve their communities.

Members of VCSEs see funding connections to local authorities and central government differently. They want to access grants over the long term in order to build sustainable programmes of work. On the other hand, they don't want to just deliver services that should be provided by the government; government goals and targets, including NHS ones, could undermine people-centred and community-focused approaches. VCSEs are not just delivering bodies, but hold extensive knowledge, networks and relationships.

An unintended effect of short-term central and local government funding for VCSEs is that skills, data and expertise are repeatedly lost. A bias towards funding the new and innovative means that organisational knowledge of local relationships and individuals with relational expertise are repeatedly lost. Data protection also means that once funding passes on to a new organisation it has to start from scratch in assembling information about local communities and networks.

*Knowledge gets dispersed when organisations are not funded again*

*- VCSE officer*

This also undermines opportunities to build long-term relationships between government and VCSEs, and with service users. Instead, marginalised and disadvantaged groups experience a bewildering succession of organisations which they have to engage with. This results in an erosion and rebuilding of trust as each new organisation appears and disappears. Sometimes, the end of provision leads to resignation and despair among service users. A sense of abandonment further elicits distrust which is counterproductive.

Government financial structures are such that they result in precarity for VCSEs. Yet all participants in our commission agreed that VCSEs provided a vital service and that the creation of a long-term trusting relationship with service users is important. People who run VCSEs are resigned to short funding cycles and the time-costs of grant applications. But the situation has been different in the recent past, when more government funding was available for VCSEs. This suggests that we need to return to a pre-austerity situation involving direct central government funding of local organisations for the provision of social welfare. Alternatively, different structures such as the formation of a national

infrastructure bank could include funding for social infrastructures. Grants for VCSEs could become a statutory responsibility of local authorities. In addition, instead of the current situation which favours social enterprises that are run as a hybrid form of businesses with some grant income, there could be experimentation with a wider range of models. The use of cooperative, charitable and other models should be supported with wider training supplied in the formation of third-sector organisations. The benefits would likely include: better welfare provision through organisations that serve marginalised groups; the creation of cooperation and social fabric; and the construction of networks of trusting relationships that could support people during national crises such as pandemics.

### 1.2 Flexible and inclusive commissioning

> *We need to be flexible and give communities the agency to use money as they want to solve local problems … a lot of government is usually top-down funding then potentially ... it isn't appropriate, not in all circumstances.*
>
> *- Civil servant*

The provision of new lines of funding for VCSEs is not sufficient in itself. All our commission participants also addressed the need for more flexible and inclusive commissioning processes (see also recent VCSE recommendations, Gov.UK, 2022). A participating public health officer described ‘flexibility’ as ‘trusting the community to support their own conditions’, and asking people what they need: ‘How can you come together to help solve your problems? And how can we help to facilitate that?’ A civil servant in central government also highlighted recognition of the need for more ‘design flexibility’, balancing demands of accountability for public funds and the risk of the potential exclusion of valuable VCSE partners. Equitable improvements would include diversified commissioning processes and increased transparent dialogue around funding and evaluation requirements between central and local authorities, and between local authorities and VCSEs.

A good example of how this might be achieved in practice came from the Community Champions programme. The underlying structure for a more open relationship between

government, local authorities and VCSEs came from the use of non-ring-fenced open grants not attached to a rigidly defined policy priority. This meant in turn that local authorities did not have a legal responsibility to spend the money within a certain time period and they could use it in the way that best fitted local circumstances. A civil servant remarked on this:

> *The main sort of policy learning … is that we need to diversify our funding approaches, how we actually work with voluntary sector and with local authorities as well.*
>
> *- Civil servant*

A further significant element of the Community Champions programme was that policy action was co-created with local authorities during and after the bidding process. This in turn led to local authorities doing the same in collaborations with local VCSEs.

> *We co-designed the plans with the local authorities more or less, and that filtered down to their approach to their voluntary sector groups*
>
> *- Civil servant*

This co-production was made a clear aim in the funding application guidelines, leading to a very varied series of interventions suited to local situations. It also modelled co-production behaviour and created relationship-building at all levels of governance.

In addition, the evaluation process was adapted to support fast action, enable relationships with micro-organisations and reduce the burden of monitoring. It was loose enough, while still making sure that public money was spent correctly.

> *We were not that heavy on monitoring and data. Because quite a lot of small, grassroots organisations, they didn't have the infrastructure to provide any of that. Also working with disadvantaged communities who are not trusting of government we didn't want to collect a lot of data … if we wanted to engage them.*
>
> *- Civil servant*

Local authorities were also consulted in online forums about the viability of different monitoring options. So the policy process was not a top-down audit regime. Instead, it

focused on dialogue and relationship-building. Civil servants consciously took on a new role as intermediaries in building connections:

> *If you have that role as … intermediaries between the local authorities … and the government, then you can … in a much more bespoke way talk realistically about what evidence might be available for an evaluation and you can have a conversation about that in different areas that's more grounded in the realities of the situation. So it's that kind of mutual dialogue … that you're having with the local authorities.*
>
> *- Civil servant*

The Community Champions initiative was an unusual crisis-time collaboration, but it does show some ways forward based on flexible, inclusive design and evaluation. A pool of money from a national infrastructure bank or central government funds to build social infrastructures not tied to short-term ministerial or political concerns would create a similar situation. The role of government civil servants and local authorities in commissioning would be similar to that described above. They would be enablers of diverse local initiatives with a common general goal. This diversity of organisations would support short- and long-term change in the ecologies of care in the UK.

### 1.3 The relational work of mediators

All participants in our commission emphasised the significance of mediators or nodal figures who negotiate the networks between VCSEs, state and society. The work of these nodal figures relies on relationships of trust built through their labour of care over time. During COVID-19, their expertise became essential to the provision of life-saving welfare, healthcare and information. Participating 'mediators' included people working with and representing Black, Asian and minoritised ethnic groups in north-west London; voluntary and community networks in a west London borough; the Somali community in the West Midlands; the Roma community in the East Midlands; local authority public health and community networks; and unpaid carers in east London. These experts lead initiatives that work to bridge the disconnect between mainstream policy and public health practice at national and local levels, being acutely aware of the everyday lived

realities of the people they work with. Among our participants, there was a clear sense that this vital relational labour has often been under-resourced and unseen, or even silenced.

Our participants told us of the intensifying relational work resulting from the pandemic, including ensuring everyday care provision and advocating for racial and health justice. This took place in a political environment that did not accept that structural racism exists (as evidenced by the Sewell report). The pandemic was also a period when stigmatisation of minorities increased, for example with multi-generational households singled out as a source of transmission and 'Black, Asian, Minority Ethnic (BAME)' communities characterised as vaccine hesitant. This added to tense local situations between various social groups. VCSE experts were suddenly called upon from June 2020 to step into intensive action and provide knowledge and resources for government and NHS organisations. Their work was tireless as they negotiated gaps in understanding and representation and navigated health systems.

A community activist with extensive experience working across communities, public health, local authority and NHS sectors, described the 'anxiety' and 'burnout' caused by taking on a role in the 'chasm between system and community'. An advocate for mental health and women's rights described her attempts to equip people so that they did not 'internalize everything' as their individual suffering. This involved giving up time to offer therapy, run workshops and write reports for free.

> *I was doing workshops … and mental health awareness and teaching them how to regulate their emotions, mindfulness. And that is how we survived through the difficult times [of COVID-19]. That was horrific … I kind of give therapy for everybody. I don't have that capacity.*

Her multi-faceted work providing mental health training, support and therapy exemplifies the ways in which people came together initially in spite of mental strain, loss and grief. The challenges VCSE and community workers faced included disrupted access to support systems, such as being unable to pray or visit family during lockdowns. Like many of their clients and service users, they also faced a complete lack of access to government provision for mental health. As with other 'mediators', the mental health advocate quoted above offers guidance to people as to which care services to seek out and trust.

> *That's my role now … I have a mother coming to me saying, 'I'm struggling with my child, what do I need to do? Do I need to go to a social worker?' If I say yes, she will call. If I say no, she will not call. That is basically it … because I know how these people think and I live with them.*

She provides an informal health system for the Somali, Black, Arab and Asian communities extending the reach of public care services and mitigating their shortcomings. This includes the lack of access to and trust in the health system. As she stated:

> *people cannot reach the service, no one looks like them and there is the fear and distrust and history of mistreatment they experienced and not trusting the system and we're doing that job now – where services never communicate or see these people.*

Through the informal health system provided by such mediators, the difficulties of accessing health and other welfare services are mitigated.

This work of bridging service gaps involves putting in time for free, showing up for people and being there over a long period of time. This vital role should be valued and resourced. Participating public health decision-makers corroborated this recommendation, similarly identifying the need for sustained resourcing of 'mediator roles'; people who can act as conduits between national, regional and community sectors, and between the public sector and communities.

The Community Champions policy did recognise the significance and value of mediators. It resourced Community Champion coordinators within a range of VCSE organisations and valued Community Champions as more than conveyors of health information. Each of these roles was rewarded as they animated links within and beyond their communities. In some of the schemes, as recommended in MHCLG guidelines, Community Champions were paid for their work and in others they were offered valuable training. In many areas, paid time for coordinators meant that there were resources available to build cooperation between VCSE groups which had never worked together before. Coordinators exchanged resources and shared information in a combined effort across community boundaries. In the first Community Champions scheme, this coordination was further supported by the work of national-level VCSEs, which gave grants to micro-groups and provided advice, training and support. It is likely that the wide impact of the

Community Champions programme was in part due to its recognition of the value of mediator roles at the national-, local- and micro-levels.

Significantly, this recognition for mediators arose in part from a broad understanding of the social determinants of health and therefore of what is needed to improve it. This was visible at all levels of governance as issues of welfare provision, housing, work and health were thought about together. The Community Champions programme exemplified this joined-up approach. For example, a public health official said that she saw her Community Champions programme not as being about health messages alone, but as an empowering process of advocacy and dialogue:

> *We want community champions themselves to take on other roles in the programme design, that are above and beyond just being a champion, because we've always said, please tell us how you want this to evolve, just keep the feedback coming.*

> *They come together and reap the benefits of each other's resource and expertise. This is a health intervention too. Because it builds community ... it builds an individual's empowerment … to be more of an advocate for their particular community … and then the Community Champions become … part of the ecosystem of the council, in … a new approach to community engagement.*

In all of these post-COVID-19 efforts, health is understood very broadly as being related to multi-dimensional inequalities that need to be addressed in a holistic way. As one public health official asserted:

> *People need to self-refer to somebody who isn't going to take a view of you as a health problem, a social problem or an economic issue or other, but is going to say, 'Okay, I'm here to try and help you navigate the system; you need a personalised care plan, which is a preventative one, because actually, I can see that in six months' time, if you don't have that in place, you're going to face a health and wellbeing issue or a social care issue that can be prevented if we intervene now.' And that, beyond the moral impetus to do that, would save the system and that individual a lot of time, energy money, resources in general.*

VCSE mediators, the NHS and public health officers have long been aware of the need for an expansion of the concept of the patient as a consumer in relation with a service. But mediators' advocacy during COVID-19 and the broad governance schemes like Community Champions have led to a new acceptance among funders of this approach. For example, one VCSE leader reported that he had been able to scale up his carers' organisation to create a new wellbeing academy. This provided extended training and support for carers to assist them in navigating their own complex mediating roles.

There are still many unresolved issues of racism, stigma and deprivation. The cost-of-living crisis, intensifying austerity and political refusals to address social justice add to these. Mediators in the VCSEs are attempting to support marginalised and disadvantaged groups through this in spite of burnout and other legacies of COVID-19. The experiments of governance in COVID-19 have demonstrated that if we are to get through situations of chronic crisis and deal with the next pandemic, we need to value their work more highly and fund it more adequately.

## 2. Decentralisation, integration and coordination of service provision

### 2.1 Service integration

During the pandemic in the UK, barriers to integrated service provision and information sharing were made visible. At the same time, there was unprecedented coordination, in spite of these barriers, that joined together the NHS, local authority social care, local public health officers and the VCSEs in vaccine and information campaigns. This has led to new experiments in regional Integrated Care Boards and local-level Integrated Care Teams within the NHS (e.g. North Central London Integrated Care System, 2021). These aim to create locally informed and integrated approaches to inequality, health and social care. At the same time, local authorities are focusing on micro-level support in libraries, community centres and churches to deal with ongoing health, cost-of-living and energy crises. This is a new arena for a more generalised process of decentralisation and integration of service provision. In this section, we draw on our participants' knowledge to point out some of the risks and potential of this shift.

The ICS model includes a Community Partnership Forum in each region that is intended as an expert group on community engagement and aims to discuss emerging issues. It includes Healthwatch UK or patient voice teams from each area along with Council of

Voluntary Sector representatives and community engagement experts and NHS ICS leads. While this demonstrates a valuable recognition of the significance of communities and engagement with them, there is a potential problem, in that consultation is not the same as challenge and co-production. In this model, views are represented and considered, and this is sufficient. On the other hand, programmes such as the Community Champions programme gave over resources and supported diverse multiple forms of action by local-level organisations.

At the local level, the ICSs have drawn in local VCSEs, which is important. But to have any real effect, these organisations need to be better resourced and given an advocacy and strategic role in the NHS system. There is a danger that the collaborations that are generated become little more than signposting to various services or a form of auditing of service users. If VCSEs are not themselves valued as a source of diverse knowledge and practices for a varied ecology of care, then they will become simply an arm of a central government scheme. To work well, VCSEs need to be recognised and included as health provision experts. This would be facilitated by greater and more sustainable levels of investment by central government and local authorities.

In addition, there needs to be more central coordination alongside decentralisation and integration. The relevant ministry, such as the Department of Health and Social Care, or even a special task force across ministries for the VCSE sector needs to investigate the inequalities between regions in terms of social infrastructures. Since the 2010s, different eco-systems of voluntary care have emerged across the UK, with vibrant sectors in places where local authorities have prioritised funding, commissioning and relationship building with them. In other places, there is a dearth of voluntary sector umbrella organisations, volunteer groups and social enterprises. Central government needs to map and ameliorate these inequalities in social infrastructures, especially if they are part of the provision of integrated care. Otherwise, the new moves are likely to intensify rather than resolve regional and community health inequalities. Places that are already abundant in interconnected and vibrant social infrastructures will do better for their excluded groups than others. If not mitigated this will create divergences between regions and sub-regions that will again become acute during another pandemic.

Central coordination and linkage between the national and local scale in terms of data would support the new integrated care experiment. COVID-19 exposed a fragmentation, siloing and incompatibility of data on the health and care of the UK's population. However, there were difficulties cited by variously positioned participants in accessing

real-time data during the pandemic. One community leader described how she previously had to manually analyse and triangulate ONS data sets herself due to difficulties accessing national-level data as a result of General Data Protection Regulation (GDPR) restrictions. A lack of data coordination between central and local government, in part due to restrictive GDPR regulations and lags in data, caused delays which are particularly problematic during health crises. Further, barriers in sharing data between privatised and public service bodies further complicated data use at the local level during the pandemic. There have been some positive shifts as a result of COVID-19 in terms of data accessibility. For example, the recent establishment of the NHS Race and Health Observatory has made data, analysis and recommendations on ethnic health inequalities openly accessible for people working across levels of the health system. Barriers to data sharing due to the privatisation and fragmentation of public sector organisations are a crucial area for consideration in crisis preparedness. There is a need to strategically link complex data sets across sectors, to consolidate information regarding social issues related to health inequalities and design programmes responsive to them. The UKHSA could be responsible for coordinating this, but there needs to be an open access element to this data, as with the indices of multiple deprivation area maps.

A key area for integrated data would be to provide combined data sets on housing and health outcomes in line with the indices of multiple deprivation area maps. Housing issues in the UK are a significant aspect of health inequity, contributing to the increasingly 'split publics' of the UK, with vastly divergent social realities related to the pandemic along classed and racialised lines. COVID-19 policy favoured white middle class 'households' of people who could work from home in relative comfort. Social restrictions resulted in negative effects for LGBTQI+ people, people living in houses of multiple occupancy, people with insecure housing, homeless people, undocumented people, and large families living in multi-generational housing. Among our participating VCSE leaders, there was a discussion around the mental and physical health strain that housing issues can cause. These include the threat of evictions by private and social landlords, and of being separated from crucial family networks. The COVID-19 pandemic made housing inequality and its health consequences a public issue, but the sense of urgency has disappeared. For example, there have been cases of people dying due to black mould in their homes, including the tragic death of two-year-old Awaab Ishak in November 2022. Poor housing conditions contribute to higher rates of mortality from

COVID-19 and other illnesses, and as such there is an urgent need to recognise housing as a right and as a fundamental component of healthcare and health equity. We recommend a cross-ministerial task force to address this issue in the round rather than housing being siloed in the DLUHC.

