



# SETTING AN ETHICAL DIRECTION — HOW THE UK COVID-19 Public Inquiry can learn from research in the Arts and Humanities. A 'META-ANALYSIS' OF RESEARCH FROM THE PANDEMIC & BEYOND PORTFOLIO.

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# **Executive Summary**

This report has been commissioned to assist the UK COVID-19 Public Inquiry's task to understand and evaluate the preparations and response to COVID-19 in the UK. It draws on findings from a set of research projects funded by the Arts and Humanities Research Council (AHRC) to consider the pandemic's impacts as these unfolded. The research not only offers substantial academic contributions on subjects relevant to the Inquiry's deliberations; they also help us centralise *ethical* reflection as an inevitable component of the Inquiry's task. In reviewing the evidence of the actions that have and have not been taken over the past two years, this report proposes that the UK Inquiry can and should help us *set an ethical direction* for the UK moving forward.

The most salient and highest level, message summarising findings across the 26 projects included within this study concerns the extent, interconnectedness and urgency of the structural problems that the pandemic has brought into view. The corpus shows how individuals and communities who were socially, economically, culturally disadvantaged before the pandemic were disproportionately harmed by it. This message applies across the diverse contexts over which the corpus ranges, from inequalities in digital access; to racial discrimination in health settings; via unequal access to green spaces for communities; to funding disparities in the cultural sector. Moreover, the strategies the government employed to protect the UK population sometimes reinforced and worsened those disadvantages.

It is not the Inquiry's task to establish what equitable policy choices and effective political decision-making might mitigate these structural inequalities. However, by recognising them, it will demonstrate that future resilience planning to effect a fairer distribution of the costs and protections in any future emergencies depends on a strategic and longer-term ambition to ensure a fairer society.

In setting an ethical direction, the Public Inquiry should:

- Acknowledge the role of structural and place-based health inequalities in the pandemic.
- Urge the UK government to take responsibility for these inequalities.
- Encourage the UK government to initiate equitable social policy solutions where harms and impacts are identified.
- Confront the harms to democratic governance and promote democratic debate over a future 'social covenant'.
- Underline the facility of arts and humanities research for ethical review and future policy making



## Introduction

RQ1: What can research in the arts and humanities tell us about the ethical challenges or issues created or revealed by the impact of the pandemic?

RQ2: How can the COVID-19 Public Inquiry learn from this research?

#### **Context**

Arts and humanities research into COVID-19 and its impact can contribute in critical ways to the task of the UK Inquiry. During the pandemic, the UK Research and Innovation (UKRI) established emergency fast-tracked routes to fund research that would 'deliver a significant contribution to understanding of, and response to, the COVID-19 pandemic and its impact'. The AHRC, which distributes UKRI funds for arts and humanities initiatives, dispensed a relatively small portion of emergency call funds (estimated at 6%) to 81 applicant research projects. However, topic analysis demonstrates that this research has punched far above its weight in areas that are crucial for appreciating the pandemic's impact and which are then highly relevant for the UK Inquiry, such as digital adoption, community resilience, and democratic governance (Appendix, II (a)).

In recognition of this significance, this analysis has been commissioned by the UK Pandemic Ethics Accelerator, one of the AHRC emergency call projects, in partnership with the *Pandemic & Beyond* — the umbrella coordination project for the AHRC's COVID-19 research portfolio. The aim has been to maximise the impact of this considerable scholarly resource by providing a statement of its relevance for the UK Inquiry. This report aims to show how the wide range of qualitative, person-centred, and interpretative approaches employed under the rubric of 'arts and humanities' research combines deeply personal insights into people's experiences, with critical oversight of how and where the pandemic's interlocking impacts have manifested, and humane appreciation of how systems (including governmental) have functioned — all of which the Inquiry needs.

## Methodology

Any meta-analysis must balance breadth and feasibility. Initially, the original call for this piece of research included only those projects in the portfolio with an explicit ethics-remit, reflecting the interest of the UK Pandemic Ethics Accelerator. However, it became clear that other projects raised ethics-relevant debates or traced ethical issues implicitly or along different trajectories. Widening the analysis from 19 to 26 projects to make the review representative of the *Pandemic & Beyond* portfolio<sup>iii</sup> has helped illuminate the pandemic's synergic societal and economic impacts and their interrelations. Yet it has also created the problem of how to place a highly variated corpus of evidence (in subject, approach, and output) into dialogue.

As well as high variation, the design has had to accommodate changing circumstances, heightened imperatives for rapid impact, and short funding timescales. In this, it shares many characteristics with the pandemic-impact research it studies. Work on the report commenced during considerable uncertainty about the timings of the COVID-19 UK Inquiry. The announcement of consultation on the draft terms of inquiry prompted a necessary diversion in the preparation of a response for the *Pandemic & Beyond*. Funding timelines of



the UK Ethics Accelerator, rather than the announcement of the call for evidence or the completion of the projects, have decided the end-date for submission. This report, therefore, is based on arguments and findings that, in some cases, are still coming to light.

For these reasons, this analysis is not the kind of 'systematic review'vi common in the social sciences. For instance, a formal quality appraisal stage could neither weigh the combination of normative and empirical literature within the corpus;vii nor judge genres of rapid outputs necessitated by pandemic-impact research and the imperatives of funders (*Appendix I(b)*). Requirements for peer reviewviii would have excluded relevant projects because of their timescales. We must accept that some of the arguments presented in this review are emerging. The UK Inquiry will have a more comprehensive set of insights to evaluate these findings, as it will draw on a wider set of evidence to balance them.

