The UK Covid-19 Inquiry Terms of Reference:

Analysis of Consultation Responses

Prepared for the UK Covid-19 Inquiry
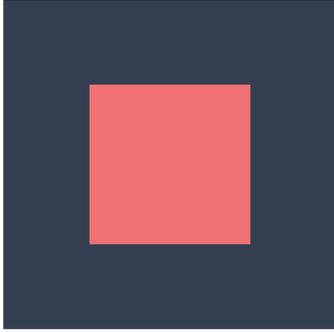
alma economics

About the authors

Alma Economics combines unparalleled analytical expertise with the ability to communicate complex ideas clearly.

www.almaeconomics.com

About the commissioning organisation

This independent analysis was commissioned by the UK Covid-19 Inquiry. The UK Covid-19 Inquiry is the independent public inquiry set up to examine the Covid-19 pandemic in the UK. The analysis and findings set out in this report are those of the authors and do not represent the views of the UK Covid-19 Inquiry. While the Inquiry has made every effort to ensure that the information in this document is accurate, they do not guarantee the accuracy, completeness or usefulness of that information.

www.covid19.public-inquiry.uk

Table of Contents

Abbreviations

CEV	Clinically Extremely Vulnerable
GP	General Practitioner
ICU	Intensive Care Unit
LGBTQI+	Lesbian, Gay, Bisexual, Transexual, Queer, Intersex
LSVC	Linear Support Vector Classification
NHS	National Health Service
PPE	Personal Protective Equipment
PTSD	Post-Traumatic Stress Disorder
QALY	Quality Adjusted Life Year
SAGE	Scientific Advisory Group for Emergencies
SPI-B	Independent Scientific Pandemic Insights Group on Behaviours
ToR	Terms of Reference

Executive Summary

Background and objectives

The UK Covid-19 Inquiry was established to examine the UK's preparedness and response to the Covid-19 pandemic, and to learn lessons for the future. The Prime Minister consulted with Baroness Hallett and the Devolved Administrations on the provisional scope for the Inquiry, which was set out in the draft Terms of Reference (ToR) published on the 7th of March 2022. To ensure that the ToR considered the public's concerns, the Inquiry sought public consultation on the ToR for 4 weeks between the 11th of March 2022 and the 7th of April 2022. The consultation consisted of 2 closed-format and 3 open-format free-text questions and focused on gaining public perspective on what the Inquiry should consider and on aspects of how the Inquiry should go about its work. Questions were asked about what should be added to the ToR, as well as what should be prioritised during the Inquiry. The consultation also sought views on how the Inquiry should be designed to ensure that it captures the voices of those who have suffered most as a result of the pandemic and its response.

Alma Economics, an independent research consultancy, was commissioned to analyse the responses to this consultation and to produce a comprehensive summary of respondents' views. This report provides an in-depth overview of the key insights emerging from responses. For closed-format questions, the report also presents results from segmentation analysis, which breaks down responses by respondent type and key demographics, to help better understand how views differed across respondents.

Key findings

Overall, over 75% of respondents felt that there were ways in which the ToR could be expanded. Most respondents believed that there were a number of topics which should be added to the ToR and that the Inquiry should add more detail around the topics which are already included in the draft ToR. Respondents were also largely united in calling for the Inquiry to set a planned end-date for its public hearings to ensure that the Inquiry can present its findings and recommendations in a timely manner. Where respondents were more divided was on the finer points of what exactly should be added to the ToR and what should be prioritised by the Inquiry.

A set of over-arching themes emerged from responses: i) the need to make children and young people a central focus of the Inquiry, ii) the desire for the Inquiry to get to the heart of how decisions were made during the pandemic, iii) the need for the Inquiry to ensure that participation is as broad, inclusive and accessible as possible, and iv) the request for the Inquiry to both include and prioritise the consideration of the management of the healthcare sector during the pandemic. A description of each of these themes is provided below.

The impact of the pandemic and its response on children and young people

The theme most emphasised in responses was the view that an attempt to understand the impact that the pandemic and its response has had, and continues to have, on children and young people should be at the heart of the Inquiry's work. Respondents cited the need to investigate the more direct implications of the pandemic response, such as school closures and adjustments to the UK's education system during the pandemic, but also the less direct impacts of the response such as the mental health implications of being isolated from classmates, family and friends. Many respondents expressed the view that the impacts on children and young people are of particular importance given

the possibility that they could become entrenched and lead to a generation of young people dealing with the ramifications of this period for the rest of their lives. Respondents felt that not only should the Inquiry make sure that these considerations are included in the ToR, but that they should also be a priority for the Inquiry as they begin their work.

Decision making during the pandemic

Another overarching theme in responses was respondents' desire for the Inquiry to provide an understanding of all aspects of the government's decision-making process during the pandemic. How were decisions made? Who was involved? And to what degree was sound scientific evidence followed throughout? Respondents brought up this underlying concern in relation to a wide range of government decisions, with lockdowns, enforcement of mask wearing and social distancing, and school closures being particular areas of interest. Many respondents were also keen for the Inquiry to investigate the roles of advisory groups like the Scientific Advisory Group for Emergencies (SAGE) in decision making; they wanted the Inquiry to investigate how these groups were selected and the degree to which their advice was followed.

Ensuring participation in the Inquiry is broad, inclusive and accessible

A further issue which shone through a large number of responses was respondents' feeling that the Inquiry should make public engagement a priority. Respondents shared their view that the Inquiry should use every tool at their disposal to make participation accessible to as wide a group of stakeholders as possible. Responses differed in the means of accessibility they suggested, be it allowing people to provide testimony from the comfort of their homes or using third sector outreach programmes to reach seldom heard groups for example, but the underlying message of ensuring wide participation was widespread. Furthermore, a large number of respondents were sceptical of the ToR only explicitly referencing bereaved families when they felt that the scope could be made broader to include the many other groups who suffered similarly as a result of the pandemic such as children and those with chronic illnesses who were deprived of NHS care.

Management of the healthcare sector during the pandemic

The final overarching theme which was pointed out by a large number of respondents was their view that the Inquiry should both consider and prioritise an investigation into the way that the NHS and the wider healthcare sector was managed throughout the pandemic. Respondents expressed the view that personal protective equipment (PPE) shortages, understaffing and the impact on care for non-Covid-19 patients required particular attention from the Inquiry to help avoid similar mistakes being made in the future. Many respondents also cited the management of the primary care sector as an area which should be explicitly considered by the Inquiry with GP practices and pharmacies not being deemed as having received enough attention in the ToR. Respondents communicated the view that GPs in particular faced massive disruption to their services and that the Inquiry should consider how this impacted both their patients and the healthcare providers themselves.

Introduction

The UK Covid-19 Inquiry has been set up to examine the UK's preparedness and response to the Covid-19 pandemic, and to learn lessons for the future. The Prime Minister consulted with Baroness Hallett and the Devolved Administrations on the provisional scope for the Inquiry, which was set out in the draft Terms of Reference (ToR) published on the 7th of March 2022. The ways in which the pandemic has affected us all are numerous and complex, and so the Inquiry held a public consultation to ensure that everyone in the UK had the opportunity to give their views on these draft Terms of Reference.

The Terms of Reference sets out the broad aims of the Inquiry as:

1. Examine the Covid-19 response and the impact of the pandemic in England, Wales, Scotland and Northern Ireland, and produce a factual narrative account.
2. Identify the lessons to be learned from the above, thereby to inform the UK's preparations for future pandemics.

Underneath these headings, the ToR goes into detail regarding the specific issues and sectors it will focus on as well as the types of experiences it will look to listen to and consider.

The online consultation was hosted on an online portal called Citizen Space and consisted of 2 closed-format and 3 open-format free-text questions (in addition to 11 questions about respondent background and demographics). Additionally, respondents could reply directly to the UK Covid-19 Inquiry through email or post, and there were a number of consultation events held across the UK where stakeholders were invited to share their views on the consultation's questions. The consultation was open for responses for the four weeks from the 11th of March 2022 to the 7th of April 2022 with consultation events also held within this period.

Questions were asked about respondents' views on the UK Covid-19 Inquiry's draft Terms of Reference which were made public in March of 2022. They sought the public's views on aspects of the ToR's content, the Inquiry's timeline and the ways in which it can ensure that people's experiences can be heard. A full list of consultation questions is set out below and an extended version which includes questions related to the respondents' demographic characteristics (which covered questions 1-11 of the consultation) is available in Annex A.

Question 12. Do the Inquiry's draft Terms of Reference cover all the areas that you think should be covered by the Inquiry?

Question 13. Please explain why you think the draft Terms of Reference do not cover all the areas that the Inquiry should address.

Question 14. Which issues or topics do you think the Inquiry should look at first?

Question 15. Do you think the Inquiry should set a planned end-date for its public hearings, so as to help ensure timely findings and recommendations?

Question 16. How should the Inquiry be designed and run to ensure that bereaved people or those who have suffered serious harm or hardship as a result of the pandemic have their voices heard?

Alma Economics was commissioned to analyse the responses to this consultation and this report provides a summary of that analysis, including a description of the methodology, an overview of the respondents' demographic characteristics and a question-by-question summary of respondents' sentiments.

Methodology

Individual and organisational responses

Respondents were able to indicate whether they were responding as an individual or on behalf of an organisation. This question was only introduced on March the 16th, five days after the consultation opened. For respondents who took part before this date, their response is marked as 'not answered'.