### 3. Expand social science analysis and evidence

The potential contribution of qualitative social science analysis and evidence to policy has been recognised in the Treasury's guide to evaluation, the *Magenta Book*. The role it is given is as part of a synthetic approach that combines qualitative and quantitative research. Unfortunately, however, its role is currently too limited. This is because the *Magenta Book* analyses policy as if it were a complex system all of its own, rather than as a series of social relationships. It is relationships of support, stigma, care, uncaring, rationing, and judgement that are the conduit of policy; qualitative evidence about these relationships is essential.

The *Magenta Book* also contains an odd characterisation of the robustness of qualitative methodological approaches. These are described as providing narratives or small-scale data. They are found wanting and/or more expensive than large-scale quantitative or experimental (modelling and randomised controlled trials (RCT) approaches (HM Treasury, 2023: 42). In addition, there is a claim that these methods are problematic because they inevitably change how people behave. This reflects a misunderstanding of participant observation, which triangulates what people say with what they do. It also underestimates the degree to which entrenched power relations remain even when the observer arrives in a social situation of policy production. In addition, it does not recognise that the researcher triangulates narratives with an institutional structure, practices and a social field of action. These omissions are significant but not because the *Magenta Book* directly shaped COVID-19 policy on its own – policy action is always a mix of the personal projects of ministers, the goals of manifestos and electoral politics with institutional cultures of expertise. Instead, these absences are important because they reveal a hierarchy of knowledge used in policy evaluation and design. Bayesian and behavioural economics, medical RCT studies, value-for-money measures and behavioural science which focus on the average person as an individual have the most prestige. The disciplines that can explain complex social processes are side-lined.

This hierarchy of knowledge in which quantitative or system modelling takes priority has a significant effect. It means that inequalities are not fully recognised in health policy design and implementation. This kind of approach cannot track how behaviour (including that of policy and decision-makers) is shaped by the social enactment of inequality in everyday encounters over the long term. Multiple interactions over time affect people's capability to access services and take part in policy initiatives. Inequalities enter into the body as specific illnesses such as diabetes or COVID-19 mortality effects. These processes cannot be evidenced, explained or altered unless there is an analysis of social relations. Nor can the value of VCSEs be measured unless this approach is taken, since the primary work of mediators within them is to ameliorate inequalities. Their work cannot be evaluated unless the degree to which they achieve this end is measured using qualitative methods.

Reflecting all of our participants' concern with complex health inequalities the significance of qualitative social analysis of policy was underlined. Participating 'mediators' described how long histories of racism, discrimination and stigma led to fraught relationships with health authorities during COVID-19. Vaccination initiatives in January 2021 targeted 'BAME' groups as being vaccine hesitant in public announcements. This was re-stigmatising for many minoritised groups, who may already be distrustful of medical authorities due to long histories of exclusion. Both the history of their communities and their everyday encounters, along with practical barriers, prevented them from taking up the vaccine in initial campaigns. For example, long-standing experiences in the Roma community meant that they did not feel health initiatives related to them as migrants and that the medical care of the state was potentially dangerous. As with other minoritised groups, it was only through existing relationships of trusted care such as churches, local GPs and volunteers form the community that this understanding changed. This hesitancy was also related to direct encounters of interpersonal racism within the health system among minoritised groups, as both service users or providers. This can elicit embodied trauma and present a barrier to formal healthcare-seeking in the future (see also Kapadia et al., 2022: 62; Bede and Lewis, 2023: 16).

A London public health officer noted the 'burden of responsibility' imparted on Black people, considered responsible for convincing their own communities to take the vaccine, without recognising a centuries-long history of medical racism. And a community advocate described how, in her Somali community, a sense of being 'unseen' by health authorities led to mistrust around vaccine orders: **'You never talked to me. You never**

**see me, yet you told me to take your vaccination.'** She also related this mistrust in the health system to higher rates of chronic illness, mental distress and disability among Somali people in the UK.

> *Now, all of that mistreatment in the health system and history of mistreatment, wrong and overdiagnosis, the government takes the initiative that* ***now we need to trust you without any open dialogue, and think that we should accept the vaccination after everything that happened, without any doubts*** *… I think that it's important to explain why that is, why the hesitancy when the vaccine happened.* ***Because we were never part of the conversation; for years we were ignored.***

Inequalities are also evident in the need to increase diversity in senior public health leadership. A lack of political representation in local authorities can contribute to the 'invisibility' of particular minoritised communities in pandemic responses. This has the potential to feed through to commissioning decisions. As one community activist and health sector expert described, there was a **'complete disconnect between the person making decisions and the people on the ground'.**

This disconnect will remain as long as health policy is designed and evaluated without attention to the social relations of inequality. By not taking these into account, the barriers people face are rendered invisible. As a Roma participant stated, 'there are some unseen, completely unseen communities in Britain today'. She refers here not only to the Roma community she works with and is a part of, but also other communities who are undocumented, such as undocumented migrants and those living in undocumented housing, people who have no data or are unbanked, and those who do not have access to computers and mobile phones. This policy neglect intensifies reliance on various forms of overburdened formal and informal mutuality and community support. Disabled, chronically ill and elderly people are also neglected and 'unseen'; as a voluntary sector leader in west London put it, 'everyone seems to have forgotten about people with disabilities … most people with disabilities couldn't get out'. She described how this had long-term effects on the mental and physical health of these two groups.

Quite simply, then, the hierarchies of knowledge in government policy that the *Magenta Book* represent are problematic. Even though policy-makers are attempting to achieve

technocratic fairness and neutral evaluation, they potentially contribute to the invisibility, and reproduction, of inequalities. All of the unequal health outcomes of the COVID-19 pandemic show just how inadequate such an approach is. In preparation for the next pandemic a more open, cross-disciplinary approach is required.

### 3.1 Evidence for what and evaluations for whom?

> *[…] you've got the researchers, you've got public health, and local CCGs, then you've got the community and the Community Champions, and they all had different priorities and a different focus. So how do you negotiate what [data] comes in? […]*
>
> *- Community activist*

In the Treasury's *Magenta Book* it is clear that evidence is collected primarily to enable insight for policy-makers and to justify the expenditure of public money. 'Stakeholders' including service users and the UK public are included as a significant audience for evaluations, but in a more minor role. Our participants working in the VCSE sector had a different vision of the role of service users and the public – this was that evidence and data should be actively co-created with and partly for them. This would result in a more democratic approach.

This co-production was achieved in many places during the pandemic within Community Champions programmes. As one experienced community activist and health service provider expressed above, the evaluations in this setting explored the aims and goals of evidence with volunteers. There was also an active process of negotiation between Community Champions and researchers, NHS agencies and public health officials. This allowed the Community Champions to contribute their significant insights and to guide the process of knowledge production. In other situations, she has found that focusing on 'for what and for whom' in evaluation re-frames the evidence, not only in a way which allows decision-makers to understand the impact of their policies, but also as evidence for communities themselves. In the process, as she put it, there were tensions and conversations around 'who delivers the message, who owns the message'. This has implications for how measures that people value are used, and choosing accessible language that people understand. The advantage of this relational knowledge-building and -sharing was that it revealed the causes and consequences of racial inequities in health. It also made meaningful evidence available to community members that they

could use to lobby for further action. Overall, co-production supported a process of mobilising better-informed action across all levels of governance.

Alternative approaches to gathering and reporting evidence could have a further important effect. One of the main barriers to smaller VCSEs applying for funding from local authorities arises out of inflexible requirements for monitoring evidence. Our participants from ministries, local authorities and VCSEs were all emphatic that a dialogue with organisations about what monitoring evidence could be collected is crucial. They suggested a flexible co-design approach. Once again, this process was a significant part of the Community Champions programme in which local authorities were able to negotiate with central government on evidence needs. In addition, smaller VCSEs were able to act with supportive and limited monitoring via larger VCSEs.

Our participants also noted the inequalities present in the requirements for evidence gathering, monitoring, and justification of policy. Central government organisations and government ministers have a duty to the public, but it is not possible to monitor the value for money, effectiveness and consequences of their actions. They are protected from scrutiny by state secrets and legal restrictions. In addition, the goals and aims of COVID-19 policy were not clearly stated to the public or within the civil service. There was also an opaqueness in relation to who and what evidence were used to make final decisions about COVID-19 policy. For example, the role of the COVID-Ops and Ministry of Defence RED committees is largely unknown to the public and their evidence processes have not been revealed. Some of our participants also reported a lack of clarity within the civil service about how or why ministers were taking particular decisions. While community-based organisations and local authority initiatives require extensive pilots and evidence, elected ministers can enforce programmes without any supporting data in a non-transparent fashion during pandemics. This suggests that we need to build an explicit legal and ethical framework for elected officials during pandemic situations. Otherwise, policy becomes authoritarian, secretive and illegitimate. Social scientists and legal experts could, according to our participants, assist in the design of this legal and ethical framework. They could also play a role within pandemic governance structures in which they make clear to civil servants and politicians the ethical frameworks and consequences that are implicit in their actions. A dialogue could then emerge explicitly about this including discussion on what the collective goal of a range of state institutions should be. This would enable greater coordination in the policies across them and result in more effective pandemic governance as decision-making would not be based on the

single political ideologies of a few powerful figures – a kind of pandemic governance that is illegitimate and deeply undemocratic.

### 3.2 Social listening and responsive policy

Pandemic situations provide very challenging conditions for the creation of policy. In crisis-times, decisions on how to act take place in a highly uncertain environment. This uncertainty relates both to the nature of the disease involved and how people are responding to it and can be mitigated by the use of evidence from previous pandemic situations, but the social dynamics can only be fully understood through social listening. This involves gathering evidence in real-time related to particular decisions or issues. Examples of this fast, evidence-based action were given by our commission participants, particularly by those involved in Community Champions programmes. The LSE COVID and Care project (Bear et al., 2020b), used an 'immersive ethnographic social listening and co-production' methodology, prioritising everyday knowledge and experience. This was employed for example in 'Good Death' recommendations, advising on consultation, policy and communications to support communities in dealing with death and bereavement in the context of the COVID-19 pandemic (Bear et al., 2020a). This project led to a focus on the importance of a dignified death in line with different faith traditions, by giving families the 'right to say goodbye to loved ones' in care homes, hospitals and at funerals and providing national recognition of large-scale traumatic losses. The LSE Covid and Care project through Professor Bear's work on SPI-B contributed to the evidence that changed the government's approach to household and community care, resulting in broader social support bubbles during lockdowns to help the elderly, carers, disabled and extended families. By August 2020, 44% of UK residents reported to the ONS that they had formed a support bubble benefitting from this policy. During the second lockdown, these bubbles were widely used for family support relationships and childcare especially by women. Furthermore, Professor Bear and Dr Atiya Kamal developed a cross-disciplinary approach to community-led public health during the pandemic advising MHCLG on the Community Champions scheme. This approach developed from ethnographic work, social psychology and international comparisons contributed to the UK's first national, community-led, public health initiative. Launched in January 2021 with £23 million targeted at 60 of England's most deprived areas, the scheme brought together local authorities, the third sector and community organisations. These groups helped to ameliorate racial stigma and provided support such as delivering health advice with food parcels, setting up vaccination hubs in places of worship,

circulating health information in multiple languages, giving debt and mental health advice.

Some Community Champions programmes provided a highly significant example of this social listening in real time. This was achieved through weekly meetings online with Community Champions volunteers where they voiced the challenges they were facing and their concerns about public health policy. In addition, WhatsApp groups were created which included the Community Champions coordinator. From these groups, the coordinator could gain immediate insight into 'resonant conversations' and ensure that public health responses were effective and relevant. These activities resulted in combining 'observation with bridging with communication', providing instant feedback on health policy. This suggests that virtual platforms and social media can be used productively during pandemic situations. But this is only the case if they are embedded within responsive policy relationships and the environment for engagement is supportive.

This kind of communicative and interpretive work can enhance the relevance of service provision and directly integrate community perspectives. This again echoes earlier observations about the significance of the relational work of mediators within health systems. From their vantage point, they have particular insight into the complex relationships in which people are embedded. This relational knowledge is key to health policy and care provision but is beyond the reach of surveys and standard public health data-gathering, highlighting that real-time social listening is vital to bridge the gaps between everyday lives and policies.

### 3.3 Expert advice: Cross-disciplinarity, reach and transparency

Our participants noted that the structures relating to expert advice in the UK COVID-19 response demonstrated the value of cross-disciplinary work in pandemic policy. SAGE had sub-committees such as SPI-B and the Ethnicity subgroup that involved experts from social psychology, public health, history, anthropology, sociology, medicine, and law. Alongside this there were multi-disciplinary task groups, such as that for the Environment or Schools, focused on a specific problem. The social sciences had a role alongside that of more specialist health disciplines. This generated an in-the-round approach that could offer a holistic perspective to issues.

The reach and transparency of SAGE evidence papers was unusual and significant. A dedicated group of civil servants worked on making sure that evidence papers circulated

to a wide range of government departments. They were active knowledge brokers or 'translators' between policy teams and scientific evidence. Their 'informal connecting work' was essential to the impact of advice. Papers were also made available to the general public from May 2020, creating an important debate in the press and wider society about the validity of various policies. This was especially important when government action diverged from recommendations in the published scientific evidence papers. This suggests that it is important to build civil service structures to support the work of external academic experts outside of emergency situations.

Aspects that were more problematic in the UK structure of evidence for policy were that teams of experts were assembled fast in the time of crisis. There needs to be greater thought outside of crisis times on the ideal mix of disciplines and decision structures to elicit scientific advice. The central scientific committee should also have the same balance and diversity of expertise as sub-groups. Most significantly there should be a transparent recruitment and appointment process before the next pandemic.

A second problem with the UK structure was that the questions which were asked of experts were provided by civil servants and ministers. There was little opportunity for the expert advisors to identify areas of growing concern themselves. This meant that policy questions and evidence on certain issues could not be addressed. Although experts might have been aware of issues other than those understood by politicians and civil servants, these could not be raised and explored. For example, the issue of stigma, in relation to COVID-19 and minoritised groups, was not discussed in SAGE.

A third problem was that while it was clear that independent experts had a duty to provide the best evidence they could, there was no requirement within government for action to be taken based on the evidence. It is important to maintain a separation between advice and policy so that it is only democratically elected politicians who are taking active decisions; however, during the pandemic the power of politicians stretched much further than usual and a small group of them decided on relevant policies often in disregard of the scientific evidence provided. This again points to the importance of developing a legal and ethical framework specifically for pandemic situations. This would map institutional structures and responsibilities to the public and in relation to their care.

## Conclusion

Along with various participants, we argue in favour of more effectively distributed and horizontal forms of pandemic preparedness and response, that are directly built on people's knowledge and experiences. This contrasts with current 'devolution' principles, which impose excessive responsibilities on people working to provide under-resourced statutory, local authority and community-based services, whilst retaining top-down bureaucratic control. These governance principles place further demands on the 'relational work' of individuals and organisations, which is unevenly distributed along classed, raced and gendered lines. It also exacerbates barriers to health and related inequalities. Instead, an equitable approach to pandemic governance would centre on the knowledge of 'nodal figures', bridging public health systems and VCSEs, and the local umbrella organisations and authorities that support them. This governance approach can be supported through 'social listening' methodologies that seek to understand, map and alleviate inequalities. Specific policy recommendations, first given at the start of this case study, are reiterated below:

### Resourcing social infrastructures

1. **Adequate and sustained flows of government funding are required for the UK VCSE sector**. This could include experimentation with a wider range of funding models, such as training and support for cooperative models. Grants for VCSEs could become a statutory responsibility of local authorities. Alternatively, different structures and supports should be put in place, such as a national infrastructure bank or central government funds to build social infrastructures. This would enable the central commissioning of diverse local initiatives with a common general goal to support short- and long-term change in the ecologies of care in the UK.
2. **Flexible, equitable and inclusive funding and commissioning** are needed at the local authority level with community-based organisations at the centre of the process. This approach is essential to ensure that funding processes are not exacerbating or causing inequalities.
3. **There is a need to recognise, reward and resource key mediators within and across the health sector** who create access to care services and mitigate inequalities, particularly for minoritised groups.