Yet, this review employs a robust approach through a 'meta-thematic-analysis', developed to accommodate the caveats and contingencies required by its research circumstances, whilst providing usable evidence for its specific purpose. This encompassed the selection of 115 extant outputs from the 26 separate projects, followed by two parallel stages of analysis. First, an inductive analysis identified the codes for topics areas relevant to the UK Inquiry through several iterative stages, which were checked by another researcher and grouped into four overarching themes explored in each chapter. Second, the identification of ethical issues raised by the main findings of research and discussion with an ethics specialist. These were then grouped according to a set of principles drawn from an ethical framework for thinking through the implications of the pandemic. Xi

# The Ethical Compass

A key purpose of this analysis is to situate ethics at the heart of the task of evaluation of the UK's response to the pandemic and its impact. It does so by employing a simple tool – the Ethical Compass – developed by a global network of ethics specialists from over 30 countries over two years for the purpose of guiding research in public health

emergencies.xii The Ethical Compass is the gathering and steering force for this review and has provided the means to organise its ethics findings and communicate them clearly and concisely. For each chapter, the arguments are organised via the three ethical principles that make up the Compass, which have been clarified by a group of associated sub-categories that connect with the sub-categories of the inductive research.xiii

	Dignity and agency of individuals
Equal Respect	Mutual respect & equal moral worth
	Transparency & Justification
	Social Value
Help Reduce Suffering	Effectiveness & Proportionality
	Collaboration & Self Reflection
	Non-discrimination & Inclusion
Fairness	Dialogue-driven
	Distributive justice & solidarity



The creators of the Compass recognise that these principles have a degree of interrelation. xiv The sub-categories have been selected from discussion surrounding the Compass for differentiation and because they usefully provide a rational framing for the specific ethical challenges that have emerged during COVID-19 and reveal tensions evident in these considerations. For instance, *privacy* (related to preserving the 'dignity and agency of individuals') has been central to public debates and governmental decisions regarding public health technologies designed to manage COVID-19. However, 'mutual respect' usefully captures an important dimension to those debates in the need to consider collective or cultural needs in public health.

The Ethical Compass has not been entirely co-opted and transformed from a tool designed to guide research design at the start of a public health emergency, to another intended for retrospective evaluation. The report remains grounded in its original guidance ethos, encouraging and supporting the Inquiry to **set an ethical direction** for UK policy moving forward from the pandemic by always keeping these ethical principles in view.



# I. Digital Infrastructures: Technologies & Decision Making

Digital infrastructures and/or digital innovation provided many of the solutions to the pandemic's public health, social and economic challenges, e.g., greater use of data and data sharing in decision making; public health technologies to manage transmission of COVID-19. Several projects in the portfolio evaluated the effectiveness of these processes, and the digital infrastructures upon which they were built. An additional set analysed the wider social and economic pivot to digital in the pandemic, giving us broader understanding of the interlocking impacts of accelerated digital innovation.

#### Discussion

Whilst noting where data-focused solutions worked to protect public health (e.g., QCovid), these projects highlight ambivalent effects of digital use across a range of areas which benefit from public investment and/or which were seen to contribute to the pandemic response: healthcare, education and socialisation of children, and cultural access and delivery. The UK Government's *National Data Strategy* celebrated pandemic-driven innovation, not just in public health (e.g., the move online in schools and the facility of learning and working from home).<sup>xv</sup> Important research has investigated the acceleration of government priorities within data and technology use, making observations to improve the effectiveness and ethics of data foundations, skills, availability, and responsibility (19a, 19f). The uneven deployment of digital solutions shows similar challenges apply to wider infrastructure (15a).

A major lesson from this corpus is that maximising the benefits of digital access or data-driven decision making in health emergencies requires digital infrastructures that are humane (skilled, ethical), robust, and transparent and which have public trust. Pandemic research demonstrates that the public were as concerned with the social purpose of public health technology, for instance, as privacy concerns and expressed worries when commercial priorities or the potential for coercion became apparent. We should be careful of pushing the 'wrong advocacy button'xvi in prioritising economic agendas in digital strategies, therefore, and think more widely of the social contexts and purpose of digital infrastructures in construction and oversight. Digital responses to future emergencies will reflect the humanity and quality of existing structures.

- The pandemic demonstrates that we should be focused as much on the collective social value, quality and humanity of digital infrastructures.
- There is further potential and public support for future use of technology and datasharing, if the **social purpose** is made clear and transparent.
- The wider **social effects** of digital infrastructure should always be under review and communicated transparently to enable public trust.
- Ensuring qualitative expertise within the making and monitoring digital infrastructures will safeguard their social purpose, ensure transparency and underwrite public trust.