Campaign responses and removal of duplicates

A number of campaigns organised by external groups or individuals coordinated responses to the consultation. While responses to qualitative questions could be flagged as close or exact duplicates, it would be difficult to robustly identify whether duplicate responses came from campaigns or from individuals and/or groups who informally consulted each other before submitting their responses (in particular, no single "cluster" of matching responses was larger than 2.5% of the total dataset, and groups of respondents who submitted duplicate responses to one question often did not submit duplicate responses to another question). In combination, campaigns and duplicates accounted for approximately 15% of responses.

Due to the small sample sizes of potential campaign responses and to ensure that all responses are considered, responses which were close or exact duplicates were not removed from the analysis presented in this report.

During the manual review of responses, the research team screened for responses that were clearly intended as offensive, abusive or explicitly vulgar. No responses were removed as a result of this screening on the basis of there being very infrequent use of potentially offensive language.

Approach to quantitative analysis

The consultation included two closed-format questions, and descriptive analysis of responses to these questions was undertaken using Python. The main text presents a breakdown of responses to each consultation question by respondent type (individual or organisation), age cohort and geographical location. Each question includes a chart that summarises responses as a percentage of consultation respondents who answered the question. Full tables of results which break down responses by a range of demographic sub-groups are included in the annex.

Qualitative thematic analysis

The consultation included three open-format questions with free-text fields. To analyse these responses, the research team followed an approach that combined manual and automated coding.

Developing an initial codebook of themes

Following the approach developed by Fereday and Muir-Cochrane (2007), the team developed an initial set of themes and ideas based on the consultation, an understanding of the policy context and wording of specific questions (the deductive phase), with further themes added as part of the review process (the inductive phase). This set of themes formed the basis of a codebook which was used to ensure consistency across members of the research team, with each theme in the codebook reviewed until the team agreed upon criteria and examples of the theme.

Initial manual coding

For Citizen Space responses, a random sample of free-text responses for each open-format question was manually reviewed and coded into themes, with team members adding to the codebook as needed. The coding was reviewed by a second coder as part of quality assurance. The event transcripts and organisational responses via email or post were manually reviewed in their entirety. Individual responses via email or post were treated in the same way as those made on Citizen Space.

Integrated manual and automated text analysis

Due to the high number and complexity of responses, automated text analysis was used to replicate the process of manual coding, following a four-step process:

- **Data cleaning:** At this point, two datasets were produced. The first had stopwords (short, common words that do not add to a sentence's meaning) removed and keywords stemmed/lemmatised (so different inflections of the same word were grouped together). This would be the input for unsupervised topic modelling and supervised learning. The second did not undergo additional changes and would be the input for supervised few-shot learning.

- **Unsupervised learning:** Two techniques were used to automatically identify topics within the free-text responses to each question: hierarchal clustering (which groups responses based on their dissimilarity) and zero-shot learning (which takes the codebook of themes identified from initial manual coding as input and applies natural language inference techniques to assign themes to responses).

- **Text augmentation and supervised learning:** To increase the size of our labelled dataset (from the initial manual coding), the research team defined and applied transformation functions (which can be applied to a single training data point to create another valid training data point with the same theme). These functions included synonym replacement (for verbs and adjectives) and random insertions, swaps and deletions (following the approach of Wei and Zou (2019)) and were applied on 50% of the labelled dataset to generate 16 augmented responses per original response. Linear Support Vector Classification (Linear SVC) and Naïve Bayes estimators were then applied on the augmented dataset to predict themes for responses not included in the initial manual coding.

- **Manual review and triangulation:** The research team then manually reviewed a sample of responses labelled through the automatic text analysis, comparing outputs from the different methods. Feedback on correctly and incorrectly labelled responses was then incorporated into the automated text analysis through changing model parameters and inputs (such as the specific wording of themes), revising how responses were assigned to different themes or applying specific programmatic rules and heuristics. This approach was iterated until the research team agreed on 90% of the themes assigned by the automated text analysis within the sample of responses.

Thematic analysis

For each open-ended question, a descriptive summary has been presented of key themes emerging from the integrated manual and automated text analysis as well as responses set aside during the data cleaning stage. While it is difficult to provide accurate counts of responses allocated to each theme, themes are presented in the approximate order of the number of corresponding responses. Individual quotes have been included where appropriate to illustrate the narrative around specific themes, and quotes were only selected from respondents who provided permission for their views to be published and with any potential identifiers (such as the name of a specific organisation) removed.

Overview of respondents

Total number of responses

The consultation was open to everybody in the UK (to the general public as well as organisations) and received 20,061 responses through the online platform on Citizen Space, email or post, and all responses have been reviewed. The vast majority of responses (99%) were submitted through Citizen Space.

Consultation events

As well as the responses submitted via email, post and Citizen Space, the Inquiry held 14 consultation events across the UK where they directly asked stakeholders for their views regarding the consultation questions. A full list of the events is available in Annex B.

Location of respondents

Respondents were asked to report the country where they lived and, in the case of those residing in the UK, they were also asked to report the county in which they lived. Overall, 41% of respondents chose not to provide this data, but of those who did, 87% were based in England, 4% were based in Wales, 6% in Scotland, 2% in Northern Ireland and 1% from outside the UK.

Figure 1. Geographic representation of respondents by UK region

The geographic representation index is the percentage of respondents living in a certain region divided by the percentage of the UK's population which lives in that region.

Region	Geographic Representation Index
South East	135
South West	133
East of England	117
Yorkshire & The Humber	104
North West	100
Wales	93
North East	88
Scotland	83
London	81
West Midlands	80
East Midlands	78
Northern Ireland	56

8,169 Respondents chose not to answer

**140** Respondents reported living outside the UK
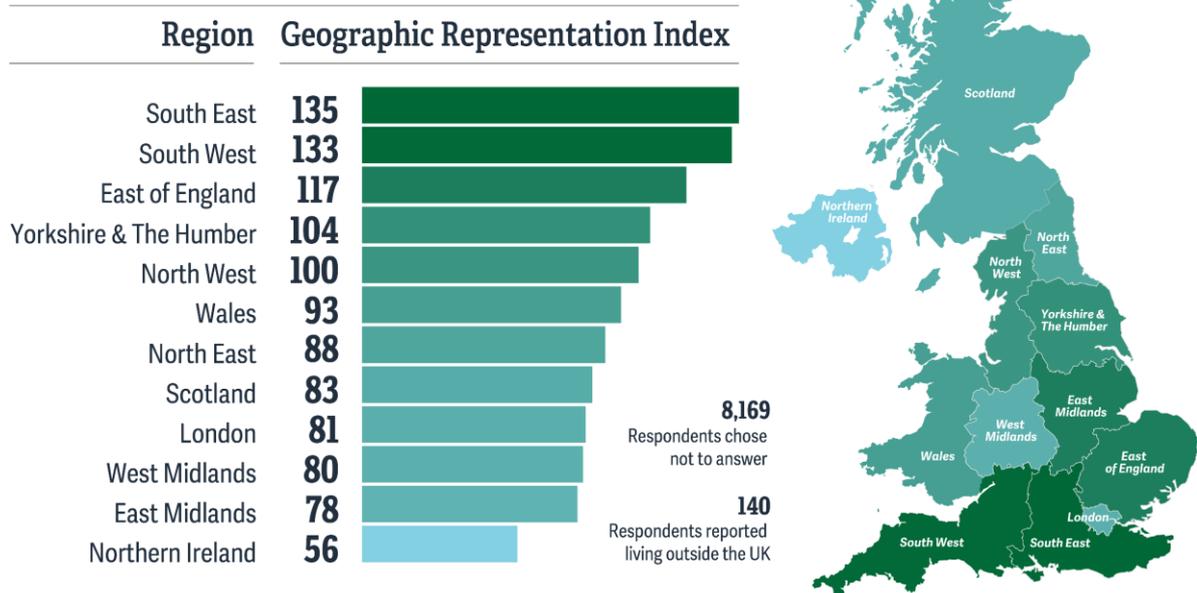
Figure 1 shows how the number of respondents in each region compared with regional shares of the UK's population using a geographic representation index. A geographic representation index of 100 would imply that the share of respondents who come from that region is equal to the share of the UK population which comes from that region. The figure shows that the South East and South West of England are relatively overrepresented among respondents with over 30% more respondents from

these areas than one would expect on the basis of their populations. On the other hand, Northern Ireland and the East Midlands are relatively underrepresented with 44% and 22% less respondents than one would expect on the basis of their populations respectively.

Individual and organisational responses

In total, 18,843 valid responses (94%) were submitted by individuals and 440 valid responses (2%) were submitted by organisations (726 respondents did not answer this question). The organisations which participated came from a wide range of sectors including charities, unions, faith groups, education and healthcare. It was not possible to verify whether all respondents self-identifying as organisations were submitting their response in an official capacity.

Age of respondents

Middle-aged and older people made up the vast majority of respondents with over-45s accounting for over three quarters of those who reported their age. At the other end of the spectrum, under-30s account for just 3% of respondents, which suggests that this group did not actively engage with the consultation (Figure 2). A full set of demographic breakdowns is available in Annex C.