4. **VCSEs need to be given an advocacy and strategic role in the NHS system as health provision experts.**
5. **Regional inequalities in the VCSE sector and social infrastructures need to be investigated by a special task force assigned to the work from across ministries.** Mapping and ameliorating these inequalities in social infrastructures is particularly important in expanding the provision of integrated care and in the resolution of regional and community health inequalities.

### Decentralising and integrating service provision

6. **Decentralised health governance**, in the form of more distributed and horizontal forms of pandemic preparedness and response, is needed. This would involve the inclusion of key VCSE organisations at all levels of pandemic response, particularly in the form of emergency planning committees.
7. **Service integration is crucial to equitable pandemic preparedness and service accessibility in the UK.** This includes the integration of health and social services at the local and national levels, with the formation of a cross-ministerial care planning team and local authority representatives who consider provision holistically. In the longer term, there should be a ministry for care that looks at the whole life-course provision for child, elder, health and organisational support.
8. **New approaches to data integration are vital to achieving service integration.** Central coordination and linkage between the national and local scale in terms of data would support the new integrated care experiment. There is a need to strategically link complex data sets across sectors, to consolidate information regarding social issues related to health inequalities and design programmes responsive to them. The UKHSA could be responsible for coordinating this, and ensuring data are open access.
9. **A key area for integrated data would be to combine data sets on housing and health outcomes** in line with the indices of multiple deprivation area maps. Poor housing conditions contribute to higher rates of mortality from COVID-19 and other illnesses, and there is a need to recognise housing as a right and as a fundamental component of healthcare and health equity. We recommend a cross-ministerial task force that addresses this holistically rather than housing being siloed in the DLUHC.

## Expanding the use of social science analysis and evidence in decision-making

10. **There is an urgent need to conduct research which traces the processes which produce inequality.** Mapping of communities and relationships in local authority areas can help to overcome complex inequalities and issues faced by 'unseen' communities. This mapping must go beyond the current population categories deployed to understand race in the UK.
11. **Social analysis and evidence provide a crucial addition to population-level public health, social psychology and behavioural science perspectives.**
12. **Social media platforms such as WhatsApp can be used productively for sharing and gathering public health evidence** through 'social listening' during pandemic situations if their usage is embedded within responsive policy relationships and supportive environments for engagement.
13. **There is a need to build an explicit legal and ethical framework for elected officials during pandemic situations.** This would map institutional structures and responsibilities to the public and their care. Social scientists and legal experts could assist in the design of this legal and ethical framework and also play a role within pandemic governance structures by highlighting to civil servants and politicians the ethical frameworks and consequences that are implicit in their actions. This would create more effective, dialogic pandemic governance as it would not be built according to the single political ideologies of a few powerful figures.
14. **It is important to build civil service structures to support the work of external academic experts outside of emergency situations**, and across disciplines and decision structures. A transparent recruitment and appointment process for experts is advised before the next pandemic.

CASE STUDY 3

# COVID-19 and One Health: Experiences from Sweden

# CASE STUDY 3: COVID-19 and One Health: Experiences from Sweden

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## Executive summary

*The COVID-19 pandemic has exposed the vulnerabilities that exist in our current healthcare institutions and crisis management capacities, as well as highlighting and exacerbating structural and health inequalities.*

The Swedish case has been highlighted as being exceptional, going against many of the international recommendations and guidelines set by institutions such as the World Health Organization (WHO), in the implementation of a voluntary strategy. This report aims to present how the Swedish COVID-19 pandemic strategy has been perceived by Swedish participants in group interviews conducted for research purposes.

Three main perceptions of the Swedish COVID-19 pandemic response, from the group interviews, related to the following themes: experiences of the pandemic; management of the pandemic by the government and its agencies; and the human-animal-environment nexus. Firstly, in relation to perceived experiences of the pandemic, many of the participants acknowledged that not everyone experienced the pandemic in the same way, highlighting the impact of age and socio-economic status. Secondly, generally, the participants indicated that they trusted the government and their recommendations for handling the pandemic. However, they indicated that the Swedish national strategy was also disjointed, leaving some groups unprotected, with certain communications and recommendations unclear and open to interpretation. Lastly, while COVID-19 is a zoonotic disease, it was found that the participants had limited knowledge and understanding of the potential root causes of zoonotic diseases. Furthermore, many of the views the participants had on the relationship between animals, humans and the environment were anthropocentric, placing human needs above all else.

Through the findings of this report, the investigators present nine policy recommendations, derived from the group discussions:

### Governance

- Ensure that recommendations are clear and consistent when communicated to the wider public
- Ensure the improvement of infrastructure and equitable resource management for future crises such as epidemics and pandemics
- Place more emphasis on prevention rather than only on response

### Inequality

- Create pandemic strategies that take into consideration what all of society can do to limit the spread of infection
- Ensure that protection is given to those who are unable to follow recommendations to limit the spread of infectious diseases
- Ensure that support, whether that be economic or social, is given to those who are vulnerable and in need

### One Health

- Create more awareness of the human-animal-environment nexus, and the spread of zoonotic diseases
- Take a less anthropocentric view of human, animal and environmental health issues during the decision-making process, which may cause a ripple effect in society
- Place a heavier emphasis on the importance of concepts such as One Health, and make it more accessible and easier to implement in various sectors and at various levels of governance

## Introduction

The Swedish response to the COVID-19 pandemic, in terms of containment measures and policies, was not only different to the response of other European countries, but also to other Scandinavian countries, which are geographically proximate and culturally similar (Petridou, 2020). Overall, Sweden employed a less restrictive policy than its neighbours and other countries worldwide (Hassan et al., 2022). According to the

Swedish Corona Commission (2022), put in place to examine the nation's management of COVID-19, Sweden was not sufficiently prepared for a pandemic. Measures were implemented too late or were too minor, particularly at the onset of the pandemic. Those who were already socially and economically vulnerable were disproportionately affected by the pandemic and responses to it which were designed to tackle the crisis. In particular, there was an exceptionally high death rate among the elderly at the beginning of the pandemic, highlighting the poor conditions in care for the elderly the country's municipalities (Allebaeck & Burström, 2022). A such, there was a failure to protect vulnerable populations and precautionary principles were predominantly applied to economic issues, and social circumstances for the young, rather than healthcare, which highlights the need for a self-critical process (Pashakhanlou, 2021; Ludvigsson, 2023; Brusselaers et al., 2022).

The COVID-19 pandemic has highlighted the need for a global and holistic framework both to prevent and respond to emerging infectious diseases (EIDs). Notably, 61% of infectious organisms affecting humans are zoonotic (Ryu et al., 2017). In the last five decades, outbreaks of new infectious diseases due to animal viruses via spillover have averaged nearly one every year (Ellwanger & Chies, 2021). As a result, it has increasingly been argued that health should not only be conceived in relation to human beings, but as an issue which relates directly to the interconnectedness and interdependence between humans, animals and the environment (Sironi et al., 2022). However, preventative efforts, and particularly the role of animal and environmental health along with human health for pandemic policies, such as the One Health (OH) framework, have remained largely undebated and unrefined both in Sweden and globally. This has been a topic for recent research (see Osika & Pöllänen, 2023; Humboldt-Dachroeden, 2023).

This report is part of a wider set of investigations on current public health policies and current socio-economic inequalities, and how to improve health policies and generate better outcomes following the COVID-19 pandemic. Therefore, the aim of this report is two-fold. Firstly, it will focus on how Sweden's COVID-19 pandemic response has been perceived and experienced and the narratives arising from group interviews. That is to say: *How have the participants in the group interviews perceived the Swedish national COVID-19 strategy?* Finally, based on their experiences, the report will provide policy recommendations on how epidemic and pandemic responses can be improved for the future, applying an OH perspective.

## Background

This section provides the background necessary to understanding how crises, and more specifically, pandemics can impact governance; it considers the Swedish case more specifically.

### Pandemic governance and the COVID-19 pandemic

In the face of a crisis, decision-makers need urgently to meet the threat and this involves a degree of uncertainty in both the nature of the threat and its potential consequences along with the potential consequences of any response (Rosenthal et al., 2001; Boin et al., 2017). As systems become more complex and interdependent on one another, threats may cascade across geographical, policy, cultural, public-private, and legal boundaries. This can result in transboundary crises, which are difficult for a single sector or country to contain and manage (Boin, 2019). Governance has increasingly become a matter of crisis management, and how crises are handled by relevant actors can positively or negatively affect the legitimacy of public institutions. As crises can lead to high uncertainty and public anxiety, and there is a need for quick and agile responses to unfolding situations, this means that a greater degree of freedom is afforded to decision-making processes in these periods compared to during regular policy-making (Boin et al., 2017). The status quo temporarily decreases in significance and new proposals that may not have been previously accepted may now enter into the political discourse (‘t Hart & Boin, 2001), both during and after a crisis.

Without timely and preventative interventions, an outbreak of an infectious disease can grow into a transboundary crisis. While some of these can be regionally contained, such as the severe acute respiratory syndrome (SARS) epidemic in 2003, others can trigger a global public health crisis, like the COVID-19 pandemic. As infections can cascade across borders, it is imperative for various sectors and countries to cooperate with each other in order to respond to the threat. There are many lessons to be learned after a crisis, and they may lead to organisational reform, policy adaptation and training for future crises (Boin et al., 2017) to improve future crisis response. For example, in 2015, South Korea battled an outbreak of Middle East respiratory syndrome (MERS). The policy response to the MERS outbreak was widely criticised as being too slow and ineffective, which led to new policies and institutional changes to help improve future responses to infectious diseases. The lessons learned from the MERS outbreak are

believed to have helped pave the way for South Korea's rapid and early response to COVID-19 in 2020 (Park & Chung, 2021).

The COVID-19 crisis has exposed how underprepared the world's health systems are for pandemics (Nkengasong, 2021). The death toll, with almost 7 million recorded deaths worldwide (WHO, 2023b), represents both a tragedy and a global failure to collaborate and coordinate, to provide and ensure adequate supplies and equitable distribution of key commodities, and to protect vulnerable populations, to mention a few (The Lancet Commission, 2022). Each country reacted more or less differently in addressing the transmission of COVID-19 (Kusumasari et al., 2022). From strict and mandatory lockdowns to lenient recommendations, there was also variation in how effective each country was in containing the spread of the virus. With our current level of knowledge, it seems impossible to conclude that there is one 'correct' pandemic response strategy, as each strategy interacts with the behaviour of a given population and its cultural orientations, as well as being shaped by institutional arrangements, among other factors (Yan et al., 2020).

Trust, and more specifically institutional trust, is believed to be an important factor in explaining social behaviour (Hassan et al., 2022) and a fundamental aspect of the decision-making process in a crisis (Christensen et al., 2016). Institutional trust can impact on how people use services and follow instructions. Greater trust in public systems has been associated with a willingness among the population to follow instructions given by the authorities and precautionary behaviours during a crisis. Nordic countries, for example, rank highly in terms of trust in state institutions. When trust in state institutions is low, individuals are less likely to follow instructions, as demonstrated by studies on the Ebola virus in Liberia and Congo (Hassan et al., 2022).

### The Swedish governance model and the response to the COVID-19 pandemic

To understand the Swedish pandemic response, it is pertinent to be familiar with the Swedish governance model. There is an organisational divide in Sweden between central (small-sized) government ministries, and more than 300 semi-autonomous government agencies (Ahlbäck Öberg & Bringselius, 2015). The government is only allowed to govern these agencies through for example, legislation, regulations, and appropriation directives, as the Constitution guarantees the independence of the state administration (Sveriges Riksdag, 1974. Furthermore, local government is organised into

21 county councils and 290 municipal counties run by representatives elected every fourth year. They have extensive freedom to manage, for example, the implementation of welfare policy, and the public sector, including elderly care and healthcare (Sveriges Riksdag, 2022). As local authorities can contract out the provision of their welfare services to private companies, the resulting decentralisation and outsourcing have led to growing fragmentation. It has become increasingly challenging to steer and coordinate the public sector (Andersson & Aylott, 2020).

There is no special Swedish law on crisis management outside of wartime. The 'responsibility principle', which states that 'those who are responsible for an activity in normal situations also have a corresponding responsibility in the event of a disturbance in society' is the cornerstone of the Swedish state's crisis management approach (MSB, 2018). This approach has been criticised in the sense that if the division of responsibility is unclear, the principle does not suffice. In addition, in the decentralised – and non-integrated – Swedish system, the regional councils are tasked with responsibility for healthcare, including physicians, while elderly care is mainly the responsibility of municipalities. It has long been asserted that these divisions lead to significant problems and involve shortcomings in, for example, coordination in response to problems that arise when two authorities simultaneously share responsibility (Ibid.).

The Public Health Agency of Sweden (PHAS, Folkhälsomyndigheten in Swedish) was central in devising the Swedish response to the COVID-19 pandemic, with their strategy implemented by the Swedish government. The strategy was based on non-binding recommendations, centred around individual responsibility and left large segments of society open. No mandatory measures were initially taken to limit crowds, and COVID-19 testing, contact tracing, source identification, and reporting were limited (Brusselaers et al., 2022).

The strategy, and many of their recommendations have since been highly debated both domestically and internationally. For example, the PHAS did not recommend the use of facemasks until late 2020, going against WHO recommendations. Instead, they argued that user failure, such as slip downs and itching may cause people to touch their noses, mouths and eyes more frequently meaning that the measure would be counterproductive (Claeson & Hanson, 2021). It is also to be noted that when the use of face masks was encouraged in elder care homes and healthcare facilities, there was a problematic shortage of such masks (Brusselaers et al., 2022). While many studies have criticised the largely voluntary Swedish strategy, claiming that scientific methodology was not

followed (see Brusselaers et al., 2022), others have shown that while death rates were high in spring 2020, the overall excess mortality in 2020–2021 was lower than in many other European countries (Ludvigsson, 2023).

Various studies have found that Swedish citizens who were surveyed communicated a high level of trust in their government to protect them during the pandemic, especially early on (Hassan et al., 2022; Bengtsson & Brommesson, 2022). Furthermore, Esaiasson et al. (2020) found support for the view that the COVID-19 crisis led to even higher levels of institutional and interpersonal trust. While there was widespread support for the Swedish strategy among the wider population, criticisms of it, in various settings, were considered to be disloyal, and critics, including highly renowned scientists, were discredited as 'hobby-epidemiologists' (Brusselaers et al., 2022).

In June 2020, the Swedish government established an independent Corona Commission to evaluate the responses of the Swedish government, its agencies, regions and municipalities to the pandemic. The Commission released several reports of its assessment, with a final report published in early 2022 (Swedish Corona Commission, 2022). The Commission found that the choices made in terms of disease prevention and control were fundamentally correct, as they allowed citizens to retain their personal freedoms. However, the measures taken were too few and too late. Sweden should have opted for more rigorous and intrusive disease prevention and control measures in February/March 2020. In particular, the government should have provided clearer information and instructions on home-quarantining for those returning from their winter sports breaks abroad, in, for example, Italy and Austria. Testing instructions and guidance on where and how to get tested should have been provided. Furthermore, clearer rules of conduct should have been issued rather than allowing citizens to interpret themselves, for example, whether a trip requiring the use of public transport was necessary or not.

### COVID-19 and inequalities in Sweden

The COVID-19 pandemic highlighted, exposed and exacerbated existing structural inequalities, including the unequal distribution of resources and delivery of healthcare that result in harmful effects for certain vulnerable groups. For example, the ability to practise physical distancing depends on factors such as household dynamics, social capital, and financial resources (Dodds et al., 2020). Studies have also demonstrated that factors such as lower socio-economic status (lower levels of education and lower

income) were associated with greater risk of infection and severe COVID-19 in various countries, including Sweden (Nordberg et al., 2022; Rollstone & Galea, 2020; Magesh et al., 2021; Fernández-Martínez et al., 2022; Folkhälsomyndigheten 2021).