	Digital Infrastructures - Equal Respect
Dignity and agency of individuals	<ul> <li>Public demonstrated willingness to forego privacy concerns in data-sharing for public health purposes. (13, 25)</li> <li>Decision-making on digital innovation failed to include children, although it then heightened risk to online harms with increased exposure. (9, 19)</li> </ul>
Mutual respect & equal moral worth	<ul> <li>Digital poverty excluded many marginalised communities and vulnerable households from social, cultural, economic, and healthcare benefits created by digital innovation, but online innovations also aggravated social health inequalities. (8,9, 14, 16, 18, 22, 24)</li> <li>Design of public health technologies did not account for diversity in uptake or use and needed greater focus on COVID-19 risk. (3,9,10)</li> </ul>
Transparency & Justification	<ul> <li>Absence of justification for some data-driven decision making, such as the sharing of health data with the police. (14, 19)</li> <li>No due process for building public health technologies and need for wider transparency requirements over data-driven decision making (19, 25)</li> <li>Important data strands, such as the number and timings of deaths of ethnic minority healthcare staff in the pandemic, have been withheld. (14, 18)</li> </ul>
	Digital Infrastructures - Help Reduce Suffering
Social Value	<ul> <li>Investment in digital infrastructures or in digital innovation is not certain to provide social value and social benefits remain unclear. (11, 15, 16, 19)</li> </ul>
Effectiveness & Proportionality  Collaborative & Self-Reflective	<ul> <li>Lack of digital and data literacy impeded effectiveness of decision making in government and the private sector. (15,19)</li> <li>Telemedicine/online health services can degrade care &amp; caring (2,17,21)</li> <li>Health infrastructures had some successes in innovation but some were proportionate but ineffective (e.g., Test and Trace, COVID-19 app) (7, 13, 14, 19)</li> <li>Design for public health technology needs greater consideration of personal and cultural beliefs, and legal frameworks (13, 14)</li> <li>Public health technologies were built in cooperation with the private sector technology companies; research highlights potential conflicts (e.g., choice of software and platform</li> </ul>
	<ul> <li>preferences). (19, 25)</li> <li>Lack of qualitative expertise and cross-disciplinary collaboration in data-driven decision-making inhibited effectiveness. (14, 19, 25)</li> <li>The design of public health technologies requires greater research and consideration. (13, 19)</li> </ul>
	Digital Infrastructures - Fairness
Non- discrimination & inclusivity	<ul> <li>Risk that public health technologies harmed those not using the technology and replicated existing inequalities. (14, 25)</li> <li>Limited diversity in the messaging around these technologies and lower uptake from ethnic minorities. (3, 10)</li> </ul>
Dialogue-driven	<ul> <li>Decision making in relation to data-driven decision making or technology design excluded the views of young people and children, cultural communities and ethnic minorities. (3, 10, 19)</li> </ul>
Distributive Justice & Solidarity	<ul> <li>The 'digital divide' privileged larger and better resourced cultural institutions (and their publics) in the pandemic. (10, 16, 17)</li> <li>Investments in equipment and services for digital infrastructures have continued in the public and private sector, with knowledge of discriminatory effects. (11, 15, 16)</li> </ul>



# II. Communicating COVID-19: Engaging Publics, Guidance & Misinformation

Public engagement has a heightened ethical significance in the pandemic because of its important role in protecting public health.<sup>17</sup> Projects within the portfolio have thrown light on different aspects of COVID-19 communication, including evaluating government messaging, analysing how misinformation spreads, and how ideas such as vaccine hesitancy are formed. In addition, others have offered practitioner and community informed pathways for improving public engagement in public health emergencies, modelling collaboration and solutions focused journalism.

#### Discussion

The collective findings of these projects provide substantial evidence of omissions in the design of communication strategies: how ambiguous guidance impeded effective public health implementation (e.g., care homes, cultural sector); or how 'one size fits all' messaging further distanced families, ethnic minorities and cultural language communities, vulnerable people and people living in poverty from advice they needed. This presents future risks for the NHS, social cohesion, and citizenship. To counterpoint, researchers have shown how community partnerships can empower people and increase the efficacy of 'cultural translation'; or how solutions-focused news affirms democracy through promoting debate and agency (E.g., 3a, 4c, 10e) The place of social media in a public health emergency is a crossproject theme. Government and public sector's increased reliance on social media heightened the status of social media companies as 'arbiters of truth.' There were community benefits, but these must be weighed against real-world harms suffered by children, ethnic minorities and vulnerable people from misinformation or abuse. Substantial analysis of these online forces demonstrates we must address this before the next emergency through understanding its political, cultural, and social bedrocks (26b): it cannot be only counteracted through regulation or online 'nudging.'

- The inquiry should recommend review of government conduct in these areas for future national emergencies and in daily governance, not least because ethicists have raised doubts regarding the self-reflection of government here.<sup>19</sup>
- Future engagement strategies, including the Inquiry's, must learn from our increased understanding of how to effect fairer communication with different publics, translate complex information to meet cultural or social needs, and how the public consume difficult news, including the need to affirm agency by presenting democratic choices ahead.
- Tackling online abuse and misinformation requires a longer-term research investment to understand and address the social, political and structural roots of this behaviour.