Figure 2. Share of respondents by age cohort
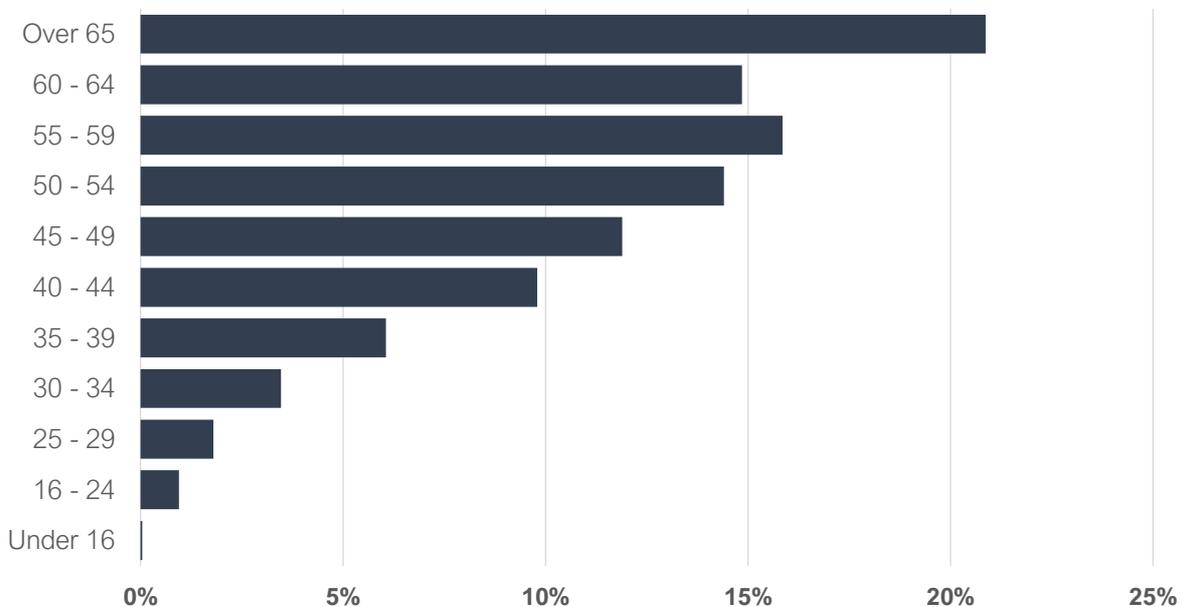
Question 12

Do the Inquiry's draft Terms of Reference cover all the areas that you think should be covered by the Inquiry?

Overall, the majority of respondents believed that the Terms of Reference do not cover all the areas that they think should be covered by the Inquiry. Looking into the regional distribution of the responses, we observe that there were no regions in which a majority of respondents found the Terms of Reference to be comprehensive (Figure 3). Wales, at 44%, was the region where the highest share of respondents reported that the ToR covers all the areas they wanted to be covered, whereas respondents in London and the South West were most likely to imply that the Terms of Reference are incomplete with only 31% of respondents there reporting that the ToR covers all the areas they wanted to be covered.

Figure 3. Share of respondents who said "Yes" by UK region

Region	Percentage of respondents who said "Yes"
Wales	44%
Yorkshire & The Humber	40%
North West	40%
North East	40%
Scotland	38%
Northern Ireland	35%
East of England	34%
West Midlands	34%
East Midlands	33%
South East	32%
London	31%
South West	31%

**45%** of International respondents **said "Yes"**
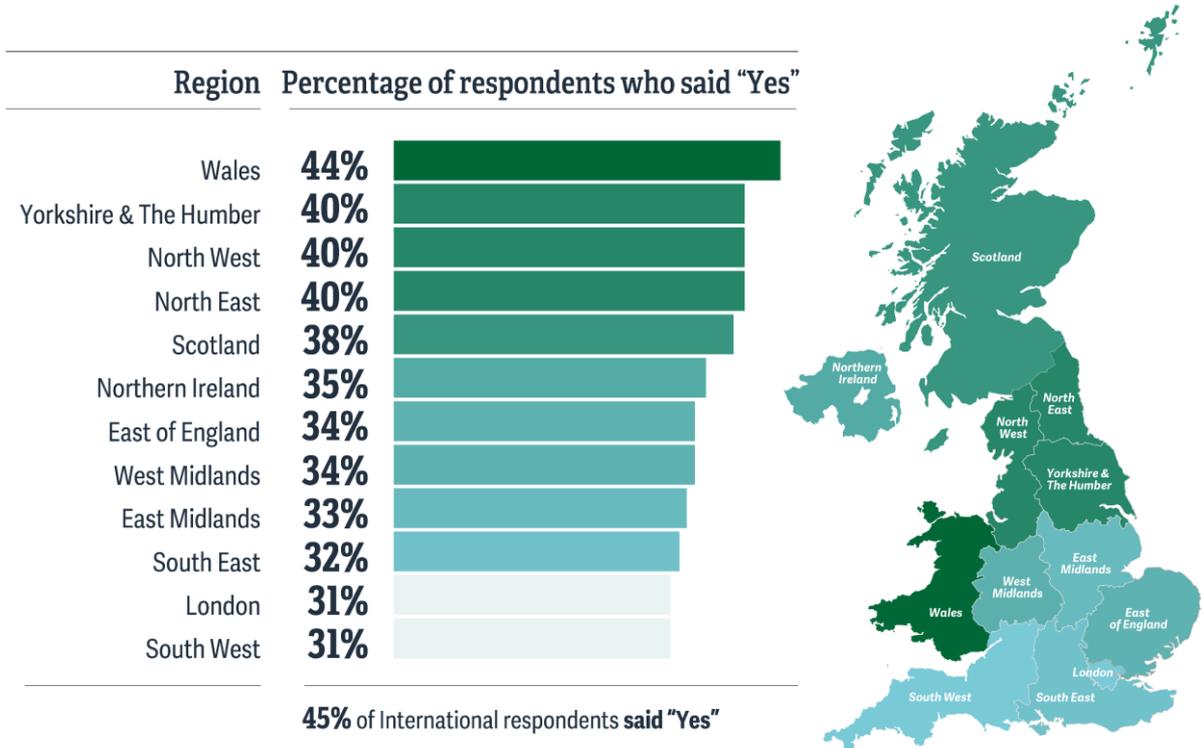
Figure 4 shows that responses were largely consistent between age groups. 35- to 39-year-olds were least likely to be of the opinion that the ToR was comprehensive with only 31% reporting that view. Younger people were slightly more likely to find that the ToR covered all the areas that they thought should be covered by the Inquiry with over 40% of those under 30 saying "yes".

**Figure 4. Share of respondents who said "Yes" by age cohort**

Responses by Age
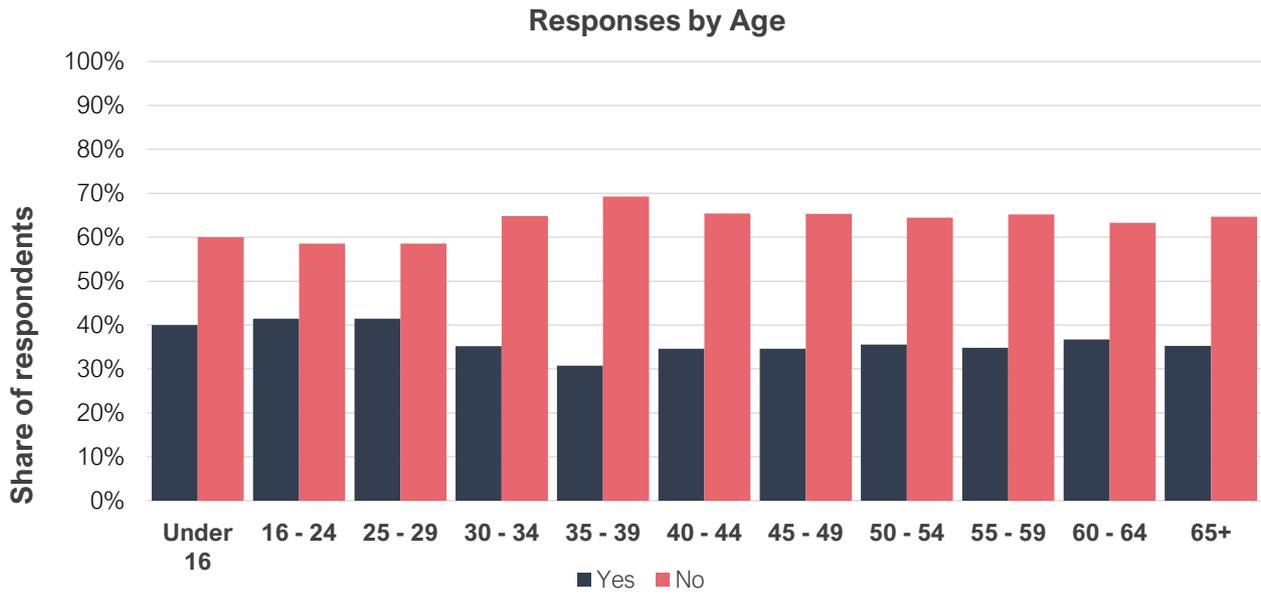
Figure 5. Share of respondents who said "Yes" by respondent type