The Swedish Corona Commission's final report (2022) acknowledged the need to implement measures for the population as a whole, rather than for certain groups, in future health crises. For example, a recommendation to work from home can only be followed when an individual has a job that allows this, whereas those in health and social care, customer service and education are unable to follow such a recommendation. A person who is dependent on public transport is unable to avoid using it to go to work and those living in a multi-generational household are unable to avoid meeting their parents or grandparents when returning from work. Those in the educated middle-class demographic hence were in a better position, due to pre-existing social circumstances, to follow the recommendations of the PHAS than others.

Ethnic minority communities in various countries, such as the United Kingdom (UK), United States (US), and Sweden were overrepresented in terms of COVID-19 mortality (Dodds et al., 2020; Ohlin, 2020). For example, Somali- and Iraqi-born immigrants in Sweden were overrepresented in terms of COVID-19 infection, ICU care and mortality (Ohlin, 2020). Structural factors were thought to have contributed to the infection rates, such as overcrowded housing, multi-generational housing, limited opportunities for working from home, and dependency on public transport (Hansson et al., 2020). Language barriers and limited access to information were also considered to be factors which contributed to increased infection rates in ethnic minority communities (Ekblad et al., 2021). Another group that was disproportionately affected was the elderly; systemic shortcomings in Sweden's elderly care, coupled with inadequate measures imposed by the government and agencies, contributed to the country's high death toll in nursing homes (Swedish Corona Commission, 2022).

Another suggested consequence of pandemic interventions was the suspected rise in isolation and loneliness, mental illnesses, especially among those who did not have a social network. In their cross-sectional, web-based survey, McCracken et al. (2020) found significant levels of depression, anxiety, and insomnia in Sweden, at rates of 30%, 24.2%, and 38%, respectively. Whether someone experienced COVID-19 symptoms along with specific health and financial worries related to the pandemic were important predictors of these outcomes. Contrary to this initial study, however, Flodin et al. (2023) found that the prevalence of common mental disorders in primary care settings

*decreased* during the initial phase of the COVID-19 pandemic in Sweden. The onset of the pandemic and the containment strategies were highly correlated, limiting strong conclusions about whether policy related to restrictions had any effects on mental health. Specifically, the authors found no evidence of associations between school restrictions and the prevalence of care for common mental health disorders.

COVID-19 emerged in the middle of Chen et al.'s (2022) ongoing two-year follow-up examination of the Study of Adolescence Resilience and Stress, and as such, they had the unique opportunity to use the COVID-19 outbreak as a natural experiment to study the impact of COVID-19 on 15-year-old adolescents in Sweden. They found that adolescents reported higher levels of stress and psychosomatic symptoms and lower levels of happiness at follow-up compared to baseline. However, these changes occurred to a similar degree in both the control group and the group that was studied during the COVID-19 pandemic, and likewise, the latter group showed no deterioration in peer relations or relations with parents versus controls.

### One Health

The spread of zoonotic viruses has caused several international crises since the early 21st century. Examples include SARS, H1N1 and H5N1 (swine flu and bird flu respectively), MERS, Ebola, Zika and COVID-19. During the COVID-19 pandemic, an mpox (monkeypox) outbreak, a zoonosis, was identified in May 2022 (WHO, 2023d). It is estimated that in the last five decades the outbreaks of new infectious diseases due to zoonotic viruses have averaged nearly one every year (Sironi et al., 2022). Climate change, deforestation, intensive livestock farming and wildlife trade, largely driven by human activities, have exacerbated zoonotic risks (Leal Filho et al., 2022).

These public health crises, especially the COVID-19 pandemic, have caused governments and scientists to recognise the need for greater interdisciplinary collaboration to prevent and control zoonoses. The term One Health was proposed as a concept to help foster interdisciplinary collaboration in the early 2000s (Gibbs, 2014). OH aims to 'sustainably balance and optimise the health of people, animals and ecosystems' (OHHLEP, 2022: 11). It acknowledges that the health of humans, domestic and wild animals and plants, and the wider environment[ii] are interconnected and interdependent and the aim of the approach is to mobilise multiple sectors, disciplines and communities at varying levels of society. Health cannot and should not be conceived only in relation

to human beings and this thinking represents an attempt to move away from an anthropocentric view of humans as the central element of existence (Sironi et al., 2022).

Within Sweden, there has been a long tradition of working with OH. However, in a study conducted by Humboldt-Dachroeden (2021), she found that none of the Swedish government agencies she studied had implemented a strategy for OH. While the interviewees had generally expressed support for the concept, there was confusion regarding how to translate the concept into concrete practices. In an effort to investigate the current status of the OH approach in Sweden, Pöllänen et al. (forthcoming) analysed 18 policy documents and four internal documents from meetings that took place during the pandemic with the Zoonotic Council and found that specific mention of OH could only be found in relation to work to prevent antimicrobial resistance (AMR), zoonotic risk and threat detection. While Sweden has integrated the OH approach in strategic plans concerning AMR, it has not embraced a wider OH approach that would include a concern for the health of animals and the environment beyond risk minimisation for zoonotic diseases.

There are some who believe that the OH conceptualisation is simply not radical enough, and does not adequately challenge the established hierarchies among humans, animals and the environment, meaning that it currently remains anthropocentric (Sironi et al., 2022; Cañada et al., 2022). For example, Sironi et al. (2022) state that conventional OH works within the parameters that are set by industrial animal agriculture by enhancing biosecurity and monitoring pathogens. However, a bolder and more radical OH philosophy would recognise that animal agriculture imposes terrible suffering on the animals themselves, as well as contributing to biodiversity loss and climate change. In another study on antimicrobial resistance and the OH approach, it was found that animal health was recognised as important in two ways: animals as ‘a resource for human health’ or as ‘potential carriers of diseases’. Therefore, animal health is only a security issue, as threats to animal health may cause human health risks (Kamenshchikova et al., 2019: 310; Cañada et al., 2022).

The relatively deviant Swedish response to the COVID-19 pandemic (at least as it is perceived by some), its arguable shortcomings in protecting vulnerable groups in society and its suggested disjointed approach to the inclusion of environmental and animal health in its national strategy hence motivates a more thorough examination. The aim of the present work is thus to better understand the perception and experiences of some of the country’s citizens and experts in the context of shared and effective governance, joint

responsibility and accountability, communication, collaboration, coordination, and capacity to understand and address co-benefits, risks, trade-offs, and opportunities for equitable and holistic solutions. Inclusiveness across all segments of society (such as by gender, ethnicity, indigenous peoples, and disadvantaged and marginalised groups, as well as non-human animals and the environment) was core to the approach.

## Methodology

One specific aim of this report is to gain an increased understanding of how citizens, experts and young people perceive the Swedish national COVID-19 strategy, through the use of group interviews. Furthermore, through their experiences, this report offers several policy recommendations on how to improve future epidemic and pandemic responses. Three group interviews were held, and the contents of the interviews were analysed using inductive reflexive thematic analysis. This section presents how the interviews were held, which questions were asked, how the themes were selected, as well as the limitations of this report.

### Group interviews

This report is based on three different semi-structured group interviews; each group was made up of one of the following demographics: citizens, experts, and youth panels, and the interviews were conducted over Zoom. Each group interview was held in Swedish, lasted one to two hours and involved four to six participants. Each interview began with a small introduction of the wider PERISCOPE project this report is a part of, and the aim of the report. The participants were recruited using convenience sampling, through emails and phone calls. For the citizen group, participants who had been involved in pandemic-related care and counselling activities were invited. The experts were invited based on their field of work, focusing on those working with the environment, human and animal health. These included those working for the government at different levels. For the youth group, the investigators invited individuals between 19 and 26 years of age, and who were living in Sweden during the pandemic.

When recruited, participants received an information sheet with the questions that would be asked and in what context the interview findings would be used. Due to the limited timeframe available for the interviews, we believed a convenience sampling method to

be the most appropriate, although this may have resulted in the participants not coming from very diverse backgrounds. This is discussed further in the Limitations section. For this report, the interviews were manually translated into English and anonymised by the authors.

### Interview questions

Selected research questions were created in order to gain an understanding of how participants perceived the handling of the COVID-19 pandemic in Sweden. Due to time limitations for certain group interviews, not all questions were asked of the participants. However, interviewers did ensure that the participants were able to contribute their thoughts and experiences on three key aspects: their own personal experiences during the pandemic; their perception of the handling of the pandemic; and how, if at all, the pandemic had impacted on their views on and interactions with animals and the environment. The main interview questions for each group that were prepared for are listed in Table 3.

The groups that were interviewed could be categorised into two different camps: civilians (youth and adults) and experts. The civilians were asked questions related to their own experiences, whereas the experts were asked questions related more to their profession and/or the agencies they worked at. There were no questions regarding sensitive areas such as ethnicity, political opinions, religious or philosophical conviction, membership of a trade union, health, sex life, sexual orientation, genetic information or biometric information.

| Citizens | Experts | Youths |
|---|---|---|
| 1. Do you believe that the COVID-19 pandemic and the response to it has affected the population unequally?<br><br>2. What are your views on how our relationship with other animals and nature might have been at the root of this pandemic?<br><br>3. Should we include nature's health in different ways than we do today?<br><br>4. How do you perceive how Sweden dealt with the pandemic in different phases and at different levels of society, such as the government, the authorities, the regions and the municipalities?<br><br>5. What are your perceptions on whether or not Sweden did enough to protect the elderly, which the Swedish Corona Commission has criticised Sweden on? | 1. Were your profession and your organisation's main areas of interests impacted by the handling of the pandemic?<br><br>2. How have decisions regarding the pandemic been taken from a One Health perspective?<br>a. Have the decisions been taken at the right level?<br>b. Have all relevant voices been heard?<br><br>5. Are there areas of improvement for the future, on a local, national and global level? | 1. What are your experiences on how decision-makers and government agencies handled the pandemic?<br><br>2. Who did you trust the most during the pandemic?<br><br>3. What are your views on the role that facts, data and evidence played in the communications regarding the pandemic by decision-makers and government agencies?<br><br>4. What was the role social media played in your lives during the pandemic?<br><br>5. What are your views on the role social media played in the spread of information and mis/disinformation about the pandemic?<br><br>6. What role has the health of animals and nature played during the pandemic? |

**Table 3. Questions asked in each group interview**

### Reflexive thematic analysis

The content of the interviews was analysed using reflexive thematic analysis (RTA). RTA is a qualitative method, understood as identifying, analysing and reporting patterns within the data using the investigators' active roles in knowledge production and their interpretive analysis of the data. The themes identified and selected have less to do with the number of times they were raised by the participants, but rather were identified based on whether they had an extensive or profound impact in understanding the topic and aim of this report. The data were interpreted and organised around core commonalities or themes that the investigators deemed to be most relevant based on the aim of the report (Braun & Clarke, 2006; Braun & Clarke, 2019; Byrne, 2022).

The participants' experiences and stories, as well as second- and third-hand experiences that they talked about, were at the forefront of this thematic analysis. Four main steps were taken to identify and organise the themes: 1) familiarisation with the data; 2) generating initial core themes and sub-themes; 3) interpreting and systematically categorising the content of interview transcripts into themes; and 4) reviewing. While one investigator initially organised and analysed the data into the themes, two other investigators reviewed the data and analysis through an open discussion regarding the differences in the interpretation of the data. As this report aims to discuss specific narratives experienced by the participants, an inductive, rather than a deductive, approach was used. That is to say, the data were observed and different patterns were recognised through various interpretations within the data, before a general conclusion was reached. The background and previous research were fundamental in organising and understanding the various experiences and narratives the participants discussed during the interviews.

Based on the aim of this report, three core themes were identified with two to three sub-themes in each theme. The first theme is first-hand perceived experiences of the participants. The second is perceived management of the government and government agencies responsible for the handling of the pandemic. The third theme is how the participants perceived the human-animal-environment nexus. The themes and sub-themes were coded and analysed manually.

### Themes

As previously mentioned, the themes are organised into: 1) perceived experiences of the pandemic; 2) perceived management of the pandemic by the government and its agencies; and 3) perception of the human-animal-environment nexus, all in accordance with the aim of the report and with two to three sub-themes under each. The organisation of the themes and sub-themes is given in Table 4. The data used, through the use of quotes, the interpretation of the data, and how they relate to each theme are presented, analysed and discussed in the next section: Results and discussion.

| Perceived management of the pandemic by the government and its agencies | Perceived experiences of the pandemic | Perception of the human-animal-environment nexus |
|---|---|---|
| • Trust in public institutions<br>• Communication<br>• A disjointed strategy | • Variation of experiences based on: socio-economic status and age | • Lack of knowledge<br>• Increased appreciation of nature<br>• Anthropocentrism |

Table 4: Themes and sub-themes that were analysed further

### Limitations

It is important to acknowledge the limitations imposed by the method and in the data used for this report. Firstly, the interviewees selected for this report did not and could not fully represent the views and experiences of the entire Swedish population. Therefore, this report does not aim to generalise the experiences and views of the Swedish population, but rather to understand how the participants selected for this investigation viewed the Swedish COVID-19 strategy and how they were impacted by them. It is also important to note that the background of the participants, particularly in the citizen and youth groups, would likely be considered homogenous in comparison to standards set by, for example, Kitto et al. (2008) and Mays & Pope (2000). This might have limited the breadth of responses given to the research questions by omitting aspects of the pandemic that were only relevant to groups not represented in the sample.

## Results and discussion

In this section, the different sub-themes selected based on the interview data are presented and discussed under each of their respective themes.

### Perceived management of the pandemic by the government and its agencies

Three main sub-themes were identified in terms of how the participants perceived the management of the pandemic by the relevant actors: 1) individual responsibility and trust in public institutions; 2) lack of clear communication; and 3) a disjointed strategy. The participants mainly referred to the government and the PHAS when speaking about the COVID-19 strategy.

#### *Individual responsibility and trust in public institutions*

Many of the participants in all three groups described the freedom individuals had to make their own decisions about whether to follow state recommendations. One participant in the youth group mentioned that within their own social circle, there were some who did not follow the recommendations, such as advice on physical distancing. On the other hand, there were also people who were not willing to meet anyone during the active pandemic period.

As found in several studies, many of the participants in the citizen and youth groups conveyed very high trust for government agencies, PHAS and their experts. The participants in the expert group interview also noted that Sweden's population does have high trust in public institutions. The only objection to the strategy was that certain groups had to bear the largest burdens during the pandemic; this reservation was voiced by a participant in the youth group and the point was made in reference to those living in elderly homes or in housing for adults who need special services. Some participants also acknowledged the difference in the Swedish COVID-19 pandemic strategies compared to other countries.

> *Generally, I have had high trust for the government agencies, but I have heard the criticisms from others in other countries nearby on how Sweden has handled the pandemic.*
>
> *- Participant in the youth group interview*

The criticisms the participant above mentioned included the lack of recommendations around the use of face masks and COVID-19 tests and the lack of mandatory stipulations relating to these. Some of the participants in the youth group interview thought that Swedes felt the need to defend the Swedish strategy and express to others that they believed in the government and its agencies rather than agreeing with their criticisms.

The majority of the participants in the group interviews indicated that they trusted the government and its agencies and followed the recommendations set by them. Therefore, as some literature has found, institutional trust among these participants was imperative in ensuring that the recommendations were followed. As also previously noted, criticism of the Swedish strategy was considered to be disloyal, as some participants noted that they felt the need to defend Sweden's strategy when it was criticised by others. There were some reflections regarding some aspects of the Swedish pandemic strategy, for example, in the observation that certain groups had borne the largest burdens during the pandemic.

*Lack of clear communication*

One participant in the youth group believed that the PHAS was transparent; the decisions taken seemed to be based on the scientific evidence that was available, and communication was the foundation of the strategy. Meanwhile, another participant in the same group felt that there should have been clearer directives from the government in the form of guidance on how to behave. One even noted the discrepancy in the recommendation around the use of face masks, when all the evidence pointed to masks being effective, and the PHAS not following the scientific evidence.