	Communicating Covid-19 - Equal Respect
Dignity/agency of individuals	<ul> <li>Individuals drew on a wealth of social networks and communication channels (local media, cultural institutions, community groups) to navigate the pandemic. These are not experienced equally and children, minorities and vulnerable people were at greater risk of harms (3,5,23)</li> <li>Overload of news consumption had negative mental health impacts. (4)</li> </ul>
Mutual respect & equal moral worth	<ul> <li>Minority and language communities have not had equal access to public health information and experienced greater risk from misinformation. (3, 10, 24, 26)</li> <li>Vulnerable groups experienced significant harms from pandemic shaming on social media (23)</li> <li>Healthcare workers have experienced heightened abuse, related to the ways in which government and media have communicated the pandemic (18, 23)</li> </ul>
Transparency & Justification	<ul> <li>The UK Government were ambiguous on what was guidance/advice and what was legal obligation in governance, which undermined transparency. (14, 25)</li> <li>Questions raised about political motives behind government rhetoric (1, 9, 14, 23)</li> </ul>
	Communicating Covid-19 - Help Reduce Suffering
Social Value	<ul> <li>Social media supported public health objectives but provided opportunity to spread vaccine misinformation that undermined public health. (3, 10, 25, 26)</li> <li>Ambiguity between guidance/advice and legal obligation undermined the social value of guidance and faith that it was done for the social good. (1, 9, 14, 23)</li> </ul>
Effectiveness & Proportionality	<ul> <li>Public health guidance was vague, which impeded effective management of the pandemic in health (care homes) and economic areas (e.g., cultural sector) (8, 12, 16)</li> <li>Shaming discourses have undermined public health efforts by discouraging health seeking behaviour (23)</li> <li>Online nudging through social media effective (25), but legitimised social media as 'arbiters of truth) and worsened damage from misinformation (26)</li> </ul>
Collaboration & Self-Reflection	<ul> <li>NHS Clinical Commission Groups require greater translation efforts and need to work with a greater range of academic and community partners to reach ethnic minority language communities. (3, 10)</li> <li>Understanding how people consume news can increase communication with various publics (4, 6)</li> </ul>
1	Communicating Covid-19 - Fairness
Non- discrimination & Diversity	<ul> <li>Social media has been a significant venue for pandemic shaming and misinformation, which has impacted on public health. (23, 26)</li> <li>Deployment of national narratives in public health guidance excluded communities and enmeshed public health in national cultural tropes, which generated harms for health workers. (23, 24)</li> <li>Shaming discourses have been embedded into public health guidance, which are discriminatory against marginalised groups. (23)</li> <li>'One size fits all' approach to public health guidance and communication was not inclusive to different models of family, cultural or ethnic diversity. (3, 10, 24)</li> </ul>
Dialogue-driven	Absence of proper engagement with cultural language community specialists. (3, 10)
Distributive justice & Solidarity	<ul> <li>Social media companies did not act in solidarity with the public health efforts in regulating shaming behaviour on platforms or preventing harms to children. (5, 23)</li> <li>Solidarity in supporting pandemic messaging from wide networks of faith, cultural sector and public services (11, 16)</li> </ul>



# III. Public Health, Economic, Social Impacts and Interventions

The Inquiry is better supported than previous Inquiries in its effort to incorporate personal experience and understand societal impacts because of the considerable evidence that has already been collected by pandemic-impact research in these areas. Arts and humanities research has not only generated a considerable archival record of personal testimony, relevant to the social and economic impacts that the Inquiry studies; it has sometimes offered the *only* evidence-based pathway for appreciating activity outside of state or institutional structures (e.g., mutual aid).

#### Discussion

Much of this research outlined in this review deployed multi-methods approaches (phenomenological, historical, sociological) to give us vital evidence of how the pandemic has synergised with pre-existing place-based health inequalities. This is yet another corpus of evidence that testifies to the critical role of structural inequalities in deciding pandemic outcomes, but this shows us the extent of these insidious impacts in family homes, households, and in workplaces. Recourse to the 'safety' of our homes was especially difficult for those with limited interior space and with poor access to green outdoor areas – lockdowns were more likely, therefore, to impact negatively on ethnic minorities and lower socioeconomic groups (24a). Furlough exacerbated inequalities in workplaces by protecting 'employees' above freelancers or temporary staff (8a, 22a). The strength of local ecosystems of support privileged some communities above others. Future resilience planning will be ineffective unless these collective questions are addressed.<sup>20</sup> However, there is clearly learning here of how processes can be better designed and implemented. A major lesson from this research demonstrates the needs for sector-specific, dialogue-driven engagement in emergency planning for economic interventions (e.g., 8a, 16d, 22b) to avoid 'one size fits all' approach and generate better guidance for employers implementing support schemes.

- The Inquiry should recognise that resilience planning depends on structural change. A
  long-term strategy to effect a fairer society will provide a better basis for a fairer
  distribution of costs/benefits in any public health emergency.
- It should recognise the invaluable evidence-grounded facility of arts and humanities research as a vital resource for **humane understanding** of the emotional, social and economic impacts of COVID-19.
- The Inquiry should incorporate this **substantial evidence** assessing economic interventions, and **how they were implemented**, into its deliberations.
- It must too consider **the implications of impacts** for future welfare planning, funding administration, education and skills support programmes. E.g., skills and career development programmes to mitigate the impacts of furlough.