Responses by Respondent type
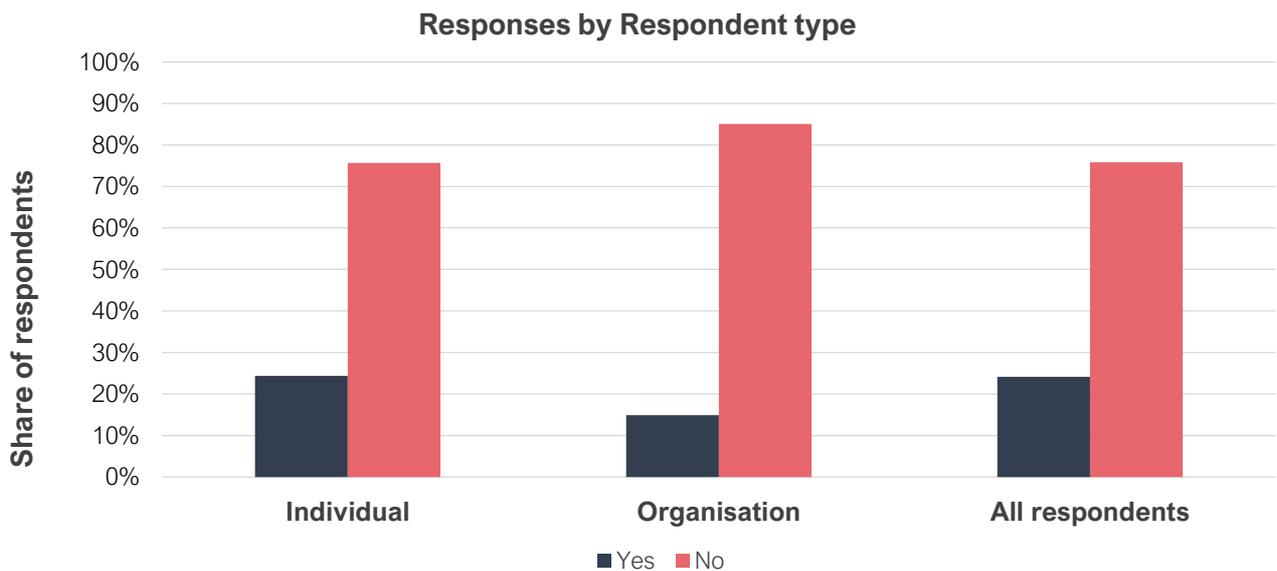
Organisations were more likely to be of the opinion that the draft ToR is incomplete than was the case for individuals with only 15% of organisations saying "Yes" in comparison to around 24% of individuals (Figure 5). Further demographic breakdowns of responses are available in Annex D.

Question 13

Please explain why you think the draft Terms of Reference do not cover all the areas that the Inquiry should address.

Theme 1: The impact of the pandemic and its response on children and young people

The most emphasised theme in responses was the view that the ToR should consider the impact of the pandemic's restrictions on children and young people. Most respondents mentioning this theme in their responses argued that children have been significantly impacted by the pandemic and in different ways than is the case for adults. The most relevant reference to the pandemic's impact on children in the ToR is that of 'the restrictions on attention of places of education', but many respondents believed that the impact on children goes beyond this and suggested several topics to be investigated as part of the Inquiry. Furthermore, some respondents suggested making explicit the consideration of children's experiences in relation to the inquiry's work in other areas. As an example, testing, contact tracing and isolation were said to have operated differently in schools compared to other settings and it was argued that this led to children being disproportionately burdened with having to self-isolate when compared to the wider population.

> *"The draft terms of reference for the UK COVID-19 Inquiry must be revised to include impacts of the pandemic response on children and young people. This is almost entirely missing from the current draft, which refers only to 'restrictions on attendance at places of education."* *(Organisation, email response)*

Within this theme, the most emphasised sub-theme was the call to consider the impact of the pandemic's response on children's physical and mental health. Respondents described a significant deterioration in children's physical and mental health (including increased obesity, serious mental illnesses and development issues), which they argued to be directly caused by the pandemic and the national response (e.g., cancellation of physical activities, play and closure of outdoor playgrounds). Respondents also believed that the Inquiry's inclusion of the impact on children's physical and mental health would help children recover from these adverse impacts and build a better understanding of how to prevent them in future emergencies.

> *"As a teacher I have seen our Student Welfare Department become the largest department in the school. We have far more school refusers and a growing number of students with mental health issues. I can never forget a student sitting in my lesson without a coat as it snowed into my classroom through state mandated well-ventilated windows and doors. She had outgrown her previous winter coat and both her parents were on furlough. She burst into tears in my lesson and has continued to suffer from mental health issues. This is just one example of many children suffering during Covid restrictions."* *(Online response[1])*

Another sub-theme which was emphasised by respondents was the suggestion to consider the impact of measures to contain the spread of Covid-19 on babies and very young children. Respondents felt that they deserved specific attention due to their different experience of the pandemic compared to other children and the importance of early years in children's development. Some respondents went

---

[1] This respondent did not answer the question of whether they were representing an individual or an organisation.

on to suggest that the ToR should consider the impact of Covid-19 restrictions on Early Years Providers. It was said that the financial pressures of the pandemic on these services was such that many providers were forced to close or scale back their service provision which could be detrimental for babies and very young children in the future.

> *"Any omission of Early Years care, education and support would be deeply concerning given what we know of the importance of brain development in the first few years of life and the emerging concerns around the impact of our Covid restrictions on that development."*
> *(Organisation, email response)*

Another frequently emphasised sub-theme was the call to investigate the impact of the pandemic's restrictions on child protection and the children's social care system to ensure better protection for children in future emergencies. Many respondents mentioning this theme were of the view that the scaling back of children's social care work during the pandemic led to vulnerable children becoming less visible and to an increased incidence of preventable incidents of harm. Some respondents also argued that the pandemic exacerbated the difficulties faced by early help services, which could lead to an increase in the needs of vulnerable families.

> *"We have seen a marked increase in serious harm incidents due to known and suspected abuse or neglect in 2020, including tragic and high-profile fatalities. Many of these harms were not only predictable but predicted, and scrutiny of the impact of decisions on children's social care must form part of the Inquiry to ensure that children are better protected in future emergencies."*
> *(Organisation, email response)*

The final sub-theme which was emphasised by respondents was the consideration of disparities in the impact of the response to the pandemic among vulnerable groups of children which do not have protected characteristics under the Equality Act 2010 and the Northern Ireland Act 1998. The most commonly mentioned group were children with special educational needs, who were reported to have been left behind as a result of the pandemic response. Children living in clinically extremely vulnerable (CEV) families were another group cited as having been significantly more impacted by the pandemic when compared to their peers and to be at heightened risk of these impacts becoming persistent.

> *"The fear and responsibility placed on these children in CEV families to protect the vulnerable people they live with has been, and is still, huge. What is being done to support these children on an ongoing basis given that for many CEV families, the pandemic is far from over? Could the Inquiry look at the support structures put in place for these children, if indeed there are any?"*
> *(Online response[2])*

Theme 2: Management of the healthcare and social care sectors during the pandemic

Another widely emphasised theme in people's responses was the suggestion that issues related to the management of the healthcare and social care sectors during the Covid-19 pandemic, and the impact this has had on service users should be a key consideration in the ToR.

The management of the pandemic in hospitals was seen as a particularly salient issue. Respondents often raised issues of hospital staff security, including the risk of contracting the virus due to the lack of adequate PPE as well as being at risk of harassment at the workplace due rising tensions.

---

[2] This respondent did not answer the question of whether they were representing an individual or an organisation.

Respondents also mentioned increased waiting lists and increasing numbers of untreated or undiagnosed (non-Covid-19 related) diseases due to the inability of NHS capacity to meet demand.

> *"Doctors and health care staff were exposed to a toxic airborne agent in the workplace without proper PPE, were bullied and harassed by NHS management for not being resilient enough, put through capability processes & with attempted sackings for not being resilient enough."*
> *(Individual, online response)*

Some respondents also reflected on what lessons learnt can be taken forward in order to be more prepared for the future. This encompassed practices that should be avoided going forward and those which should be continued. An example of a practice that respondents criticised was the pressure on frontline workers to operate beyond their contracted capacity to cover for sickness leaves and other absences of colleagues during the period of the pandemic. On the other hand, the promising advancements in digital health and delivering healthcare remotely were seen as positives.

The way in which the pandemic was handled in care homes was highlighted by respondents as a particularly contentious issue. Under this sub-theme, respondents discussed the appropriateness of measures taken to reduce the spread of Covid-19 in care homes, such as limiting family and relatives' visits, the impact this lack of physical contact has had on those in care and whether it was a violation of their visiting rights. Others mentioned the need to include investigations of the processes related to death protocols in care homes in the Terms of Reference, as well as the extent to which care homes ignored official guidance or their operations contradicted government guidelines.

> *"There needs to be discussion as to why the care homes themselves were allowed to make their own decisions and in doing so ignored the guidance given by the Government… The impact of the restrictions on those in care homes has been omitted. Whilst long covid is to be considered during the Inquiry the devastating effect of being denied contact with next of kin and other family members doesn't seem to warrant consideration."* *(Individual, online response)*

As was the case in hospitals, the absence of adequate personal protective equipment and the risk this posed to care home staff, and by extension residents, was also raised in some responses. Another issue identified in responses was the lack of coordination between care homes and the NHS, with the inadequate testing of patients who were due to be transferred from hospitals to care homes cited as a glaring example.

The response to the pandemic in primary care facilities was another area which was frequently cited by respondents as a potential addition to the ToR. Responses in this sub-theme raised concerns over operational issues faced by primary care facilities, such as GPs, pharmacies and dentists, due to the pandemic's impact. Respondents were of the view that the management of the pandemic in the healthcare sector needs to expand beyond what is currently outlined in the Terms of Reference to include such providers of primary care and to consider how recipients of primary care services were affected by reduced delivery. Some respondents also discussed the reasoning behind the decision to exclude primary care facilities such as GPs from being first points of contact and treatment for people infected with the Covid-19 virus.

> *"So it feels to me like particularly when you get into the response of the health and care sector bit of the terms of reference, it feels quite heavily leaning towards big institutions, so hospitals and care homes. But we know there was huge positive and negative transformation and disruption to a whole range of services. So primary care, dentistry, mental health services, home care provision. So whilst what was going on in hospitals and care homes was significant, I think at the moment, it feels like it shifts a bit too much in today's kind of big institutions, rather than the full range of healthcare services."* *(Consultation event attendee)*

Respondents also highlighted the social care sector as a sector which should receive focus in the ToR. Responses reflected, to an extent, an underlying complaint about the social care sector not having been equally heard in the decisions taken during the pandemic, or the needs of the NHS being prioritised over those of social care. Wider issues, such as a lack of understanding in how social care is being delivered nationally, were also raised.