During the citizen group interview, one participant stated that their elderly parent had been unable to fully access and absorb information about the pandemic as information was disseminated on a digital platform. A participant in the youth group also pointed to the spread of rumours on social media platforms, through videos posted of people clubbing, for example. Social media also became an outlet for the spread of anti-vaccination sentiment. That is to say, digital illiteracy was an issue during the pandemic, leading to an inability to access information and increasing the risk of falling victim to the spread of dis/misinformation.

Additionally, one participant in the youth group interview pointed out that while there was a lot of discussion surrounding the need to prepare for the next pandemic, there was no debate or discussion on what exactly this would entail. Another participant in the expert group interview echoed a similar sentiment:

> *You should listen to the experts, but something also needs to be done. It's like forgetting that pandemics and risks of contagion exist. What is happening right now is that you pay the affected farmers when there is an outbreak of bird flu or salmonella, and it's very costly for the state. But there is no money being spent to prevent these outbreaks, which would cost less in the long-term.*
>
> *- Participant in the expert group interview*

Some participants felt that the PHAS and the government set clear guidelines and recommendations and were transparent with the reasoning behind their recommendations. Other participants felt that some of the recommendations that were given could have been clearer, to provide better guidance on how to behave. Another issue that was raised was the lack of clear communication and guidelines on how to prevent future pandemics. There were discussions identifying that something needs to be done, but there were no concrete directives on what changes should and would be made for the prevention of future outbreaks.

### *A disjointed strategy*

While there were individuals in certain groups who were able to follow the recommendations to stay at home, limit in-person interactions, and work from home, there were also individuals who were unable to do so, whether due to their work requiring them to be on-site or housing that was too crowded and/or small. For example, if, due to economic hardship, their only option was to take employment that could not be undertaken via an online platform, their exposure to the virus was necessarily higher than the exposure experienced by someone who was able to work online. Additionally, some of those who were already vulnerable became even more vulnerable when the recommendations included staying at home. One example given by a participant in the citizen group was of domestic violence victims.

*[…] We talk about how it [the pandemic and lockdown] can impact differently in different groups so something that we have been very attentive to is domestic violence, for example, as a topic about vulnerable groups that are even more vulnerable when there are tight social spaces and so on […].*

*- Participant in the citizen group interview*

This necessarily meant that certain groups bore a heavier burden than others, whether they were working in customer service jobs or healthcare, with higher risks of exposure to the virus or whether they were further exposed to violence when isolating with their abuser. This is a criticism that has been vocalised by the Swedish Corona Commission, and internationally, regarding lockdowns, staying at home and physical distancing. This lack of support and disjointed resource management was also mentioned in reference to people who worked in elderly care homes during the pandemic. Employees needed to ration face masks and hand sanitisers as they were not available in sufficient quantities. Employees at care homes were overworked, exposed, and there were simply not enough resources for a safe and sustainable working environment.

One participant was frustrated over the lack of governmental support on any level (municipal or national), to help to ensure that individuals of varying socio-economic status with differing preconditions would be able to comply with the recommendations they had set. This has been a recurring topic of discussion, as both the experiences of the participants and studies have shown that those of a lower socio-economic status were disproportionately affected by the COVID-19 virus. Therefore, socio-economic status is a factor that needs to be taken into consideration for pandemic and other crisis strategies.

Thus, it can be argued that some of the participants observed a disjointed strategy implemented by the state. The strategy did not take into consideration the whole of society and how to best protect them. For example, since employees in the healthcare sector could not work from home, they should have been provided with proper resources and equipment to limit their exposure to the virus.

### Perceived experiences of the participants

In this category, two main sub-themes were integral to the experiences of the participants: the varied experiences of the pandemic based on 1) socio-economic status

and 2) age. The participants stated that they believed that the pandemic had affected different groups unequally, based on their income, socio-economic status, and the age group they were in.

*Socio-economic status*

One topic that the participants in all groups discussed was the impact of the pandemic based on an individual or group's socio-economic status. For example, one participant in the citizen group stated:

> *It is very much a class issue, with those working from home in a villa can enjoy sitting on the balcony when it's summer, or go down to the summer house to have a longer holiday, and it's just a bonus for them. But it's not necessarily the case if you don't have a job where you can work from home or if you don't have that kind of space at home, living in a cramped apartment. So, this was very much a class issue and had very unequal effects in terms of age too.*
>
> *- Participant in the citizen group interview*

For example, as we have discussed above, those with the opportunity to do so, were able to follow COVID-19 recommendations to work from home, but there were many in different professions, such as healthcare and customer services, who were unable to do so. Furthermore, several participants in all three groups noted that even if an individual could work from home, many had to work in small or limited spaces. Some work environments were more impacted than others, such as the food services industry, and many people became unemployed due to companies cutting costs. Some participants stated that they knew people who had not been able to, personally or business-wise, 'survive financially', and noted the lack of support from the government for those who were most vulnerable, such as low-income individuals and families.

One participant in the expert group interview discussed the disproportionately high numbers of migrants who died from the COVID-19 virus, especially those who were working-class who were unable to work from home.

*[It was] a structural difference in society that we don't [seem to want to] talk about. [...] [The government agencies said] yes, it's good if you work from home, but for these people they had no choice, they couldn't work from home. [...] You say yes, it's great that you can work from home, those that have Zoom and Teams. But those who drive taxis and the buses, and those who worked here and there, and in elderly homes, they couldn't work from home, and they couldn't take the buses, because you needed someone to drive those buses who would become exposed.*

*- Participant in the expert group interview*

The participants' discussions are aligned with the findings in various Swedish and international studies on the disproportionate effect of the pandemic. As previously mentioned, the Swedish Corona Commission stated that the educated middle class were better able to follow the recommendations of the PHAS. In other studies, those of lower socio-economic status are identified as having been associated with greater risk of infection and acquiring severe COVID-19.

The existing structural inequalities resulted in harmful effects on those who did not have the opportunity to work from home, physically distance from others, or have access to personal protective equipment. For future pandemics, governments need to ensure that infrastructure and equitable resource management are improved. Pandemic strategies need to take into consideration what all of society can do, as well as ensure that protection is given to groups who are unable to follow recommendations, to limit the spread of infection.

### *Age*

The difference in how COVID-19 restrictions impacted different age groups between youths (upper-secondary school and university), adults, and the elderly was a common topic of discussion brought up by the participants. One participant in the citizen group interview brought up the differences in their experience as an adult in comparison to their child. While the participant and their partner were gladly working from home, their child felt robbed of the opportunities that they hoped to experience as part of graduating from upper-secondary school:

> *When the pandemic broke out, we had one of our children living at home at the time and in [their] last year of high school and it was really hard for [them] socially not to be able to spend time together, not to have a proper graduation party […]. You feel a bit robbed [...] of this nice conclusion that they had looked forward to for many years. Meanwhile my partner and I thought it was incredibly restful and have also been very privileged to be able to adjust and work from home.*
>
> *- Participant in the citizen group interview*

This was a common topic discussed by participants in the youth group interview. One participant in this group recollected their upper-secondary school experience, having had most of their classes online:

> *During the period we had online learning, people relaxed and took shortcuts. You just took attendance [and left the online class]. Grades went down during the pandemic. People didn't take it seriously. The students didn't receive help from the teachers in the same way [as physical learning] as they sit at home and try to explain something over the camera and microphone. When schools opened up again, you felt that you were behind.*
>
> *- Participant in the youth group interview*

This was a similar sentiment shared by a participant in the citizen group interview, whose child was in secondary school during the pandemic.

> *Regarding learning and homework, you don't get anything when you're just trying to figure things out on a screen without guidance from a teacher in the room, and if you're not used to working with your own drive either… So in the past you might have gotten used to performing well by just attending. [...] But you can't get away with it now. You have to listen to the lesson online, but get no support.*
>
> *- Participant in the citizen group interview*

One participant in the youth group interview reflected that they had lost more than two years of their youth, and that it had affected them, and many other people, more than they thought or believed it would. A different participant in the same group considered the loss of social networks, such as parents, experienced by young people who had

started university and/or moved away from home before the start of the pandemic. As they were just learning to manage their own home, they felt unprepared and did not, for example, have the items they needed to function well at home, while the family home would have been well set up depending on its socio-economic status. This participant was recollecting the panic-buying that ensued at the beginning of the pandemic period, that created shortages in toilet paper and non-perishable food items.

This loss or lack of social networks was an issue across age groups. For example, one participant from the citizen group who worked in a social setting mentioned that it was difficult for those who were alone when the pandemic began.

> *[...] people who already can't get to things and who now also have not been able to receive visitors, so very difficult of course. [...] And of course difficult also for people who may not know someone who can go shopping for them or solve these practical things.*
>
> *- Participant in the citizen group interview*

Furthermore, those starting university during the pandemic period were unable to experience an induction period organised by the university to meet new friends and create social networks. Another participant in the youth group stated that they believed it was important for young people's social development, especially for those under 20, to be surrounded by a social group, which was not really possible during the pandemic.

Participants in both the citizen and youth groups also raised the hardships experienced by the elderly, who were especially encouraged and recommended to isolate. One participant in the youth group described their grandparent not leaving their house for a whole year and not meeting anyone in that time. There are many people who have still not begun to socialise as they did before the pandemic began. This is a long-term impact they believed the government and its agencies have not supported the elderly to recover from.

According to many participants in the citizen and youth groups, the pandemic and related measures have negatively impacted the youth and the elderly the most. For students, online learning was difficult and demotivating, especially for those in secondary and upper-secondary school. For first-time university students, it was difficult for them to live alone and without an established social network nearby. Furthermore, there was also a sentiment that there was a loss in the celebration of milestones, a diminution in people's

social skills and impacts on mental health. As there were strong recommendations for the elderly to isolate, it was difficult for them to socialise and meet others for the duration of the active pandemic. In future scenarios, governments should ensure that resources are allocated to provide support to those who are vulnerable and in need.

### Perception of the human-animal-environment nexus

Three main sub-themes were identified under this theme: 1) lack of knowledge; 2) increased appreciation of nature; 3) anthropocentrism.

#### *Lack of knowledge*

When all three groups were asked whether they had previously heard of the concept One Health, only the participants in the expert group had heard of it and knew what it was. Interestingly, when asked about the One Health concept, one participant in the expert group interview stated:

> *We see One Health as not enough, but rather we need to talk about One Welfare. To discuss how humans, animals and nature could feel good in terms of all aspects of welfare.*
>
> *- Participant from the expert group interview*

Furthermore, there was some confusion regarding the relevance of the health of the environment and animals in relation to the pandemic, as some participants in the citizen and youth groups were unsure how to answer the question: *What role has the health of animals and nature played during the pandemic?* The answers to this question varied from participant to participant. One participant in the citizen group mentioned taking better care of houseplants while working from home while participants in the youth group brought up the culling of mink in a neighbouring country, Denmark, due to fears of a COVID-19 mutation, as well as the wet markets in Wuhan, which are believed by some to be the starting point of the COVID-19 pandemic.

There seems to be a lack of knowledge and only some limited understanding of how the relationship between humans, animals, and the environment can be linked together in policy discussions, as demonstrated by some of the answers provided by the participants in the citizen and youth group interviews. The experts seemed to be more aware of the

One Health concept and the interdependent relationship the health of humans, animals and the environment have on each other.

*Increased appreciation of nature*

One common discussion point when asked about the environment and animals which was raised by participants in all groups was the increased appreciation of nature people had during the pandemic. In addition, there was decreased human activity as people were staying at home, leading to a decrease in greenhouse gas emissions, albeit short-term. Participants did, however, acknowledge that emissions increased again as societies opened up.

The participants in the expert group interview discussed how there was an immense surge of people wanting to be out in nature. However, this caused concern regarding littering and pollution, as well as overcrowding during the pandemic. One participant, who worked for an environmental government agency, discerned that the agency was not prepared for the surge in visitors to nature areas and forests, and there was a lack of resources and management to deal with the problems, relating, for example, to parking issues or waste disposal management. The same participant also noted that there is a need to develop and share knowledge regarding the use of nature as a resource:

> *There is a need to develop and spread knowledge – we may not be able to meet the elderly but maybe you can meet them outside. That the outdoor environment is a resource, and it's a fantastic resource. More knowledge, and if there is a new pandemic it would mean that we may not be able to meet inside, but we could meet outside while staying healthy.*
>
> *- Participant in the expert group interview*

This enthusiasm was also something that other participants in the citizens group interview noted:

> *I live in [redacted] and there we have a nature reserve [redacted] which is very large and there was a record number of people there and suddenly there were people everywhere. [...] So you would seek out the nature reserves so you can see there is an awakening and with the biodiversity, there is something positive about it all.*
>
> *- Participant in the citizen group interview*

The appreciation for nature and greenery in everyday life which gave them a newfound fulfilment was also something one participant in the citizen group noted, as staying at home necessitated a slower lifestyle:

> *I just think about what I experienced in myself, it was how well I took care of my houseplants at home. So my balcony kind of burst forth with flowers, it was incredible and it gave me so much to water my flowers and take care of them and that's something that you don't really have time to do when you're moving around and different places in the city and between cities, together with the time pressure.*
>
> *- Participant in the citizen group interview*

Using nature as a resource was a recurring topic; using nature and the outdoors as a way to meet family members during the pandemic, as well as simply appreciating the nature that Sweden has to offer. The slow pace of life during the pandemic, for those who were able to work from home, as well as the isolation of staying at home, seems to have caused a newfound appreciation of nature for many of the participants. This may have had a positive knock-on effect for participants' wellbeing, and created a healthier relationship with nature which allowed for a greater understanding of the need for a healthy environment and easy access to nature.

### *Anthropocentrism*

The concept of anthropocentrism was discussed by one of the participants in the expert group interview explicitly:

> *The virus comes from an animal, then how could it be that humans become infected? And the longer the pandemic continued, the more anthropocentric it became, becoming more about how I and those near me will be affected and so on, going from the collective plane to the individual plane.*
>
> *- Participant in the expert group interview*

However, it is important to note that throughout the discussions between the participants within all groups on this topic, there was an underlying question: 'What can the environment and nature do for us (humans)?' rather than a focus on what we can do to improve the health of the environment and animals, together with humans. For example,

in a discussion with the experts, while there was mention of the worry of littering that may occur with the increased presence of humans, this was overshadowed by the importance of humans using nature as a resource, primarily for the benefit of physical and mental health, and the importance for humans to have easy access to nature especially in urban areas.

The central role and the space occupied by humans on earth is also something that was mentioned. A participant in the citizen group interview reflected on the amount of space humans take up, especially in urban areas, when asked how they view the relationship of humans with animals and nature:

> *[...] something that became very tangible, at least my experience, was animals in the city. I live right in the middle of central [city] and to hear birds chirping, to see butterflies, to see a lot of squirrels and birds. It was just like nature came alive, when there was not so much traffic and noise and it was something that felt very powerful in some way. It was such a strong response in this that we take so much space with all our stuff, all our sounds, all our machines, and the animals are kind of pushed back in some way [...], and also the way that we look at animals as a society, like we look at animals in very different ways depending on what kind of relationship we have with them.*
>
> *- Participant in the citizen group interview*

Similarly, another topic of discussion that was raised by the experts was the use and treatment of animals for the purposes of human consumption. One participant in the expert group mentioned that children need to learn that humans are just one of the many animal species that exist. They also discussed the disconnect among children in terms of their knowledge of the connection between food and livestock:

> *If we are to teach about pandemics early on, then we also need to teach that humans are one animal species among many, and we all impact the environment. What children learn about animals nowadays are often about dogs and cats that they might have in their family, and not about the animals you eat. They don't see that, but instead they are hidden in large animal factories. [...] It is wrong how children learn about animals today, that can be much better. [...] Right now, there are many children who have never seen a pig, or a chicken, or a cow and don't understand that a pig is pork that you eat.*
>
> *- Participant in the expert group interview*

Some of the discussions between the participants about the health of animals and the environment, together with human health, assumed that the health of animals and the environment can be a resource for humans. While one participant reflected upon the amount of space humans take up to the detriment of other animals, many people's perspectives seemed to be more anthropocentric. Therefore, more awareness needs to be created about the human-animal-environment nexus, and how zoonotic diseases are spread. Furthermore, a less anthropocentric view of human, animal and environmental health should be taken into account during decision-making processes in various areas, which may have a ripple effect in society.