Pub	lic Health, Economic, Social Impacts and Interventions - Equal Respect
Dignity/agency of individuals	<ul> <li>Lockdowns impacted on children's mental health and sense of wellbeing and there was a lack of support to help them navigate outside of networks that were important for their collective wellbeing. (5, 24)</li> <li>Junior staff and ethnic minorities made more vulnerable to infection, due to choices made by management and employers (11, 18)</li> <li>Cultural sector workforces burdened by policy towards the sector and workforce on the brink of burnout and collapse (8, 22)</li> <li>Lockdowns, closure of schools, and health services may have led to increased morbidity and severity of illnesses for certain long-term conditions (2)</li> </ul>
Mutual respect & equal moral worth	<ul> <li>Pandemic involved a greater use of domestic space (lockdowns, orders, closures), but home is not experienced equally, which made the pandemic especially difficult for those with limited space, poor access to green space, as well as histories of abuse or complicated family dynamics. (24)</li> </ul>
Transparency & Justification	<ul> <li>Social restrictions led to increased food poverty and need (9, 17, 23)</li> <li>Lack of enforcement of social interventions (e.g., face masks) suggests measures not taken seriously. (7, 14)</li> <li>Little understanding of purpose of lockdowns (national and regional) (7, 8, 24)</li> </ul>
Public Heal	th, Economic, Social Impacts and Interventions - Help Reduce Suffering
Social Value	<ul> <li>There is disagreement over the social utility of lockdowns, considering the wide-ranging impacts (7, 14)</li> <li>Economic interventions and welfare (E.g., furlough) had mental health impacts and longer-term consequences, even for those 'saved' by the scheme. (8, 16, 22)</li> </ul>
Effectiveness & Proportionality	<ul> <li>Government support for the cultural sector was not built on sound knowledge of how the sector functions (8, 16, 22) and the impact of COVID on the public sector was decided by long term staffing shortages and funding gaps (11)</li> <li>A combination of less restrictive alternatives, properly enforced, might have struck a reasonable balance between life, health and healthcare, fairness and collective wellbeing. (7, 14)</li> </ul>
Collaboration & Self Reflection	<ul> <li>Community embedded groups better placed to understand of vulnerable community members (9, 14)</li> <li>Work better with employers – government could have foreseen some of the impacts of furlough (8, 16, 22)</li> </ul>
F	Public Health, Economic, Social Impacts and Interventions - Fairness
Non- discrimination & inclusivity Dialogue-driven	<ul> <li>Failures to consider children's viewpoints in planning for social health interventions (19)</li> <li>Deployment of national narratives may have excluded minority and migrant communities from guidance (23, 24)</li> <li>'One size fits all' economic solution to sectoral support: dialogue-driven planning may have better supported different sectoral people (8, 16, 23)</li> </ul>
Distributive justice & Solidarity	<ul> <li>better supported different sectoral needs. (8, 16, 22)</li> <li>Increase in food insecurity not effectively tackled by state welfare (9)</li> <li>Furlough exacerbated inequalities between employees, freelancers and precarious staff, thereby exacerbating social inequalities. (8, 16, 22)</li> <li>Unequal access to funding due to systemic inequalities in cultural sector(8, 16, 22)</li> <li>Greater need for employers to act in solidarity to support workers (11, 18)</li> </ul>



# IV. Health and Social Care Settings

One of the Inquiry's primary aims is to evaluate the response of the health and care sector across the UK. Arts and humanities research has taken us into the pandemic's health and care settings via interviews, focus groups, and surveys. They have provided uniquely valuable understandings of how health and care delivery has functioned during the pandemic, from the perspectives of patients themselves, and the workers upon whom that delivery depends.

#### Discussion.

A significant element of this research demonstrates the importance of long-term structural issues, such as the underfunding and staff shortages created by austerity and aggravated by Brexit, in deciding pandemic outcomes. Already under-resourced areas of healthcare have fared particularly badly; a good example being the de-prioritisation of children long-term health conditions, which is itself obscured by absence of research funding in that area (2a). Working at crisis capacity with limited resources, and rising abuse from members of the public, contributed to widespread staff overwhelm. Structural discrimination worsened outcomes for black and brown health workers, who were put at greater COVID-19 risk than white colleagues.

Research in this corpus also shows how systems can better support staff in a public health emergency (21d, f) The lack of an appropriate ethical framework for this pandemic's various 'reset' phases, for instance, undermined professional autonomy and ability to translate relational values of caring to pandemic healthcare contexts. These findings chimed with observations (12b) of how guidance did not empower managers to prioritise wellbeing holistically or make decisions according to their contexts. The undermining of autonomy contributed to the deterioration of care, an undermining of human rights, and a wide disparity in experience for patients and families.

- There must be a **co-ordinated** and **systemic response** to address structural racism, which incorporates immigration policy and institutional action.
- Instituting better and more appropriate **systems of ethical support**, modelled for different pandemics and reset phases, can support health and care worker's professional autonomy and care for patients.
- **Building moral support** into existing health systems may prove a more flexible way to help workers manage their own feelings of moral injury during a PHE.
- The Inquiry should inspire an honest dialogue with the public about future standards and pandemic harms, acknowledging the historic and political choices that have undermined the NHS.