> *"How much profile and emphasis was given to adult social care from the outset, as at times it felt as if social care was very much an afterthought." (Organisation, email response)*

Responses also suggested that the state of the social care sector was already fragile pre-pandemic, and respondents suggested that the Inquiry should investigate how the increased workload, combined with the absence of timely mitigation measures during the Covid-19 pandemic, have affected operations and the sectors' capacity to safeguard those who are vulnerable or in need.

Theme 3: The government's communication strategy and the role of the media

The third most emphasised theme in responses was the view that the ToR should include the government's communication with the public (including both the content shared and how communication was approached) and the role of the media in spreading useful as well as false information.

Respondents requested a review of a wide range of issues pertaining to the government's communication with the public. Regarding the information communicated by the government, there were complaints about the perceived failure to report facts as known and to highlight areas of uncertainty. Respondents cited perceived contradictions between the government's advice and scientific evidence (with respondents citing the example of the use of PPE) and perceived "fear messaging". Furthermore, respondents suggested investigating the role of the Behavioural Insights Team in designing the government's communications and policies around the use of language and imagery.

In addition, respondents suggested that the ways in which the government communicated with the public should be reviewed, including:

- The means and frequency of communication. For example, some respondents argued that digital means were used as the primary mode of communication and called for the Inquiry to evaluate their effectiveness and cases where they could have excluded parts of the population.

- Timeliness of communication. Many respondents complained about guidance and rules being communicated at very short notice.

- Accessibility and clarity of government communication. For example, some respondents argued that the government's communication on the behavioural changes required during the pandemic was not well targeted at vulnerable populations, such as people living with disabilities. There was also a range of other claims made regarding the lack of clarity of government's communication, including contradictions between various publications (e.g., between government regulation and guidance) and confusion in devolved administrations, where there was a perception that the Prime Minister's announcements applied to all four administrations rather than solely to England.

> *"I think communication is worthy of good examination in itself, actually, because that makes a big difference in a crisis of any sort, how well you communicate. So, that covers, you know, networks. Do you know who you need to communicate with when the crisis happens and can you reach them? And timeliness and the quality of communication."* (Consultation event attendee)

Furthermore, respondents suggested that the role of the media (including social media) in influencing both positive and negative behaviour during the pandemic be looked into. The majority of responses mentioning this sub-theme argued that the perceived role of the media in spreading false information and conducting what was described as a "media fear campaign" should be investigated, with media outlets described as conveying "relentless bad news" instead of "balanced facts". In addition, respondents argued that the Inquiry should examine whether the government made efforts to address misinformation and should propose effective interventions to use in the future to avoid perceived abuses by the media.

> *"I think specifically in relation to 'Communication' there should be a specific section looking at the role of funded Covid denying/minimising/anti-vax groups, the lobbying efforts of these Groups with politicians, TV/Radio media channels and social media and the harms they caused spreading false information. It should examine did the government look to challenge this misinformation, how did it do it and how it could do it better next time."* (Online response[3])

> *"Alongside of that really, sits for me, communications, and the role of media, and comms and how media influenced positively or negatively the messaging which the devolved administrations were trying to put out. So we picked up there's nothing in here really around media and that side of that, and the influence of media."* (Consultation event attendee)

Theme 4: The role of experts, advisors, science and data in informing the government's pandemic response

The next most emphasised theme was the view that the role of experts and advisors in the government's decision-making processes and the degree to which science and data were followed by both decision makers and advisors should be added to the ToR. Respondents suggested that the Inquiry should include scope in its terms of reference for a consideration of how advisors were selected, what role they played and to what degree did they and the government follow the appropriate science, data and evidence when making decisions over measures such as lockdowns and mask wearing.

Within this theme, respondents were most likely to reference the role and composition of advisory groups like the Scientific Advisory Group for Emergencies (SAGE) as a particularly important avenue for the Inquiry. A large number of respondents questioned the diversity of SAGE, both in terms of demographics and areas of expertise, and suggested that the ToR should be augmented to include consideration of how this group was selected. Furthermore, many respondents expressed the view that the way in which SAGE and the government worked together should be a core consideration for the Inquiry; how often was SAGE's advice followed by the government and how often was their advice ignored?

---

[3] This respondent did not answer the question of whether they were representing an individual or an organisation.

> *"Why were so few people from a crisis management background involved and why was the advice to government overwhelmingly from academia which has no expertise whatsoever in crisis management. In particularly (sic) SAGE had very little experience in cost, time and safety critical decision making, which is the bread and butter of many professionals." (Individual, online response)*

A significant number of respondents had similar concerns regarding the Scientific Pandemic Insights Group on Behaviours (SPI-B), with respondents suggesting that their role in the government's decision making, especially regarding communications, should be investigated by the Inquiry.

A large number of respondents also expressed their desire for the Inquiry to consider the degree to which government decisions were based on scientific evidence and appropriate data.

> *"The decision making process taken by government in assessing scientific evidence and how this advice was used." (Individual, online response)*

Many respondents held the view that the ToR should explicitly commit to investigating whether decisions around rules such as the '2-metre rule' and 'the rule of six' were based on rigorous scientific evidence. Moreover, they questioned whether the use of non-pharmaceutical interventions (NPIs) such as lockdowns and enforced mask wearing were based on sufficiently sound science and data.

Theme 5: The impact of the pandemic and its response on mental health and wellbeing

The fifth most emphasised theme emerging from the responses was centred around the respondents' opinion that the ToR should refer to mental health and wellbeing in the UK as a result of the pandemic and its response. Respondents commented that the ToR should make reference to the direct impact of the pandemic and its response on mental health and wellbeing as well as to the reduced provision of mental health support and the associated difficulties accessing services throughout the pandemic. There was a concern among respondents that mental health was considered as a peripheral issue by the government and was not treated with the seriousness it merits. Respondents also expressed the view that additional emphasis should be given to the mental health implications for children, students, the workforce and vulnerable groups.

> *"The nation's mental health and mental wellbeing has been an enormous element of what's been going on here. And that feels very silent in this." (Consultation event attendee)*

> *"Lockdowns, self-isolation, furlough and the closure of schools, community services and cultural spaces have had a huge impact on mental health and wellbeing, and those who now regularly work from home have also had to adapt psychologically to a new way of life. Local parks and green spaces, as well as other community and public spaces, have been a lifeline for some. Of course, many have also suffered hugely from the loss of loved ones and from the impact the virus has had on their own health." (Organisation, email response)*

Many respondents expressed the view that the ToR should consider the pandemic's impact on the mental health of young students and pupils and how this was detrimental to their education outcomes. Respondents made clear that they felt that the mental health implications for young people could end up being a generation-defining issue if efforts were not made to understand it and steps taken to address it.

> *But then, as has also been mentioned, the long-term educational outcomes or disrupted learning, and the ongoing lack of willingness to re-engage with school, predominantly to do – reported as being due to levels of – high levels of anxiety and poor mental health. So this can - these are really generational issues, in terms of impact of the – of Covid-19. (Consultation event attendee)*

Respondents also mentioned that the ToR lacked a section on the mental health impacts of the pandemic on the workforce, including workers (particularly those working in the health and social care sectors), people that lost their jobs and those that couldn't work due to the pandemic.

> *"I know you're talking about impact on health and care workers. But I just wonder whether that could be slightly expanded, to make it clear that that covers mental health, burnout and stress. I know, it's the terms of reference, but it is drafted narrowly, but I just think having some inclusion of that, which is still being felt by those professions, would be a helpful addition." (Consultation event attendee)*

Furthermore, respondents argued that the Inquiry should look into the mental health impacts of the pandemic on victims of abuse and crime. It was argued that many people will have faced a heightened risk of mental and physical abuse as a result of being in lockdown with their abuser which could have induced high levels of trauma and, in the long term, post-traumatic stress disorder (PTSD). Similarly, respondents referenced the fact that victims of crime (including domestic abuse) may have faced increased trauma as a result of the early release of prisoners. They stated that this policy did not sufficiently take into consideration victims' safety and how early release of the perpetrator of the crime might be detrimental to the victim's mental health.

> *"The other kind of key point for us is about early release of prisoners through COVID emergency legislation. Early release of prisoners became possible. However, it was not done through a kind of victim-centred or trauma-informed lens. And moving forward, we feel it's imperative to take this into consideration, victim safety and security being considered in early release of prisoners. So, for example, the prisoner is going back to the victim's home. What harm will it cause to the victim mentally and physically if that prisoner is actually released?" (Consultation event attendee)*

Theme 6: The economic costs of the pandemic and its response and the role of cost-benefit analysis in lockdown and other closure decisions

The next most emphasised theme was around the suggestion by respondents that the ToR should consider the numerous avenues by which the pandemic response has impacted on the economy. Respondents often suggested that the impact and decision-making process behind the government's economic response should be investigated. Respondents also called for the Inquiry to consider economic impacts of the pandemic beyond those of the government's economic response, including the impact on businesses. Furthermore, they called for transparency around the role of cost-benefit analysis in key policy decisions during the pandemic and for the Inquiry to retrospectively undertake a comprehensive cost-benefit analysis of the wide-ranging impacts that restrictions had on the UK's population.