## Conclusion

This report aimed to understand perceptions of Sweden's COVID-19 pandemic response through group interviews and analysis of participants' responses using reflexive thematic analysis. Three main themes were identified: perceived experiences of the pandemic; perceived management of the pandemic by the government and its agencies; and the perception of the human-animal-environment nexus. Relevant sub-themes were then organised under each theme: age and socio-economic status; trust in public institutions, communication, and a disjointed strategy; lack of knowledge, increased appreciation of nature, and anthropocentrism, respectively.

Many of the participants acknowledged that not everyone experienced the pandemic in the same way. The young and the elderly, for example, were thought to have been more negatively impacted by the pandemic and its measures, than the middle-aged. Socio-economic status was also mentioned, as it was perceived that those with a lower socio-economic status were more negatively impacted by the virus and the measures taken in response.

Generally, the participants indicated that they trusted the government and their recommendations for handling the pandemic. However, they believed that there were those who bore a larger burden, namely people who were unable to work from home or physically distance. There were some participants who believed that the relevant actors were able to communicate the recommendations and the reasoning behind them, while there were those who thought the recommendations could have been clearer, leaving

less room for interpretation. In addition, there was a belief that the Swedish strategy did not take the whole of society into consideration, and that some vulnerable groups were left unprotected, leading to a disjointed strategy.

Finally, while the COVID-19 virus is a zoonotic disease, there was limited knowledge about how the health of animals and nature played a role during the pandemic. That is to say, there was a lack of deep understanding behind the potential root causes of zoonotic diseases, outside of the expert group. The participants expressed some understanding of the importance of the environment and nature in the context of physical and mental health during the pandemic, which allowed people to move around freely and meet and socialise with others from a distance; however, many of the views the participants had were anthropocentric and asymmetric; how can the animals and environment benefit humans, rather than how can human, animal and environmental health be mutually beneficial? There was a lack of knowledge about how best to harmonise the different health considerations, for example through the One Health perspective.

While many of the participants found Sweden's handling of the pandemic to be somewhat satisfactory, they felt that there were key areas that could have been improved. These included ensuring that all groups of society are included in consideration of recommendations and restrictions, and making sure that key support and necessary resources are available to those who are particularly vulnerable. There also needs to be a deeper understanding of the relationship between humans, animals, and the environment, how zoonotic diseases emerge, and how best to prevent them rather than solely focusing on managing them when they spread.

### Future recommendations

From the findings of this report, there are nine main policy recommendations aimed at preventing the spread of future infectious diseases and improving epidemic and pandemic responses.

*Governance*

- Ensure the improvement of infrastructure and equitable resource management for future crises such as epidemics and pandemics
- Ensure that recommendations are clear and consistent when communicated to the wider public

- Place more emphasis on prevention rather than only on response.

*Inequality*

- Create pandemic strategies that take into consideration what all of society can do to limit the spread of infection
- Ensure that protection is given to those who are unable to follow recommendations to limit the spread of infectious diseases
- Ensure that support, whether that be economic or social, is given to those vulnerable and in need.

*One Health*

- Create more awareness of the human-animal-environment nexus, and the spread of zoonotic diseases
- Take a less anthropocentric view of human, animal and environmental health issues during the decision-making process, which may cause a ripple effect in society
- Place a heavier emphasis on the importance of concepts such as One Health, and make it more accessible and easier to implement in various sectors and at various levels of governance.

## CASE STUDY 4

# Towards Optimal Multi-Level Governance

# CASE STUDY 4: Towards Optimal Multi-Level Governance

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## Executive summary

*After presenting an overview of key contextual factors during the emergency phases of COVID-19, we will introduce considerations about the methodology and the research approach that framed our case study and the recommendations.*

We will then present our analysis according to the themes from the key findings of our research activities. Among them are the need for stronger, well-managed coordination between the different stakeholders and bodies involved, both at a subnational and supranational level, as well as the need to strengthen science-based policy options. Finally, we will summarise the main challenges emerging, with the intention of identifying wide-ranging health policy recommendations that could benefit the countries involved, and can be summarised as relating to:

- Improving communication and coordination for pandemic preparedness and responsiveness between European Union (EU) Member States and EU agencies
- Building connections between the EU and other countries in support of surveillance, capacity building and strategy development
- Strengthening health-science-policy interfaces and their linkages between EU and country levels
- Addressing One Health challenges
- Doing more to understand and tackle the diverse problems of vulnerable groups

***Disclaimer**: This case study is a neutral reflection of the discussion which has taken place and opinions expressed in this document do not necessarily represent the views of all participants involved in the activities, nor of the Federation of European Academies of Medicine (FEAM).*

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## Introduction

With the advent of the COVID-19 pandemic, identifying better policy options in public health has become a priority. Health policy proposals – at the national, European, and international level – have embraced a broad series of topics and strategies, from the mitigation of the actual impacts of COVID-19 to the need to implement preparedness and crisis management strategies for future pandemics. European institutions, policy-makers, national governments, researchers from academia, and other stakeholders have been working to develop and implement objectives for stronger, science-based, and more comprehensive policy responses. The common ground which has formed the basis from which they have worked is that COVID-19 has resulted in a period of redefinition of public policies and the need to articulate synergies in the responses from institutions and the different countries in Europe. One of the main issues has been to identify how COVID-19 policy measures were implemented at different governance levels and how they differed across Europe. Achieving these objectives with a view to supporting more robust policy responses going forward may be challenging and requires further collaboration between health experts and decision-makers, two of the key groups engaged with COVID-19 response. This is the focus of this case study on multi-level governance, which is based on qualitative research conducted by FEAM between February 2023 and April 2023, through two online activities: a participatory workshop and seven interviews with health decision-makers.

FEAM represents a group of National Medical Academies, and its membership network is composed of 23 National Academies of Medicine, Veterinary Science, and Pharmacy from 19 countries of the World Health Organization (WHO) European region. FEAM's mission is 'to promote cooperation among its members, encourage them to articulate a common position on European relevant medical themes (concerning human and animal medicine, biomedical research, education, and health), and bring their advisory support to the European authorities'. Moreover, FEAM aims 'to underpin European biomedical policy with the best scientific advice drawn from across Europe, through the FEAM network of Academies representing over 5,000 high level scientists from the whole biomedical spectrum' (FEAM, n.d.). In order to ensure that research was in line with this mission, our research activities were framed accordingly. Indeed, our research approach reflected the need to establish an indirect dialogue between biomedical experts and health decision-makers.

Thus, the objective of this research was twofold: on the one hand, it aimed to gather insights from medical experts and, on the other, to evaluate qualitatively these insights in relation to the lived experience of policy-makers. A recurring theme highlighted across these activities and discussed in detail in the present case study was the need for dialogue, and for stronger cooperation and coordination between experts, policy-makers, different institutions, and Member States. In this regard, both groups of experts were supportive of the need for prompt sharing of biomedical information about COVID-19 from the earliest stages of the pandemic. The context of the need for dialogue was the initial disharmony within the EU response. Departing from this experience, experts were key to developing solutions and initiatives to strengthen more centralised management of health risks at the EU level. As we shall see, an important key finding is that better pandemic preparedness response and health governance rely on clear leadership at the supranational level.

## Background: FEAM's case studies on multi-level governance during the COVID-19 pandemic

Since 2020, there have been a considerable number of publications on COVID-19 policy and pandemic governance. The literature has stressed the need, for example, to reinforce healthcare systems, particularly local services (OECD, 2020). It has also underlined the importance of protecting health workers and carers (FEAM, 2020; WHO, 2020) and safeguarding people's mental health during lockdowns (WHO, 2022a), in particular, that of vulnerable groups (RCCE, 2020). Even the definition of vulnerable groups has become broader, including categories not previously considered as such before the start of the pandemic (ECDC, 2020). Moreover, prioritisation of vaccination has become a common focus for research, analysed not only from a medical perspective (FEAM, 2021a), but also for its ethical, political, and economic implications, as demonstrated by multi-dimensional concepts like 'vaccine equity' (UNDP, 2021). In addition to its publications on the protection of health workers during the pandemic and FEAM's participation in the PERISCOPE work on multi-level governance – summarised below – FEAM has also highlighted the impacts of the pandemic on mental health and health inequalities (Eur-Lex, 2004) and advised on the importance of integrating European and global response strategies (FEAM, 2020). Thus, the spectrum of topics examined in the literature on pandemic governance is vast and heterogenous.

One of the main issues has been to identify how COVID-19 policy measures were implemented at different governance levels during the pandemic and how they differed across Europe. The findings underlined in this case study explore these challenges, and they build on some of the results already gathered during a first case study led by FEAM on 'International social infrastructures' (PERISCOPE, 2022) – which was also conducted through the framework of the research project PERISCOPE, between March and May 2022. This was conceived as a comparative and qualitative study targeting specific countries and certain FEAM medical academy members, through a survey and then interviews. The previous research examined how multi-level governance operated during the COVID-19 pandemic, with a focus on the coordination of decision-making at various levels and the role of science in policy. This topic has since been explored through research conducted between February and April 2023, but with a different category of participants and modality of participation. Before moving to the presentation of the key outcomes of this research exercise, it is worthwhile to explore some preliminary findings highlighted by the first case study, some of which have been explored further in the second case study.

### Results from the previous case study

The first case study looked at four countries – the Netherlands, Spain, Italy, and the UK – with insights from policy staff at their national medical academies. Based on the insights of these participants, the research described how the European response unfolded at national, regional, and local levels, highlighting some best practices and areas for improvement. For example, the report discussed instances where the COVID-19 pandemic had generated spontaneous and innovative policy solutions at the regional level. This included the relocation of patients within intensive care units in a Spanish region in response to the needs of communities, as an example of adequately sophisticated co-ordination in decentralised health systems. Another finding involved the flourishing of multi-disciplinary research initiatives and collaborations as part of a commitment to stronger pandemic preparedness in the future. Nevertheless, the pandemic response across European countries as presented in the study was not without challenges. In line with other emerging findings in the PERISCOPE report, evidence supported the conclusion that the integration across levels of governance was critical to the implementation and enforcement of pandemic policies. Unsurprisingly, FEAM research observed structural differences between centralised and decentralised health systems. The pandemic exposed weaknesses in the latter, which usually delegate

crisis management to regional authorities and therefore require more sophisticated coordination. As explained by experts, coordination, both at the European and international levels, was particularly arduous in the earliest stages of the pandemic, according to the rationale that regional health authorities in decentralised health systems were less accustomed to coordinating with other institutions when compared to centralised health systems. Specifically, decentralised health systems required stronger coordination at the local as well as at the transnational level for cross-border health risks.

In addition, the mixed role of scientific evidence in informing policy-making has also been identified as controversial. The response to the pandemic in Europe suffered from broken lines of communication between health organisations and national policy-making fora. In some cases, difficult communication resulted in failures to translate scientific advice into policy in a timely way.

Finally, the previous research disclosed how the interconnectedness of the health of animals and humans received little consideration in the response to the pandemic: in fact, the urgency of the crisis necessarily led to the prioritisation of human health. There is a continuing need to consider the wider context of One Health – a collaborative, multi-sectoral, and transdisciplinary approach that acknowledges the interconnected relationship between the health of humans, animals, and ecosystems (World Bank, 2022).

These emerging conclusions from this first case study have helped to set the context and focal points for the second case study. Drawing upon and validating these preliminary findings, FEAM's research activities were based on the facilitation of a cross-disciplinary discussion – including those focused around animal as well as human health challenges – on how health policies could generate better outcomes with regard to pandemic management. Reaching these objectives would entail the generation of 'best' practices and sharing of policy options that would benefit the countries involved, as we shall see below.

## Research methodology

This case study, which explores certain issues related to multi-scale governance, is based on the results of two research activities: the first was an online workshop held over

two hours on 15 February 2023 and the second consisted of seven interviews conducted with health decision-makers during April 2023.

Ahead of the workshop, a background document compiling the four themes and related research questions – on public health policy, public authority and legitimacy, evidence and data, and social networks and infrastructures – was distributed along with a consent request (see Appendix). The same document was also shared with participating health decision-makers before their online interviews, with clear instructions allowing participants to target the most appropriate questions according to their profiles. These questions were then discussed in an open-ended, semi-structured manner during the workshops and interviews.

The workshop was attended by nine participants from the Medical Academies' network of FEAM. Among them were professors, international policy managers, experts, researchers, and clinicians. The second research activity involved the participation of policy- and decision-makers from European institutions, international organisations, and national public health institutions.

In order to guarantee confidentiality and the open expression of perspectives, both research activities were held under the Chatham House Rule: 'When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed' (Chatham House, 2023). This facilitated exchanges and dialogue with interviewees, whose positions might be politically sensitive.

During the workshop, an exception was requested to allow the country of residence of each participant to be mentioned, in order to enable some cross-country analysis and follow up on the points from the research conducted for the previous report on multi-level governance best practices (PERISCOPE, 2022) by the FEAM team. The discussion benefited from broad European geographical coverage, with experts from France, Greece, Italy, Ireland, the United Kingdom, Romania, Spain, and Sweden.

Participants then had the opportunity to provide feedback on the case study. Three participants proposed edits which were implemented.

During the second phase of the research activities, involving seven interviews with health decision-makers, the Chatham House Rule was strictly applied to facilitate exchanges and dialogue with interviewees, whose positions might be politically sensitive.

In the following sections, we present some insights gathered during these phased activities related to five cross-cutting themes that emerged across both stages of the research: coordination, both at the subnational and supranational levels; political tension, influence and interference; science advice to policy; socio-economic health inequalities; and communication and information to the citizens. For each main issue, we have condensed the findings and quotes from both activities.

## Discussion

### 1. Coordination of sub- and supranational levels

One of the recurring messages during the online workshop and the subsequent interviews was the need for stronger, well-managed coordination between the different stakeholders and decision-making bodies involved, both at the subnational and supranational levels, in order to facilitate equitable future pandemic preparedness.

In this regard, participants recognised that future pandemic responses would rely on public health measures which can be implemented and monitored at several policy levels: global, European, national, and local. Whilst it was noted that varying governance levels necessitate several considerations and bring different challenges, there was an appreciation of the need to develop overarching frameworks and interventions to foster coordination and communication between the multi-level actors involved in emergency responses.

#### *Global governance*

Participants identified specific challenges pertaining to specific levels of governance. Referring to the global level, it was noted that the overall global health architecture is nominally determined in accordance with the regulation of the WHO. The revised International Health Regulations (IHR) (WHO, 2016) are an example of how the WHO provided leadership which aims to foster international collaboration in relation to global public health and pandemic responses. Defined as ‘an instrument of international law that is legally-binding on 196 countries, including the 194 WHO Member States […], the IHR create rights and obligations for countries, including the requirement to report public health events. The Regulations also outline the criteria to determine whether a particular event constitutes a public health emergency of international concern’ (Ibid.).

Whilst there has been significant critique and analysis of the IHR (e.g. Broberg 2020), our participating experts pointed to further areas which made global coordination problematic.

From the discussion, it emerged that the unequal status of health systems between countries – in particular in terms of financial capabilities – was problematic, and additionally, the contingent geopolitical tensions, particularly between the United States and China, made the political scenario more delicate. One significant consequence of these global inequalities was the difficulty in allocating vaccine supplies worldwide in a fair manner. As underlined in the case study on the multi-level governance of public health led by the Centre for European Policy Studies (CEPS) in this report, the more advanced economies were prioritised qualitatively in the access to vaccines, meaning that lower-income countries were confronted with a less advantageous situation.

Despite these concerns, WHO generated very valuable tools to deal with the pandemic, even if sometimes the difficulty of the situation made them less effective than intended. Discussants underlined the importance of one such instrument, the Joint External Evaluations (JEE) initiative, that was very useful for rendering smoother communication between countries and ensuring a proper functioning of the preparedness system. The JEE is 'a voluntary, collaborative, multi-sectoral process to assess country capacities to prevent, detect and rapidly respond to public health risks whether occurring naturally or due to deliberate or accidental events. The JEE helps countries identify the most critical gaps within their human and animal health systems in order to prioritize opportunities for enhanced preparedness and response' (WHO, 2022b).

### *EU governance*

At the European level, several institutions operate to manage health crises and to identify preparedness strategies.