	Health and Social Care Settings - Equal Respect
Dignity/agency	Patient experience of healthcare services has worsened and the public feel more distanced
of individuals	from NHS decision making. (2, 17, 21)
	Black and brown workers had less autonomy to decide tolerable COVID-19 risks for
	themselves. (17, 18)
	Mandating infection measures impaired autonomy of healthcare professionals. (12, 17, 21)  The distribution of the second of
	The dignity of care home patients was impaired use of DNACPR orders, failures to protect  human gights and called a farm and the care of the property of the care of the
	human rights, and collapse of framework of mental capacity support by lockdown
Markan I was a sak	restrictions. This impacted severely on health and wellbeing. (12, 14)
Mutual respect	<ul> <li>Children's healthcare needs were deprioritised during the pandemic (2, 21)</li> <li>Healthcare was delivered at a physical, emotional, and moral cost to workforces. (12, 17, 18,</li> </ul>
& equal moral worth	
WOITH	<ul> <li>21, 23)</li> <li>Black and brown workers managed the emotional toll of COVID on top of historic</li> </ul>
	experiences of bullying and abuse. (17, 18, 23)
	<ul> <li>DNACPR orders impacted widely on decisions made about patients. (12)</li> </ul>
	<ul> <li>Minority ethnic and language communities were less able to navigate the healthcare system,</li> </ul>
	due to inappropriate guidance/messaging. (3, 10)
Transparency &	The ethical framework of the pandemic did not meet the context of COVID-19, with waves
Justification	of infection followed by intervening reset phases. (7, 21)
Justinication	Care home Sector professionals felt some of the restrictions were not adequately justified
	in the specific context of care homes and for the protection of patients (12)
	Health and Social Care Settings - Help Reduce Suffering
Social Value	The social purpose of the NHS was undermined by years of staff shortages and long-term
Social Value	funding deficits, aggravated by Brexit. (17, 18)
	<ul> <li>Disregard of the care sector's unique social value by the UK government (12)</li> </ul>
Effectiveness &	<ul> <li>Online delivery of healthcare has trade-offs (misdiagnosis and missed diagnosis) (2, 17, 21)</li> </ul>
Proportionality	<ul> <li>Mandating infection measures in the reset phase had trade-offs especially for end-of-life</li> </ul>
roportionalty	care, which caused considerable distress for patients and their families. (12, 17, 21)
Collaboration &	Collaboration between NHS Trusts improved healthcare services and delivery (21)
Self-Reflection	Workers need ethical framework appropriate to the reset phase to increase effective
	professional autonomy and avoid moral injury (21)
	<ul> <li>Absence of necessary mental health and psychological support for healthcare professionals</li> </ul>
	and care home staff. <b>(12, 17, 21)</b>
	Health and Social Care Settings - Fairness
Non-	Black and brown health workers were put at greater risk of infection and mental distress
discrimination	due to systemic cultures of racism in the NHS. (17, 18)
& inclusion	Children's health care has not been fairly considered due to systemic lack of resources (2)
	<ul> <li>Health guidance and communication was not culturally inclusive (3, 10)</li> </ul>
	Failures to support the NHS with realistic messaging led to increased levels of abuse from
	members of the public of professionals, which took place online and in hospitals. (21, 23)
Dialogue-driven	Healthcare become less dialogue driven in the pandemic because of the mandate of
	infection measures. (21)
Distributive	NHS Trusts and Managers did not adjust targets which caused stress for workers. (17, 21)
justice &	Difference in treatment between NHS and social care, despite similarity of functions. (12)
Solidarity	Government should rebuild public trust in the NHS through an honest dialogue,
	<ul> <li>which clearly sets out how historic funding decisions have impacted on services. (17, 23)</li> </ul>
	The NHS must be resourced to cope with knock on effects of health avoidance and mental
	health distress, created during the pandemic (3, 10, 17, 23)



## V. Democratic Governance

Governing institutions accept the need for Inquiry to review harms to democratic governance during the pandemic, and to propose alternatives or additional safeguards for future emergencies.<sup>21</sup> The UK Inquiry has no such stated intention, but its acknowledged investigation of 'legislative control and enforcement'<sup>22</sup> infers review of those broader questions. Moreover, examining 'collaboration between' the state and 'voluntary and community sector', the Inquiry may be drawn into debates around the government's recalibration of state/society cooperation in governance.<sup>23</sup>

#### Discussion

Strands of this corpus informs both areas of deliberation through:

- a) Legal/empirical analysis into governing/oversight mechanisms functioning.
- b) Documenting expanded social roles of voluntary organisations, religious communities and cultural institutions during the pandemic.

There is consensus that the constitutional mechanisms designed to protect human rights and safeguard democracy did not function well.<sup>24</sup> Research highlights government overuse of devolved legislation and statutory instruments, circumvention of parliamentary scrutiny, and the marginalisation of human rights in parliamentary oversight. These insights may inform constitutional resilience, e.g., examining the facility of the Civil Contingencies Act (2004) vs Coronavirus Act (2020); how the judiciary might play a role in balancing constitutional relationships; means to fully integrate human rights into parliamentary process.<sup>25</sup> There is less consensus about what pandemic experience tells us about the 'who' and 'how' of an expanded 'social covenant'. On the one hand, projects suggest good reasons to cede power to groups that exist closer to vulnerable communities and understand their needs, demonstrating the need to recalibrate social/state relations in governance.<sup>26</sup> However, the potential contribution of these groups to *values* of governance is unsettled. Concerns exist regarding whether the government can share power with ideologically dissimilar groups, or whether it will deploy relationships for the status quo.<sup>27</sup>

- The Inquiry should establish need for better legislative framework, and a set of ethically informed expectations for the conduct of governance, as part of resilience planning.
- The Inquiry should be aware of its potential **scope for politicisation** in debates about the social covenant as it validates 'lessons learned'.
- The Inquiry should establish the **need for clarification** regarding the **values**, **justification**, **and mechanisms** for any expanded 'social covenant' if its deliberations highlight increased social cooperation as a 'lesson learned'.