A key sub-theme within responses was around the suggestion that the Inquiry should look at the impact of the pandemic on businesses. Respondents frequently mentioned the need to investigate the effect of Covid-19 restrictions on the hospitality and leisure sectors in particular and respondents called for a thorough evaluation of the effectiveness and proportionality of measures imposed on these sectors. Furthermore, respondents highlighted the difficulties faced by businesses during the pandemic, particularly in relation to the volume of government guidance and regulations and their variation between local authorities and devolved administrations. As a result, respondents requested

that the Inquiry evaluates the guidance and regulations which businesses were subject to during the pandemic and to investigate ways in which they could be improved and streamlined in the future.

> *"If we are able to have something which focuses on the impact that, you know, of hospitality, that would be incredibly valuable. And I think it would be helpful for the inquiry to look at those and to see, you know, whether they were helpful, useful, whether the damage was greater than the benefits." (Consultation event attendee)*

In addition, respondents raised a wide range of issues to be investigated that are associated with the government's economic response to the pandemic, including:

- The inequality in outcomes achieved by the Job Retention Scheme and how these considerations were taken into account. For example, it was argued that women were more likely to be furloughed and less likely to have their salary topped up.

- The impact of the choices made around eligibility for government support, including the perception that support should have been more targeted and that larger businesses benefited disproportionately.

> *"The third one would be around the seeming disconnect between the willingness of government to help big business and small business. We represent companies of varying sizes and some saw a great deal more support than others." (Consultation event attendee)*

Finally, respondents emphasised that the Inquiry should investigate whether there was a rigorous cost-benefit analysis underlying policy decision making, particularly with regards to lockdowns and school closures. These respondents often questioned the proportionality and effectiveness of these measures. In addition, respondents called for the Inquiry to assess the actual costs and benefits of the measures implemented during the pandemic as they relate to their impacts on health, the economy, and welfare. Similarly, some respondents also suggested assessing the value-for-money of public expenditure during the pandemic.

> *"The decision-making processes around school closures both at the time of the March 2020 lockdown and then again in January 2021, particularly the cost/benefit analysis at the core of those decisions, must feature front and centre in the Inquiry." (Organisation, email response)*

> *"There needs to be a more comprehensive cost/benefit assessment of the wider societal health and socioeconomic impacts that have materially resulted as a direct result of both lockdowns and other imposed interventionist measures." (Individual, online response)*

Question 14

Which issues or topics do you think the Inquiry should look at first?

Theme 1: The impact of the pandemic and its response on children and young people

The most emphasised theme in responses was around the need to make an investigation into the pandemic's impact on children and young people a priority for the Inquiry. Many respondents did not specify which aspects of the impact on children and young people should be prioritised. Of those who did, many respondents felt that it was of vital importance to assess the wide-ranging impacts of school closures and all the associated disruptions to education, as well as the impact of the wider pandemic response on children's development and mental health. A large number of respondents also specified that the Inquiry should prioritise consideration of the impacts on children living in poverty and deprivation and the inequality implications this has had and will continue to have going forward.

> *"It feels to me like there are two fundamental questions with the inquiry, which are, was the balance between measures to constrict – control the spread of the virus and maintaining the role – the balance between controlling its spread and maintaining the welfare and rights of children the right ones given that available evidence? So that's sort of question one. And then were the steps taken to mitigate the impact of the measures on children the right ones, with particular emphasis on children who were already likely to be disadvantaged. So I think that's that sort of inequalities gap that I talked about before. Seems to be the sort of top-level priorities."*
> *(Consultation event attendee)*

Respondents were also concerned about the degree to which school closure decisions were based on rigorous clinical and scientific evidence and a consideration for costs versus benefits. They would like to see the Inquiry prioritise an investigation into how these decisions were made and what evidence was used to support them.

> *"Why were schools closed down? Who decided this and based on what clinical evidence? Investigate thoroughly the ongoing developmental damage to children. Assess QALY effects on the future generations due to educational and social disruptions."* *(Individual, online response)*

The impacts of lockdowns and closures of places of education on children and young people's mental health was also seen as a priority issue with respondents suggesting that the isolation caused by these policy decisions may have damaged mental health and wellbeing.

> *"The mental health consequences to children and young people, the damage caused to them by the unnecessary closure of schools and colleges, the disruption to their education and their isolation from friends and family."* *(Individual, online response)*

Theme 2: Management of the healthcare and social care sectors during the pandemic

The second most emphasised broad theme raised by respondents as the first priority for the Inquiry was around the management of the healthcare and social care sectors during the pandemic. A significant number of responses under this broad theme raised both healthcare and social care as priorities, but for respondents mentioning only one of the two, there were more respondents suggesting healthcare should be a priority for the Inquiry to cover first than was the case for social

care. In many cases these sectors were raised as priorities by respondents who then did not go on to list specific sub-topics. Among more detailed responses, a number of sub-themes emerged.

The most emphasised sub-theme was in relation to equipment and practices at hospitals and care homes, particularly in terms of preparedness and during the earlier stages of the pandemic. Within this sub-theme, there was a focus on PPE and cases of inadequate levels of PPE provision to staff. This included considering procurement processes for PPE and the distribution of equipment. A number of respondents raised the related suggestion of the Inquiry initially focusing more broadly on the issue of prevention efforts against Covid-19 transmission in hospitals.

A number of respondents thought that the Inquiry should focus first on practices related to controlling the number of individuals in care homes with Covid-19, including testing of patients ahead of being discharged to care homes. Other concerns included healthcare management and communications.

> *"The management of the pandemic in care settings such as nursing homes, hospices, supported living accommodation, congregate facilities and domiciliary care provision (home-care visitors) … The Health and Care sector's preparedness in terms of equipment such as PPE, oxygen, medicine, ventilators, ICU beds, and contingency planning." (Individual, online response)*

A common sub-theme focused on issues of reporting and testing. On reporting, there was the suggestion that the Inquiry should focus first on decisions around reporting of Covid-19 cases and deaths, particularly around the definition of what counted as a death caused by Covid-19. On testing, a number of respondents raised the issue of understanding the effectiveness of the UK's testing regime as a priority for the Inquiry.

> *"The flawed recording of infection and death statistics resulting in inflated counts of mortality. For example, any death within 28 days of a positive Covid test is clearly not an accurate representation of the actual cause of death in many cases. The relaxing of reporting requirements on death certificates also allowed deaths from other conditions to be misrepresented as deaths from Covid." (Individual, online response)*

Another emphasised sub-theme related to the view that the Inquiry should focus initially on the impacts of the pandemic response on healthcare issues other than Covid-19. Within this sub-theme, there was a particular focus on waiting lists for hospital treatment of healthcare issues other than Covid-19. There was also concern about the impact on GP surgeries, including potential impacts on availability of appointments, availability specifically of in-person appointments and potential impacts on the quality of care provided.

> *"Why the NHS was more or less totally shut down which has caused the horrific waiting lists we have now, even for the treatment of cancer!" (Individual, online response)*
>
> *"The long term consequences of lockdowns on hospitals and GP surgeries and the continued difficulties of diagnosis backlogs and securing appointments." (Individual, online response)*
>
> *"The decision to allow most GPs to stop seeing their patients face to face." (Individual, online response)*

A number of respondents suggested that vaccinations should be an immediate priority for the Inquiry. Respondents' views under this sub-theme focused on how decisions were made relating to the vaccine roll-out, including various issues such as the decision to proceed with a vaccination programme given the lack of long-term data on its effectiveness and decisions around how to prioritise which groups received the vaccine first. There was a general appetite for understanding more about the evidence base relating to long-term vaccine safety and efficacy.

> *"Priority groups for vaccination -why were people with mild asthma excluded although the link with long covid was already known." (Individual, online response)*

> *"Why the decision to only vaccinate the most vulnerable morphed into vaccinated all age groups even now including children who [are] very low risk?" (Individual, online response)*

A number of respondents raised the issue of Long Covid as an area for the Inquiry to focus on first given the potential for this to be of immediate benefit. Particular concerns involved understanding the long-term implications of Long Covid, reviewing the provision of treatment so far and reviewing treatment options going forward.

> *"…ongoing provision for Covid and long covid sufferers should be looked at first given that these areas may be of immediate concern." (Online response)*

> *"Long Covid - medical support for people who developed long term chronic illness due to Covid has been completely inadequate, also dependent on postcodes. Some people had been ill for over two years with little or no support." (Individual, online response)*

Theme 3: The use of non-pharmaceutical interventions (NPIs) during the pandemic

The next most emphasised broad theme raised as the first priority for the Inquiry was around the use of non-pharmaceutical interventions (NPIs) during the pandemic.

The most emphasised sub-theme on this topic related to the use of lockdowns. There were a number of respondents suggesting that the Inquiry should focus on the timing of lockdowns, particularly the first lockdown, to understand how effective the timings were. A number of respondents thought the Inquiry should focus first on fully assessing the wider impacts of lockdowns on economic activity, society, specific groups and specific industry sectors.

> *"Timetable for Lockdowns and how dates and times were determined and by whom. Was Public Health guidance followed closely?" (Individual, online response)*

> *"Information and time-frames which led to lockdown in March 2020, should it have been sooner given what was happening globally." (Individual, online response)*

> *"Lack of cost/benefit analysis of measures, including not estimating the quality-adjusted life years (QALYs) lost by everyone. Whether the three lockdowns were justified from a health standpoint and from an overall cost benefit standpoint." (Individual, online response)*

The next most emphasised sub-theme on this topic related to face masks, with a number of respondents suggesting this should be a priority for the Inquiry to review first. Respondents raised similar issues to those noted on lockdowns above, including interest in the timings of policy decisions on mask wearing, the process of decision making and a review of the wider impacts of use of face masks to reduce the spread of Covid-19. The use of face masks in schools was also raised as a priority by a number of respondents.