An important regional body during pandemics is the European Centre for Disease Prevention and Control (ECDC). This EU agency was discussed positively during the workshop with regard to its action on data collection and monitoring. Even after the acute phase of the COVID-19 pandemic, the ECDC is continuing its monitoring operations. The ECDC has seen its mandate strengthened, with the final adoption of the regulation in

October 2022,[15] on surveillance, monitoring, training, and response to infectious disease threats. While there have been criticisms elsewhere of this institution, particularly in terms of lack of coordination and preparedness when the pandemic hit, participants noted that the 'ECDC depends on Member States, and their capacity to provide with data. And at the beginning of the pandemic, national and regional systems collapsed, in terms of data collection and monitoring'. Therefore, ECDC encounters difficulties if there are inconsistencies and heterogeneity in national data collection objectives and methodologies, and this weakness is particularly pronounced in the early days of a pandemic when there may be no consensus about what data should be collected. It must be a shared objective for the ECDC and national public health agencies to implement standardised approaches for the collection of epidemiological data and their use in risk management.

Participants also underlined the importance of the rapid creation of the Directorate-General for Health Emergency Preparedness and Response (DG HERA) by the European Commission in 2021, a separate entity from the DG SANTÉ, and with a central role in preparing for and responding to pandemics. DG HERA aims to coordinate and improve coordination between EU countries, and with partner countries on the European continent and on the global stage (FEAM, 2022). The objectives and activities of HERA have been discussed in further detail in previous workshops organised by FEAM (FEAM, 2021b). DG HERA, with a robust governance board, good flexibility, access to multiple sources of information and commitment to engage with civil society, 'will anticipate threats and potential health crises, through intelligence gathering and building the necessary response capacities. When an emergency hits, HERA will ensure the development, production and distribution of medicines, vaccines, and other medical countermeasures – such as gloves and masks – that were often lacking during the first phase of the response to the COVID-19 pandemic' (European Commission, n.d.a). See the CEPS report for a detailed case study with recommendations on how DG HERA can improve to meet this potential.

DG SANTÉ also has a major role to play in conjunction with the specialist EU bodies such as HERA, ECDC and the European Medicines Agency (EMA), and recent initiatives to strengthen epidemiological expertise within DG SANTÉ should help to enhance and accelerate the linkages between evidence collection and its interpretation for policy

[15] Regulation of the European Parliament and of the Council amending Regulation (EC) No 851/2004 establishing a European centre for disease prevention and control (ECDC).

development. In the case study on multi-level governance for public health led by CEPS in this report, the importance of defining a clearer collaboration scheme between HERA with other EU agencies is underlined, in order to strengthen the 'quick detection of supply chain bottlenecks and rapid mitigation actions'.

The advent of the European Health Union, launched during the pandemic and incorporating early lessons learnt, is resulting in greater ambition for EU-level coordination in preparedness and builds on other recent developments, for example in cross-border health regulation. Strengthening the EU Health Security Committee representing Member States, to enhance collective risk management, is also an important step taken during the pandemic and the desirability of further reinforcement was discussed. There has been recent progress in defining the remits of HERA and ECDC and promoting their strong interlinkages to develop infrastructure for a common evidence base and EU-wide recommendations to inform country-level actions under national competencies. As a result of the pandemic, there is also increasing momentum to develop innovative, centralised procurement processes for the necessary medical countermeasures.

Nevertheless, this task may be challenging, because of the heterogeneity of the EU countries and bodies involved, which has generated bureaucratic and communication difficulties. One of the criticisms directed at the EU during the pandemic was the abundant bureaucracy; at times, this slows down the effectiveness of political and emergency actions.

Further, while the FEAM research focused on issues related to infectious disease within the EU, there was recognition from medical experts that internal disease control can be strongly influenced by events outside EU borders, for example in neighbouring regions such as the Eastern Mediterranean and in the wider geographical area covered by WHO Europe. The agreed importance for the EU of sustaining these wider geographical connections in support of surveillance, capacity building and, for example, the input to broader political thinking, was emphasised in the interviews with policy-makers.

### *National level*

At a national level, state constitutional structure was identified as playing a pivotal role in the handling of and response to the crisis, and the influence of this was stronger than that of the EU. In fact, some decision-makers agreed that 'the EU may only recommend,

but there are no sanctions if these recommendations are not followed. It is just a question of suggestions. There are strong guidelines that are coming from the EU, but Member States can choose to apply them or not. It's always up to the Member States. Guidelines are there, but it is always related to every State's situation.' For example, since the pandemic hit different countries at different times, some countries, in which the pandemic arrived late, could develop better responses and preparedness strategies. As one participant stated, for example, 'in Latvia, there was no first wave, and then, when the second wave appeared, the country was better prepared, thanks to the learnings from other countries'. Therefore, one pervasive theme emerging during the FEAM research was uncertainty about whether the present legal basis (allocating major health responsibilities to Member States, with EU institutions having a supporting/coordinating competency) acts as a barrier to better preparedness for cross-border health emergencies.

As an overarching potential solution to this weak regional coordination, in addition to the need to foster multi-level support, and bilateral and international cooperation among countries, participants from the first workshop recommended that upward authority delegation is key in times of crisis, in order to ensure equitable decisions. For example, it was noted that, when Italy entered lockdown in March 2020, solidarity was lacking from other European countries. Member States were competing to secure enough personal protective equipment (PPE), respiratory devices or medical supplies, an attitude undermining empathy and mutual support among countries. Therefore, it was suggested that authority delegation is fundamental to decrease competitive national behaviours, like those which emerged at the very beginning of the COVID-19 pandemic in Europe, even if the last word is always left to the Member States involved.

There was also retrospective discussion amongst medical experts around issues within national health systems during the first few years of the COVID-19 pandemic and the complexities of effectively devolving health care at the local level. In Spain, for example, participants in the workshop noted that the decentralised health system with 17 regional ministries of health made coordination difficult at the beginning of the pandemic. This included slower coordination mechanisms for decision-making, in terms of both content and administrative procedure. However, in some instances, this was effectively overcome through various initiatives introduced during the pandemic. For example, patients were efficiently reallocated within Intensive Care Units (ICU) in Spain through

the use of a simple WhatsApp group offering the opportunity for quick and efficient requests followed by patient transfer to free beds.

Medical experts also highlighted that a lack of coordination within and between health services has caused huge and ongoing disruption. In Ireland for example, COVID-19 infection control was prioritised to the detriment of other services, particularly cancer treatment, with health consequences in the long-term.

### 2. Political tension, influence, and interference

Another main theme that emerged from the discussions was the political tensions, both in terms of influence and interference, that affected political action and policy-making processes during the COVID-19 pandemic. Participating medical experts argued that the lack of scientific background among people overseeing high-level decisions during containment and vaccination policies, remains pervasive in EU policy circles and national circles.

Decisions and discussion about decision-making have, in some cases, been politicised, and economic pressures have played an important role in this process across contexts, at the expense of science-based evidence and health-based solutions. As examples, experts pointed to how in Italy it was challenging to find a balance between epidemiological and economic pressures, in particular in the early stages of the pandemic: in fact, a constant conflict between the medical and public health needs on the one hand, and the social and economic pressure on the other, made the decision-making process very difficult. Along the same lines, a participating medical expert highlighted how, in Spain, ‘the epidemiological aspect was underestimated at the beginning, and the difference between expected and real mortality was huge. This issue might be attributed to the political process and the interventions of politicians, often in conflict with scientific advice’.

During the pandemic, participants noticed that a paradox arose between the slow pace of democratic decisions and the need for fast adoption of actions to react efficiently. That is, the pandemic context legitimised a subversion of democratic legislative processes.

Participating health decision-makers agreed that a balance must be found between respect for democracy and efficient pandemic responses, since the option of adopting

containment measures like long-term lockdowns, for example, is destined to lose effectiveness with time. On this point, it was shown how, in the earlier stage of the pandemic, the lack of available information for containment favoured majority acceptance of the lockdown measures and restrictive policies. Nevertheless, once alternative responses, informed by new evidence and information, became feasible, those earlier more restrictive provisions became politically sensitive: 'Within a state of alarm, only the sanitary criteria are considered to make decisions. But once the crisis is felt less, economic, social, and political aspects must be considered. […] It is always hard to figure out to what extent the common good must be above individual rights'.

Finally, participants noted that political action at the EU level not only suffered from a lack of coordination in terms of the *content* of its responses to COVID-19, but also from a lack of legal and formal infrastructure to put into practice a unified European emergency response. In this regard, discussants underlined how complicated it was to make any legal movement before the declaration of a Health Emergency.[16]

### 3. Science advice to policy

The necessity and difficulty of building credible evidence-based health policy responses is another issue that was highlighted during the research activities.

Discussants praised the importance of long-term dialogue between science and policy, a relationship that should become a praxis for the wellbeing of the population. However, this dialogue is commonly complex due to what was often described as a different pace with which political actions and science proceed, with the potential for political interference and the possibility that the credibility of policy-makers will be undermined. Several participants in the workshop highlighted the need to have diversified and multi-disciplinary expertise seated on advisory boards, including researchers, patient advocates, ecological biologists, and social scientists. Following on from the pandemic, several institutions, both at EU and national level, are incorporating researchers and health experts into their policy units; these individuals are able to interpret and adapt scientific data to policy proposals.

At the national level, for example in the UK and as expanded on in the London School of Economics (LSE) report, science advice was given through two institutional channels,

[16] A WHO declaration of a public health emergency triggers a set of rules to guide disease responses, such as the fast-tracking of supplies.

with the Scientific Advisory Group for Emergencies (SAGE), composed mainly of mathematics modelers and epidemiologists as well as social and behavioural scientists, and the Chief Medical Officer advising the Prime Minister's cabinet. Recently, a COVID-19 inquiry was launched to collect evidence of governmental responses and identify blind spots in the COVID-19 response. At the EU level, several committees have been created or reinforced, respectively, the European Commission's advisory panel on COVID-19 (European Commission, n.d.b) and the EU Health Security Committee (European Commission, n.d.c). Further, an EU scientific platform comprising the Chief Scientists of all Member States reinforced the link between EU-level developments and the science advisory mechanisms at national level. See the CEPS report for a discussion on how to further the role of scientific advice at an EU level. At the international level, the EU assisted in the creation of the IHR Emergency Committee for COVID-19 by WHO (WHO, 2023a).

As a transnational issue, a further point was underlined by discussants about the One Health thinking – 'an integrated, unifying approach to balance and optimize the health of people, animals and the environment, […], particularly important to prevent, predict, detect, and respond to global health threats' (WHO, 2017) – which is often implicit in some of the science-policy linkages, for example in surveillance for emerging zoonoses. Progress in coordination in relation to tackling One Health challenges can be discerned globally, for example, in the closer linkages between the UN bodies responsible for human, other animal, and global health, and at the EU level. In some respects, One Health operationalisation is more advanced at the EU Institutional level than in some Member States, but discussants suggested that more might be done. For example, improving a coordinated focus on One Health by bridging different DGs (perhaps forming an Inter Service Group) that could also provide a mechanism for liaising with all the relevant EU agencies such as ECDC, European Food Safety Authority (EFSA), European Economic Area (EEA). See also the Karolinska Institute (KI) report for discussion on refining One Health thinking at a national level in Sweden.

### 4. Communication and information to the citizens

Communication with citizens was cited several times as being a key element in ensuring high rates of compliance and adherence to public health measures (testing, vaccination, distancing, lockdown), essential for their effectiveness.

At the onset of the COVID-19 pandemic, communication from central governments with the public was poorly managed across EU contexts, with unclear messaging on vaccines, PPE, such as masks, leading to growing mistrust of governmental guidelines. This observation was particularly shared by experts from the UK, Italy and Sweden. Throughout the pandemic, changes in the knowledge gathered about the COVID-19 virus and its variants, have impacted public credibility and support. In this regard, 'fake news' is considered to undermine the credibility of science-based messaging, as well as political actions, both at the international and EU levels. Participants involved in the research activities talked about the merits of a recent initiative promoted by WHO, Infodemic, a 'new scientific arena, gathering social scientists, biologists, physicians, to address the specific question of fake news, in particular when political leaders are promoting or disseminating false information' (WHO, 2023c).

In several instances, inadequate communication and lack of science-based policy responses were connected and resulted in similar consequences. For example, one of the most worrying points underlined by the participants was the disconnect between robust, validated scientific research and public health communications. In France, for example, some scientists were frequently invited onto TV talk shows, conveying unverified or unreliable information. Altogether, this had a negative impact on the implementation of public health policy, sometimes privileging political reasoning more than the scientific inputs. In addition, experts raised the difficulty of accessing the epidemiological and biological data from French databases, most of the results coming from the centralised systems of the UK and US databases. This contrasted with high-level basic science findings on the SARS-CoV-2. Similarly, another important point that was underlined was the need for rapid information sharing. Some discussants stressed that the problem was demands on 'how fast communications and notifications had to circulate, considering the amount of epidemiological information that had to be transferred at different levels'.

### 5. Socio-economic health inequalities

Experts were cogently aware that COVID-19 has, in various respects, worsened socio-economic health inequalities. Even if COVID-19 public health measures are the result of economic and political compromises between priorities for fulfilling medical needs and their acceptability in society, pandemic measures did not have the same effects on all

social groups and minorities, in particular those in already socio-economically deprived areas.

The effects of the pandemic can be seen as entrenching marginality as pandemic policies intersected with regional inequities, biological health, socio-economic inequities, and citizenship rights. Globally, less wealthy countries and regions were more impacted. In this regard, participants discussed the sensitive issue of global vaccine allocation and distribution, as discussed in detail in the CEPs report. Regional disparities were evident in various contexts, often resulting from differential funding in health systems within countries. In Italy, for example, historical disparities between the north and the south of the country are striking (Putnam, 1993), and people from lower income groups can no longer afford health services, in terms of availability, affordability and rapid access, and because of a long-standing de-financing of health systems.

This structural backdrop of wide-reaching socio-economic inequalities intersected with biological factors. Experts noted the widespread health advice that circulated during the pandemic that COVID-19 held particular risk for individuals with existing health conditions, particularly diabetes, obesity, cardiac insufficiency conditions, as well as respiratory problems. People facing barriers to accessing health information and services were also particularly impacted.

The pandemic also had an unequal impact along gendered lines. For example, women, often assigned the role of caregivers and, in particular, 'working mothers with school-age or younger children' experienced an increasing burden in terms of work, since they 'were nearly three times as likely as fathers to report that they took on the majority or all of additional unpaid care work related to school or childcare facility closures' (OECD, 2021). New terms like 'shecession' or 'momcession' have arisen.[17] In addition, gender-based violence increased and access to shelters for victims was also reduced because of restrictions (UN Women, 2021).

COVID-19 has made *visible* these geographic, gendered and economic inequalities that were previously often *overlooked* in public policies. This includes stigma towards

[17] The term 'shecession' and 'mothercession' refer to the negative effects for women caused by the recession shadowing the COVID-19 pandemic. Nevertheless, 'the COVID-19 "shecession" should more accurately be called a "momcession". Women's work losses were driven in large part by the outcomes of mothers, specifically, who often took on additional hours of (unpaid) care of their children during school shutdowns. Yet cross-national comparisons of the effects of the recession on mothers have thus far been limited due to lags in the cross-national availability of detailed labour force microdata by parenthood status' (OECD, 2021: 3).

marginalised groups, such as the homeless or migrant and refugee populations,[18] which has been made more visible during the pandemic. Migrant and refugee populations in camps, for example, were further stigmatised and blamed for the spread of COVID-19.

Therefore, evidence gathered in this case study confirmed that working mothers, as well as migrant and refugee populations, are among the most vulnerable to the impact of pandemics; this issue should therefore be addressed by targeted public policies in order to better fulfil their needs.

In conclusion, COVID-19 has exacerbated and introduced socio-economic inequalities and worsened the situation of already marginalised people, but it has also stimulated discussion on the definition and inclusion of addressing inequalities as an important basis for more targeted public policies.

## Conclusion and recommendations

The findings from this case study identified some areas of policy-making that could be improved and, consequently, underpin some recommendations to policy-makers.