	Democratic Governances - Equal Respect
Dignity/agency of individuals	<ul> <li>Pandemic has seen crisis in democratic governance, with undermining of human right protections. (14, 20, 25)</li> <li>Reinvigoration of democratic citizenship seen in mutual aid networks, increased civic engagement, and social solidarity from institutions (6, 9, 16, 24)</li> </ul>
Mutual respect & equal moral worth	<ul> <li>Disregard for human rights has unfairly harmed ethnic minorities, those with long term health conditions elderly, and those already experiencing poverty throughout various strands of COVID-19 legislation. (12, 14, 20, 25)</li> </ul>
Transparency & Justification	<ul> <li>MPs concerned at failures of transparency, but MPs also failed to hold government to account over human rights protections (14, 20)</li> <li>Limited data about the number of prosecutions under either public health regulations or the Coronavirus Act 2020 (14)</li> <li>Concerns raised about the motivations behind government policies and rhetoric.</li> <li>Lack of transparency regarding scientific evidence (14, 25)</li> </ul>
	Democratic Governance - Help Reduce Suffering
Social Value	<ul> <li>Opportunity/need to recalibrate state/society relations in governance (4, 6, 9, 16, 24)</li> <li>Pandemic shows extent of structural inequalities as urgent problem for governance (9, 18, 20)</li> <li>Politics influenced public health decision making (25)</li> </ul>
Effectiveness & Proportionality	<ul> <li>Concerns about the legislative framework used for COVID-19 (14, 20, 25)</li> <li>Disproportionate use of secondary legislation and statutory instruments. There were clearly alternatives to employ primary legislation on specific areas (14, 20)</li> <li>Concerns about the proportionality and necessity of lockdown restrictions already tested in courts and may be more come (25)</li> <li>Failures to observe and protect human rights protection in parliamentary oversight (20)</li> </ul>
	<ul> <li>Pandemic restrictions devolved to the business, cultural and third sector without effective enforcement. There was a strong ethical case for state coercion on face coverings. (7, 14)</li> <li>Failure of scrutiny and accountability mechanisms. Parliamentary committees have functioned effectively, but other areas have not. (e.g., courts). (14, 25)</li> </ul>
Collaboration & Self Reflection	<ul> <li>Strengthen the judiciary's role in deciding the margin of appreciation of government in the context of the presence or absence of parliamentary scrutiny (25)</li> <li>Strengthen parliamentary oversight of human rights protections through guidance and frameworks that fully integrate the IHRA in parliamentary process. (20)</li> <li>Absence of a governing framework for public health emergencies – need to establish primary legislation to deal effectively with emergencies. (14, 20, 25)</li> </ul>
	Democratic Governance - Fairness
Non- discrimination & Inclusion	<ul> <li>Virtual court hearings were less fair for people with impairments or disabilities and may have resulted in more punitive rulings overall (14, 24)</li> </ul>
Dialogue-driven	<ul> <li>Absence of dialogue driven governance initiatives to support cultural language or ethnic communities. (3, 10)</li> </ul>
Distributive justice & Solidarity	<ul> <li>There were deficiencies in international legal frameworks that impeded international co- operation, but government should adhere to international obligations under current international health regulation and other instruments, cooperate and share information and resources in good faith. (1, 25)</li> </ul>



# Conclusion – a question of ethics

Ensuring the right response to the pandemic has been intrinsically a normative and ethical challenge – the same is true for the task of the public inquiry. Through the preceding analysis of arts and humanities research, we have demonstrated the ways in which evaluative scrutiny and ethics must coincide in weighing policy taken and formulating a policy approach for the future. It is important to reiterate the vital role that arts and humanities research plays in generating data on which a better, more ethical, trajectory for policy can be based as lessons of the effects of the pandemic are learned. *Any* and *all* consideration of what should or should not have been done, what should and should not be done in future, is a reflection on how values should be weighed, for whom, and why. Since values cannot be captured quantitively, qualitative testimony is indispensable as a guide for how to proceed, and this review therefore stands as an articulation of the way forward.

Determining what ought to be done is not *simply* a question of collecting qualitative data about views or perspectives, or experiences. It will also involve weighing conflicting evidence and balancing priorities to arrive at recommendations that will improve government approaches so we can avoid similar harms in future crises or pandemics. Qualitative evidence is not equivalent to an ethical recommendation; the evidence can provide morally relevant facts about harm, and these facts can be used as the basis for adjudication about how to proceed and ameliorate the situation. The evidence presented here, incorporated into broader evidence that the Inquiry will handle, may be rebalanced by other findings, or indicate several currently unforeseen courses of action. The purpose of this review has been to illuminate the landscape through which an ethical direction can be plotted in full recognition that this course itself may change as that landscape develops greater coverage and depth.

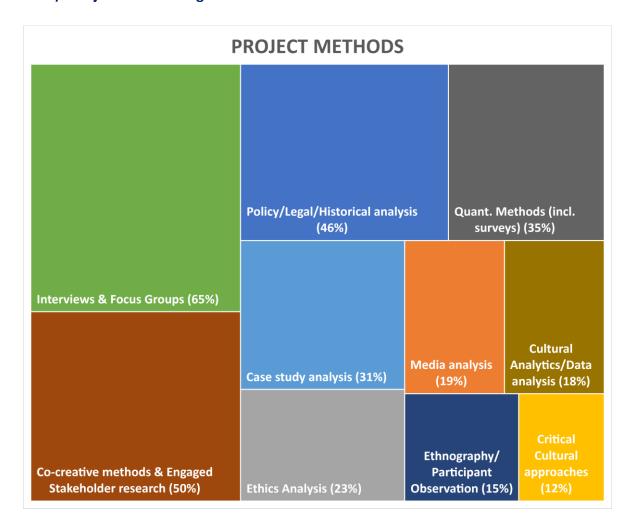
Without this research, we would not know as much at this juncture of how the pandemic has disrupted people's lives and for what reasons; we would bear little understanding of insidious ways in which structural harms and pandemic harms have interacted; the cracks in constitutional and democratic governance would be less visible. The qualitative, interpretive, value-laden nature of what is produced by the arts and humanities lends itself ideally to the kinds of insights into people's lives that can tell us what the ethical shortcomings of the government's response have been. It provides a critical and crucial route for effective scrutiny of power across multiple, interlocking governing and institutional contexts, helping safeguard democracy, promote fairness, and undergird legitimacy in our systems of governance. Arts and humanities research has a vital future role to play in the *ethical* direction of the UK.