> *"Timing of interventions and measures such as face masks… Including public messaging regarding these." (Individual, online response)*

Whilst responses relating to lockdowns and face masks were far more emphasised than any other sub-themes, a smaller number of respondents suggested that the Inquiry should initially focus on other NPIs such as social distancing, travel restrictions, school closures and quarantines.

> *"Closing of borders, adequate testing, location of travellers - was this robust and effective? What advice was followed and by whom? Was the medical advice followed or largely ignored?" (Individual, online response)*

> *"Where was the risk analysis for forced social restrictions, for masks, for school closures?" (Individual, online response)*

Theme 4: The role of experts and advisors and the degree to which science and data were used to inform the government's decisions

The fourth most emphasised theme expressed by respondents was the view that the Inquiry should make an investigation into the role of experts and advisors in government decision making a priority. Respondents frequently questioned the degree to which experts and advisors informed government decisions and the degree to which these decisions followed rigorous scientific evidence.

> *"Decision-making, in particular with lifting restrictions - were they made according to science / based on SAGE advice?" (Individual, online response)*

> *"The relation between the scientific evidence, government decision making and when that information was given to the public and safety measures put in place." (Individual, online response)*

Respondents often expressed concern around the make-up of advisory groups such as SAGE, and requested that an investigation into how these groups were formed and into whether or not they were sufficiently interdisciplinary should be made a priority.

> *"Who determined the composition of SAGE and which disciplines were represented. Who decided the composition of its sub-committees?" (Individual, online response)*

A number of respondents also suggested that the Inquiry should prioritise an investigation into the ways in which the government interacts with science in fields where the evidence base is nascent and frequently being updated; how do they deal with uncertainty that this creates?

> *"How does government interact with scientific advice and knowledge, when scientific advice and knowledge is learning as it goes into the emergency? And there's a whole host of government agendas at the moment, which have a similar set of dilemmas where we don't quite know how to kind of move with an evidence base that moves or make a decision without a firm evidence base." (Consultation event attendee)*

Question 15

Do you think the Inquiry should set a planned end-date for its public hearings, so as to help ensure timely findings and recommendations?

The majority of respondents believed that the Inquiry should set a planned end-date for the public hearings. This finding was very consistent across different regions of the UK with the percentage of respondents in favour of a planned end-date ranging from 78% in the North East to 83% in the West Midlands (Figure 6).

Figure 6. Share of respondents who said "Yes" by UK region

Region	Percentage of respondents who said "Yes"
West Midlands	84%
South West	82%
Wales	82%
Northern Ireland	81%
East Midlands	80%
London	80%
North West	79%
Yorkshire & The Humber	79%
East of England	79%
South East	79%
Scotland	79%
North East	78%

85% of International respondents **said "Yes"**
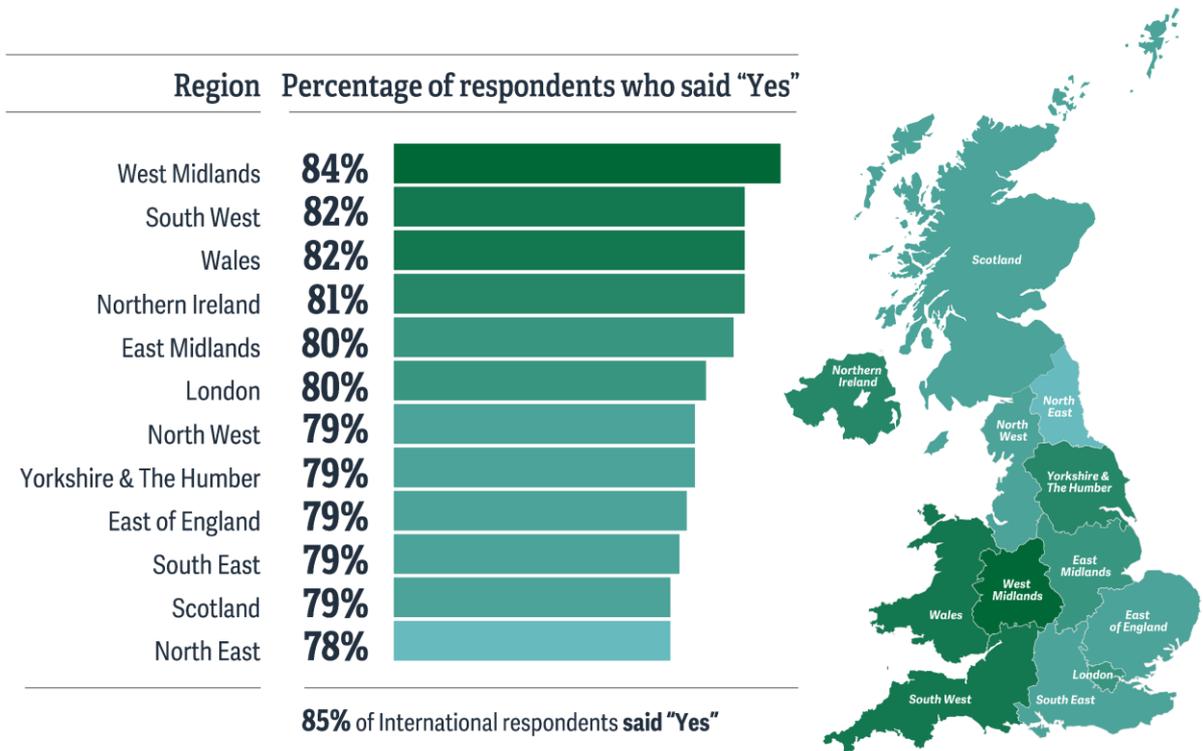
Figure 7 presents the share of respondents who were in favour of a planned end-date by age cohort. We observe that older respondents were increasingly likely to report a preference for a planned end-date. The lowest share was found in the group of people aged between 16 and 24 years old, where only around 69% were in favour. The highest share was observed in the 60 to 64 year old group where around 84% of respondents were in favour.

Figure 7.   Share of respondents who said "Yes" by age cohort

Responses by Age
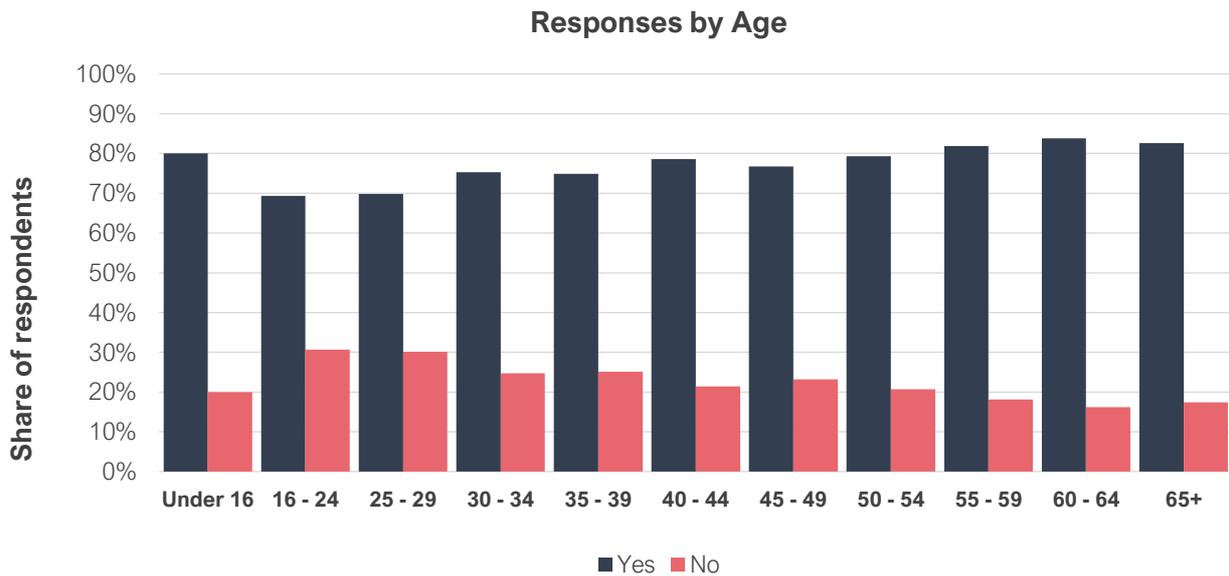
Figure 8. Share of respondents who said "Yes" by respondent type

Responses by Respondent type
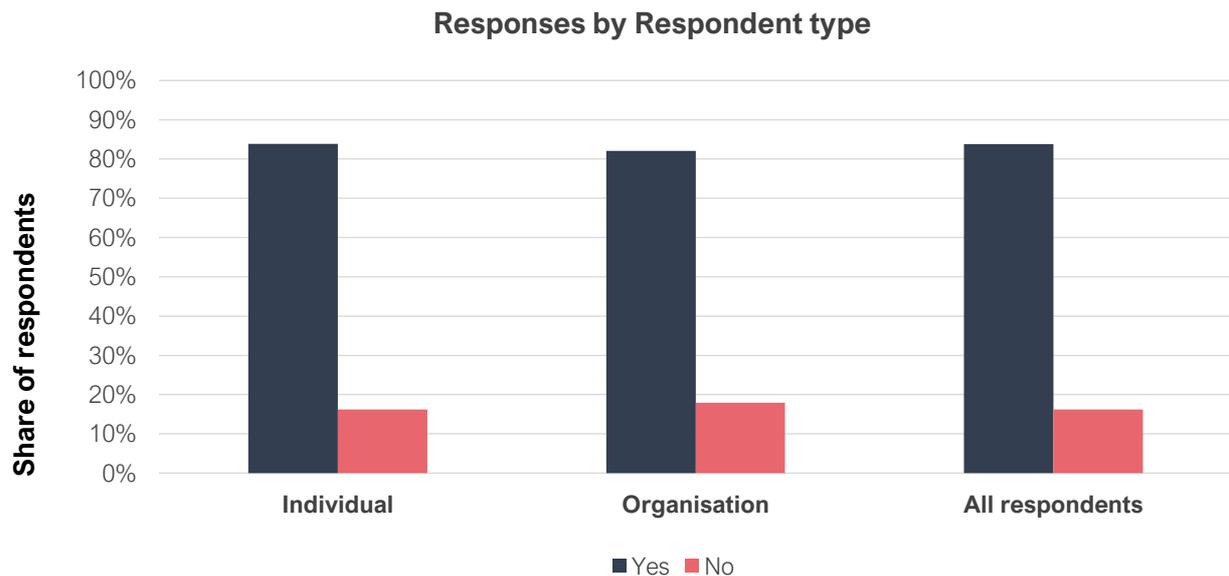
In Figure 8, we can see that individuals and organisations were both highly in favour of a planned end-date for the Inquiry's public hearings with rates of over 80% for both groups as well as for those who did not report their status as representing an organisation or an individual. Further demographic breakdowns of responses are available in Annex E.