### Fostering EU inter-agency coordination and communication among countries

Participants in both research activities underlined how poor coordination and disharmonious communication entailed difficulties in conceiving a shared and joint response to the pandemic, in particular in its earlier stages. This situation improved during the pandemic, both at the international and EU levels. Some tools, like the implementation of the JEE, have proved useful for this purpose. The creation of DG HERA was noted to have strengthened inter-agency coordination, for example with ECDC, but the definition of a clearer collaboration strategy with other EU agencies should still be implemented, as discussed in the CEPS report.

New legal frameworks and legislations, such as the strategies and information from the Regulation on serious cross-border threats to health (Eur-Lex, 2022b), are now

[18] Another research stream for the PERISCOPE project focuses on COVID-19 impacts on health inequalities and mental health inequalities, the interim analytical report: PERISCOPE. 2021. 'Analytical report on health inequalities with emphasis on vulnerable groups'. Available at: https://backend.periscopeproject.eu/multimedia/periscope/5KVTsNKMU-d2.2---analytical-report-on-health-inequalities-with-emphasis-on-vulnerable-groups.pdf

operational. Nevertheless, an EU mechanism that seeks to coordinate local and regional authorities in times of crisis could help European governance in the context of future pandemic risks. More stable and consistent communication channels could also bridge the gap between health and scientific associations and policy-makers.

Participants stressed the importance of encouraging stronger geographical connections at the EU level, in order to foster joint actions among countries to deal with broader surveillance, capacity building and political thinking. The need to build shared thought and strategies, overcoming geographical borders, would ensure the proper functioning of the preparedness system in the case of future pandemics.

### Building science-based policy and improving dialogue between health experts and decision-makers

Participants agreed on the importance of building stronger links between the science-policy interfaces at the EU level and at the national level. In this regard, the creation and reinforcement of certain committees at the EU level, like the the European Commission's advisory panel on COVID-19 and the EU Health Security Committee, as well as the IHR Emergency Committee for COVID-19 by WHO at the international level, were commended during the discussion. The importance of generating links between these bodies and Member States in using science to inform pandemic policy could be effective in the fight against future pandemics.

Strong and consistent public messaging is necessary to deconstruct conspiracy theories, fake news, and limit vaccine hesitancy. This could require, on the one hand, ensuring the prompt exchange of scientific information and evidence on public national platforms. On the other hand, there is also the need for the scientific and research community to communicate in a way that is understandable to all, both during a pandemic but also in the long run for educational purposes.

### Implementing more integral policies, including for One Health

Something that emerged from the discussions as a transversal point, is that there is an increasing need to address the health of other animals and of our ecosystems in our policy responses, at the international, European and national levels. In fact, the health of animals and ecosystems needs to become an integral part of healthcare management.

Thus, there are significant opportunities for cross-sectoral assessment and action that can be addressed at all levels of governance.

### Targeting 'vulnerable groups' not as a unique category, but recognising intersecting axes of inequality

Public policies tend to target 'vulnerable groups' and 'vulnerable individuals' as a unique and broad category, but there is an increasing need to recognise the complexity and heterogeneity of related – and often intersecting – inequalities. Inequality and related problematic population categories are now at the forefront of policy discussions, even at a global level, made visible through COVID-19. This has highlighted the need for intersecting structural health inequalities related to geography, gender, ethnicity, and socio-economic position to be urgently addressed in global-, regional- and national-level public policies in order to prevent the worsening of inequalities and related health outcomes for future pandemics.

In summary, our concluding points are relevant for all levels of governance and emphasise that health priorities are not a matter for the health sector alone but must be taken into account in all public policy-making. The evidence and perspectives compiled in this case study research are a useful resource that should be considered further in policy-making, from the global to the local level.

# CASE STUDY 4 APPENDIX: Supporting Information

## Background document shared with participants ahead of the workshop, 15 February 2023, and interviews

### Guiding questions:

*1. Public health policy*

- Discuss 'The evolution of COVID-19 policies, their history and comparison between countries'.
- What are the key institutions involved in COVID-19 policies in different settings? How have these affected differences in the unfolding of policy and its effectiveness in different EU settings?
- What were the difficulties that were encountered at the local, regional and national levels during the pandemic response?
- What are the learnings and priorities for pandemic preparedness and response on the EU level? What is HERA planning to improve in the future and are we heading in the right direction?

*2. Public authority and legitimacy*

- How do relations of authority between institutions and within society affect the impact of health policy?
- How can we deal with the tensions between scientific measures and democratic processes?
- How are health inequalities perpetuated or reduced by public authority?
- What are the different historical and contemporary examples of EU and national COVID-19 policies that have been effective/ineffective because of issues of legitimacy?

*3. Evidence and data*

- The FEAM report highlighted that the core response to the pandemic suffered from broken communication between health organisations and national policy-making fora. In some cases, difficult communication resulted in the impossibility of timely translation of scientific advice into policy. Does this resonate with your experience and how should this be addressed?

- What evidence has been the basis for policy in the pandemic and what new forms of evidence might we need? How could we design data and data analysis templates for EU- and national-level evidence and statistics?
- To what extent have various national governments in the EU followed the evidence when introducing COVID-19 policies? When have they ignored it, why have they put it aside and what trade-offs are involved in this? To what extent have political and economic interests affected the extent to which public health has been protected? How might we resolve these issues in future pandemics? Should governments have to follow the evidence?
- What kinds of experts are needed to advise governments on public health policy to produce the best interpretation of data and evidence? Have these experts been too limited during COVID-19 at different national, EU and global levels?

*4. Social networks and infrastructures*

- What are the longer-term inequalities from the legacies of COVID-19 in relation to formal and informal relations of elder, child and long-term illness care? How and why do these differ between distinct national settings? How and why do these differ between different minoritised groups?
- What are the most effective and equalising ways to invest in and fund social infrastructures to overcome post-COVID-19 mental health and care burdens?
- How do non-human relations and the environment in which people build their relations of care impact on both those relations and health outcomes? How could we build a version of measurements of ‘health’ that take the non-human, the environment and care into account?
- How might we radically reconsider the form and nature of pandemic interventions, so they recognise the social needs of populations?

# REPORT CONCLUSION

# REPORT CONCLUSION: Pandemic governance and inequalities

*This report is based on the cross-disciplinary and cross-European Commission for Pandemic Governance and Inequalities. Taken together, this commission has offered retrospective analysis of policy-making during the COVID-19 pandemic to date, with a view to future pandemic preparedness.*

This research has highlighted issues and opportunities at global-, regional-, national- and local-level governance that need to be considered now for future pandemics.

All of the studies outlined in this report present evidence to support the need for sophisticated decentralisation and co-ordination across levels of governance. This involves establishing and building on strong communication networks across national, local and community-based authorities. This is based on a principle of mutuality in responding to a shared global crises. The failures to collaborate and co-ordinate globally during the COVID-19 pandemic contributed to the tragic deaths of 7 million people worldwide (WHO, 2023b). This included failures to equitably distribute resources and protect marginalised people (The Lancet Commission, 2022). As highlighted in the reports by researchers at the Centre for European Policy Studies (CEPS) and the Federation of European Academies of Medicine (FEAM), the dangerous implications of competitive approaches to the pandemic response are exemplified in the unequal global distribution of vaccines and the failures of COVAX, which relied on donations from wealthier countries such as the United States, United Kingdom and European Union (EU). Competitive procurement processes excessively favoured these wealthier countries who had invested in research and development, leading to wastage and preventing access in less wealthy countries and regions. To prevent this, as outlined in the CEPS report, mechanisms of global joint procurement should be considered, and Intellectual Property (IP) rights of emergent technologies should be publicly acquired to prepare for future emergencies.

The cross-Europe, high-level expert and policy-maker perspectives offered by the FEAM and CEPS reports emphasise the diversity of national-level responses to the pandemic (Kusumasari et al., 2022). This is expanded in the Karolinska Institute (KI) report which outlines civil society, expert and youth perceptions of the exceptional case of Swedish health governance during COVID-19. KI's research has been analysed through a One

Health framework, which demonstrates how pandemic policy thinking should be global, holistic and cross-disciplinary in order to respond to 'transboundary' infectious health threats like COVID-19. Failure to take this approach will exacerbate existing structural inequalities and undermine human, animal and environmental health.

As outlined in the London School of Economics (LSE) report, examples of effective collaboration between organisations and local authorities, as in the Community Champions programme, have demonstrated the potential of people working together across sectors and contexts to respond to the crisis. Best practice cases of this have often been facilitated through strong social infrastructures, and the unpaid relational work required to sustain them. Community-based, third sector, civil society, grassroots, faith-based organisations and informal networks among the voluntary, community, social enterprise (VCSE) organisations were often best placed to act responsively and provide life-sustaining support in the immediate health emergency, being embedded in their communities and having extensive knowledge about what was needed and available. This support was particularly vital for marginalised people, including undocumented people, people on low incomes, elderly people, disabled people, young people and people of minoritised ethnicities. The additional burden of work occasioned by the pandemic was therefore unevenly distributed, particularly taken up by women, minoritised groups, and particular community leaders or 'nodal figures'; people able to mediate between their communities and the public health system. This kind of labour and the public provision it sustains should be adequately recognised and resourced by national governments and international agencies as a crucial component of pandemic preparedness and response.

Overall, this multi-disciplinary policy experiment has revealed how social infrastructures, including informal networks of care and relations across levels of governance, have been crucial in the COVID-19 response. We therefore argue that social infrastructures and related inequalities should be at the core of pandemic response and preparedness. This is most crucial for marginalised and disadvantaged communities for whom the impact of the pandemic has been disproportionate. It would prevent the worsening or introduction of inequalities that have been seen across European contexts and at global, national and local levels during COVID-19.

As outlined in the introduction, this report has explored evidence-based recommendations for better and more equitable pandemic policy across the following five principles:

1. First, **decentralised public health governance**. Top-down approaches based on balancing economic and epidemiological priorities have dominated public health governance during COVID-19. There is a need for effective and democratic discussion of the role of scientific, social, economic, political, legal and ethical responsibilities in pandemic governance at national and EU levels. More inclusive, distributed and horizontal forms of pandemic preparedness and response are needed. This would involve the inclusion of key VCSE organisations at all levels of pandemic response, particularly emergency planning committees.
2. Second, **accessible data and evidence**. Pandemic preparedness requires data preparedness, including integrated and open-access data across borders, ministries, health bureaucracies and private entities. There is also a need for an improved understanding of the role of qualitative social science approaches such as 'social listening' and co-production methods in mapping inequalities to inform pandemic policy.
3. Third, **renewing public legitimacy and trust**. National governments need to focus on health and care provision for minoritised and disadvantaged people in order to build trust and reduce inequalities.
4. Fourth, **resourcing social infrastructures**. This research highlighted the crucial role of flexible and sustained government funding for a centrally resourced, integrated ecosystem of VCSEs, public health and social care services. This would help to bridge macro and micro levels of governance in pandemic response and preparedness.
5. Fifth, **refining One Health frameworks**. A One Health framework should be foregrounded across contexts, sectors and levels of governance to account for the interdependence of human, animal and environmental health in pandemics.

This Commission, as part of the wider PERISCOPE project, is testament to the significance of multi-disciplinary and cross-contextual research in providing policy recommendations focused on responding to complex global health emergencies such as the COVID-19 pandemic. Our research participants include a range of experts who were key COVID-19 decision-makers across levels of governance, including nodal figures in VCSEs, medical experts, public health practitioners, scientific advisors, and national- and regional-level policy-makers. The report has demonstrated the need to

underpin decision-making with guiding principles focused on the reduction of social inequality, and the value of social relationships in enabling health policy.

### A social movement for an international declaration of pandemic rights?

There is much ongoing work at the international level that sets standards and legal regimes for pandemic responses. The World Health Organization is currently negotiating a pandemic treaty that nation states can sign up to. Our research shows that the treaty's emphasis on human rights, One Health, doing no harm to disadvantaged groups in society and all-society community approaches is correct and valuable. Yet what our report adds is a concrete exploration of the forms of organisation within state and society that can generate effective recovery from pandemics and preparation for the next one. It is clear, too, that there are unequal power relations between groups in society, the state, the voluntary sector and between different forms of knowledge. Additionally, this report does not assume that within society there is 'social capital' that can be tapped into to produce effective responses to health emergencies. Instead, it emphasises that the hard, challenging work of building social infrastructures is a joint project between state and society that needs to be led by the voluntary and social enterprise sector. Such infrastructures need to be actively funded for their relational work in a way that treats them as vital, just like internet infrastructures and railways. We can talk of social infrastructure poverty and rights to social infrastructures. This poverty is not a failure in trust or inability to 'reach' certain communities. It is a product of years of neglect in terms of vital provisioning services for formal and informal care. As we have shown in this report, the COVID-19 pandemic led to many policy experiments fuelled by qualitative social science insights. We hope that this report and its findings can support more of these in the present so as to create better holistic health outcomes and prepare for the future. Perhaps our research can also serve as a call to academics, civil society and policy-makers across Europe to work towards greater pandemic rights. COVID-19 led to a concentration of power in governing institutions with few constraints. To build better health for societies in the present and future we need a more democratic and distributed approach. Crucial to this is widespread debate and inquiry beyond various expert commissions into the successes and failures of policy responses.

# ABBREVIATIONS

## Abbreviations

| | |
|---|---|
| **AMR** | Antimicrobial resistance |
| **BAME** | Black, Asian, Minority Ethnic |
| **CCG** | Clinical commissioning group |
| **CDC** | Centers for Disease Control and Prevention |
| **CEPI** | Coalition for Epidemic Preparedness Innovations |
| **CEPS** | Centre for European Policy Studies |
| **CSO** | Civil society organisation |
| **DG** | Directorate-General |
| **DLUHC** | Department for Levelling Up, Housing and Communities |
| **EBRD** | European Bank for Reconstruction and Development |
| **ECDC** | European Centre for Disease Prevention and Control |
| **EEA** | European Economic Area |
| **EESC** | European Economic and Social Committee |
| **EFSA** | European Food Safety Authority |
| **EIB** | European Investment Bank |
| **EIDs** | Emerging infectious diseases |
| **EMA** | European Medicines Agency |
| **ERC** | European Research Council |
| **EU** | European Union |
| **FEAM** | Federation of European Academies of Medicine |
| **GDPR** | General Data Protection Regulation |
| **GP** | General practitioner |
| **HaDEA** | Health and Digital Executive Agency |
| **HERA** | Health Emergency Response Authority |
| **ICS** | Integrated Care System |
| **ICU** | Intensive Care Unit |
| **IHR** | International Health Regulation |
| **IP** | Intellectual property |
| **JEE** | Joint External Evaluations |
| **KI** | Karolinska Institute |
| **LGBTQI+** | Lesbian, gay, bisexual, trans, queer/questioning, intersex + |
| **LSE** | London School of Economics |
| **MERS** | Middle East respiratory syndrome |

| | |
|---|---|
| **MHCLG** | Ministry of Housing, Communities and Local Government |
| **MSB** | Myndigheten för samhällsskydd och beredskap |
| **NHS** | National Health Service |
| **NPIs** | Non-pharmaceutical interventions |
| **OH** | One Health |
| **OHHLEP** | One Health High-Level Expert Panel |
| **ONS** | Office for National Statistics |
| **PHA** | Public Health Agency |
| **PHAS** | Public Health Agency of Sweden |
| **PHE** | Public Health England |
| **PPE** | Personal protective equipment |
| **PPR** | pandemic preparedness and response |
| **RCT** | Randomised controlled trials |
| **RED** | Resilience and Emergencies Division |
| **rescEU** | Union Civil Protection Mechanism |
| **RTA** | Reflexive thematic analysis |
| **R&D** | Research and Development |
| **SAGE** | Scientific Advisory Group for Emergencies |
| **SARS** | Severe acute respiratory syndrome |
| **SPI-B** | Behavioural science advisory group under SAGE |
| **TEV** | Transferable Exclusivity Voucher |
| **TRIPS** | Trade-related aspects of Intellectual Property Rights |
| **UK** | United Kingdom |
| **UKHSA** | UK Health Security Agency |
| **UNGA** | UN General Assembly |
| **US** | United States |
| **VCSE** | Voluntary, community and social enterprise sector |
| **WHO** | World Health Organization |
| **WTO** | World Trade Organization |

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**PERISCOPE**

Pan-European Response to the ImpactS of COVID-19 and future Pandemics and Epidemics