# **Appendix**

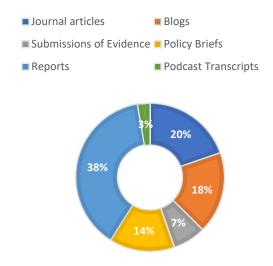
# I. Evidence and Methodologies

# a) Project Methodologies



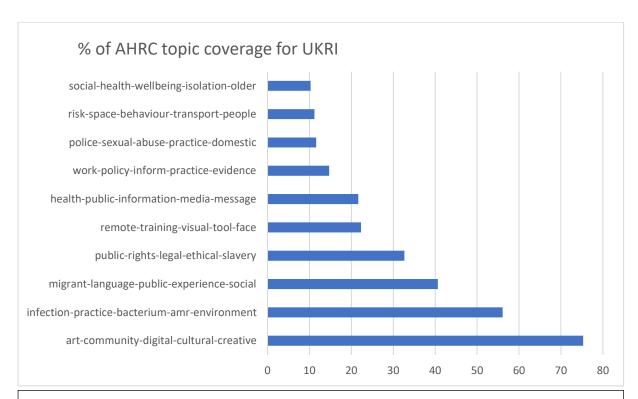


# b) Grey literature



# **II. Topic and Subject Reach**

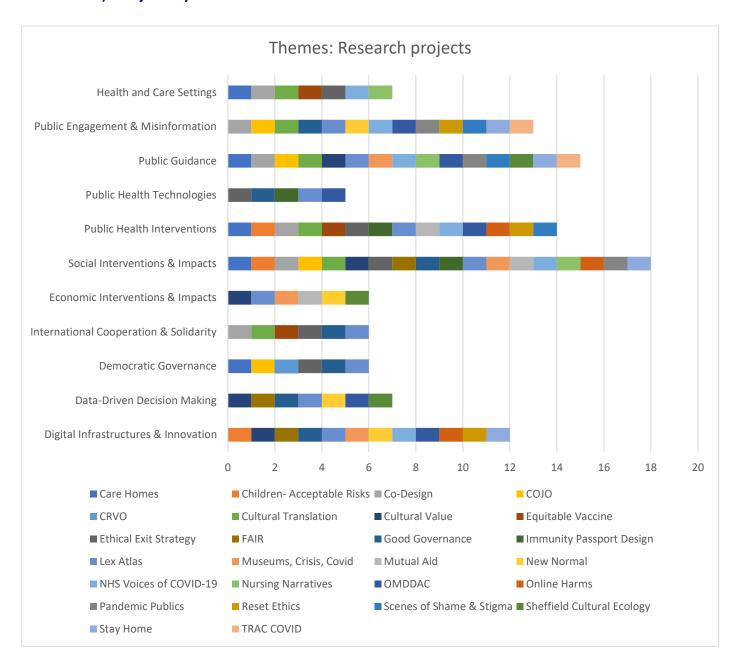
## a) AHRC % contribution to total UKRI topics



Calculation that the AHRC has received c.6% of total UKRI funding for COVID-19, estimated from the UKRI-280222-AllFundedCOVID19ResearchProjects.xlxs spreadsheet downloaded from the UKRI website, from which Research Councils were extracted from the grant project IDs.

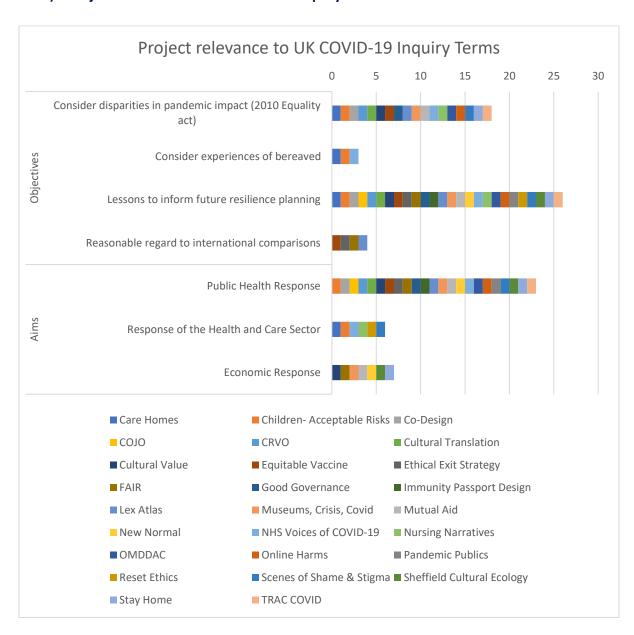


# b) Projects by theme





# c) Project relevance to UK COVID-19 Inquiry





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- 7. COVID-19: The ethical Exit Strategy: the path from relaxing measures to vaccination
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This is not final or complete data. The figures were obtained by analysis of a spreadsheet downloaded from the UKRI website UKRI-280222-AllFundedCOVID19ResearchProjects.xlxs, which was the summation of all award activity as it stood in February 2022. This data has now been superseded by an update in July. <a href="https://www.ukri.org/publications/covid-19-research-projects-and-awards-funded-by-ukri/">https://www.ukri.org/publications/covid-19-research-projects-and-awards-funded-by-ukri/</a>. Note that the *Pandemic and Beyond* represents 77 of these projects.

iii Selection of an addition 7 projects was undertaken to increase representation in the wider areas of Pandemic and Beyond, which found <u>four overarching thematic clusters</u> within its 77 projects: Ethics and Governance; Arts, Health and Wellbeing, Creative industries, and Communication, Information and Experience. Selection prioritised research that focused on societal impacts, rather than others that focused, for instance, on practitioner experiences in the creative industries. Other considerations, such as duplication, and project stage, including the availability of evidence, were also taken into account.

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<sup>&</sup>lt;sup>26</sup> Projects examined very different elements of societal action, and not all engaged actively with the question of governance. However, many projects did provoke considerations related how 'shared citizenship' might be best effected, or made calls for religious or community organisations to be funded to support their local communities, others noted the increased sense of social relevance for museums and cultural institutions and calls for funding models to recognise more of this social work.

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