Question 16

How should the Inquiry be designed and run to ensure that bereaved people or those who have suffered serious harm or hardship as a result of the pandemic have their voices heard?

Theme 1: Ensure data collection and public engagement is from as broad a group as possible

The most emphasised theme in responses was about ensuring that methods for collecting information on lived experiences and sharing findings would be as representative as possible of the UK population.

A range of opinions were shared by respondents about the ways data could be collected. These included inviting those eligible to share their stories in open discussions and open forums, or even to attend open hearings. Another method suggested was to use questionnaires, both accessed online and provided in paper format to ensure equitable participation that is not hindered by low levels of digital literacy. Respondents also raised the importance of listening to the voices of professionals in direct contact with those experiencing bereavement during the pandemic – such as NHS staff, staff of funeral homes and legal practitioners – to acquire a broader understanding of the circumstances affecting them. Similarly, it was suggested that eligible participants can be identified with the help of the charitable and voluntary sector, which should have an existing understanding of who was affected and how.

There was a recognition among respondents of the need to motivate local organisations to effectively reach out to people throughout the UK, or to organise events such as focus groups at a local level with the outcomes of the discussions held being reported at a UK level. Respondents also raised the point that regional circumstances (e.g., urban settings as opposed to rural and island ones, differences between the devolved nations, etc.) and the breadth of cultural norms across the UK need to be taken into account as they may well have affected participants' experiences.

> *"There's definitely a need to vary it between the four nations because the restrictions were different at different times. And so, different people's experiences were different and there are also, with regards to funerals and funeral customs, there are differences culturally between the nations as well." (Consultation event attendee)*

There was some disagreement noted regarding the terms of participation. Some respondents argued, for the sake of transparency, that information gathered or people's testimonies should be made publicly available. However, others argued for the anonymity of participants to be retained given the anticipated high volume of data and the desire to ensure that people feel comfortable and safe to share their experiences. Nonetheless, these two seemingly different approaches attempted to reconcile the need for the voices of those affected to be widely heard, while at the same time enabling participants to be able to do so without hesitancy or regret.

> *"People should be given a forum to speak publicly without fear of censorship." (Individual, online response)*

Another inquiry that was used as an example by respondents or as a point of reference when making suggestions was the Grenfell Inquiry with respondents referencing both positive and negative lessons learnt which could be relevant for the UK Covid-19 Inquiry. As an example, the Grenfell Inquiry decided to split up the work of the present Inquiry into thematic areas or working groups in anticipation

of the wide range of experiences that those affected are expected to disclose and so respondents suggested this might also be appropriate in this context.

> *"Again, I was thinking about parallels with the Grenfell inquiry. And what they tried to do there was to strike a balance between on the one hand, making sure that a voice was given to the people who were affected and the bereaved families. But at the same time, in order to manage things appropriately within the course of the inquiry, they tried to get people to group together for the purposes of representation. So, you had teams of lawyers who were focused on particular issues, common issues among those who've been affected to try and pull those together into groups so that that was more manageable. So, I guess the parallel question here would be, are there particular themes about things that happened, experiences that people had, things that maybe went wrong with public services that led to the problems that people experienced that could be grouped together in a similar way to try and keep this as effective and streamlined as is possible in the circumstances." (Consultation event attendee)*

Regarding the dissemination of the Inquiry's results, the appetite for public engagement was made clear by respondents. In particular, respondents suggested that the wider public should be able to participate and share their opinions with the Inquiry. Sharing results in a timely fashion was also seen as a way to bring the Inquiry to the public domain, again with references being made to outputs being made accessible to those who have low levels of digital literacy.

Theme 2: Emphasise listening to experiences of groups beyond bereaved families

The next most emphasised theme was about expanding the target population beyond those who would strictly be categorised as 'bereaved' or expanding the definitions of 'hardship' and 'loss'.

Respondents raised the point that the effects of the Covid-19 pandemic have been multifaceted, and the Inquiry's focus cannot only be restricted to bereaved families. Instead, it needs to consider the entire population.

> *"We all suffered, whether bereaved or not. It was a calamity to ordinary people." (Individual, online response)*

Groups of the population that came up repeatedly in people's responses included: students whose education was impacted (especially those at the A-level stage); young children and babies born during the pandemic; vulnerable groups whose conditions were further deteriorated over the course of the pandemic, such as people dealing with mental ill health, people living with disabilities, patients of chronic illnesses who could not access the NHS, and people who were at greater risk by having to stay at home with a perpetrator of domestic violence or abuse; people whose mental health was impacted by losing their peer networks due to the restrictions imposed; businesses that were forced to suspend – either temporarily or permanently – their operation due to restrictions or the financial impact these restrictions have had.

> *"There should be a public invitation for people to offer oral or written (including online) evidence. This should embrace people who have suffered not only directly as a result of the pandemic, but those who have suffered indirectly; including for example, loss of full educational experience; lack of access to medical care for unrelated health issues; mental health issues, especially from loneliness and social isolation; economic and financial losses, especially for small businesses and start-ups; the impact on young people and their formation of relationships." (Individual, online response)*

> *"To make sure that we don't draw this too narrowly, as to just – I mean, there's nothing just about it, but just people who have been bereaved or directly affected by COVID. But to look much more widely, this isn't like the infected bed scandal[4] in that it has been a nationwide experience. And, you know, people have been affected by domestic violence because of lockdown, or, or, you know, become addicted to alcohol or young people who are still struggling with their mental health. And that's deteriorated or particular communities that because of, you know, deprivation and lower social capital, have really been hit harder. So I think it needs to be wider."*
> *(Consultation event attendee)*

Theme 3: Provide a range of inclusive and accessible avenues through which people's personal experiences can be included

Another emphasised theme was around the suggestion that the design of the Inquiry should be such that it allows for people's personal experiences to be captured. Respondents indicated a range of formats for engaging with participants, including: (a) encouraging those affected to share their emotions and feelings through their stories, (b) seeing people in their own space or a space which they feel comfortable speaking in, and (c) requesting in-person or video-taped testimonies and signed witness statements. Respondents did not primarily raise the importance of the breadth of information collected, but instead emphasised a preference for depth of coverage of the stories shared by those participating in the Inquiry so as to fully comprehend the ways in which their lives were impacted.

> *"The experience of every bereaved family will have been different. It will be very difficult to identify a representative cohort and those who are put forward by Solicitors representing the bereaved may have very defined views or positions which are not necessarily shared by the wider public who may also have been impacted. Voices need to be heard from people representing a broad range of different experiences, ethnicities, from different locations and from a wide range of different patient groups. Not all those who have things to say will feel speaking publicly and support might be needed to secure some written contributions as well as verbal contributions. Where the bereaved are heard the space should not be designed or feel like a court if this can be avoided."* *(Individual, online response)*

Respondents were mindful that, in order to ensure equitable participation, the Inquiry should be accessible to people with disabilities as well as people whose first language is not English. It was also noted that extra effort and resources will be necessary to enable the voices of seldom-heard or marginalised groups to be included, both in terms of successfully reaching out to them as well as supporting them throughout the process.

> *"Obviously, we know that black and minority, ethnic people have been disproportionately impacted by bereavement during this crisis. And obviously, a significant minority of those people will be migrants or of migrant backgrounds. We think it's really important, therefore, that community outreach is done in a way that recognises some of these people's hesitancy or reservations about engaging with formalised procedures, government sort of bodies, authority broadly spoken. And that makes you sort of community outreach, community groups, community champions in order to spread the word and create trust for people to be able to come forward and share their stories in spaces that they know are safe because they're mediated by trusted groups."* *(Consultation event attendee)*

---

[4] Respondent most probably refers here to the Infected Blood Inquiry, but the wrong word (bed instead of blood) has been captured in the transcript.

There was generally a strong focus on attending to people's individual circumstances and needs regardless of their socioeconomic background, with particular reference to any support (practical or emotional) they may require during the Inquiry. References to support ranged from resolving practical and financial obstacles to people's participation (e.g., travel costs and childcare) to ensuring that the participants feel comfortable during the process and that their mental health does not deteriorate as a result of the Inquiry.

> *"I think, just in terms of that – the part of the question around kind of having the voices heard, and the design of it, I'm sure you'll be thinking about this already, but just making sure that that's a space that is supportive and safe, and isn't just about reliving trauma and sort of the risk of retraumatising people, but is framed in a way that's – that is supportive and not extractive, I guess." (Consultation event attendee)*

Annex A – Questionnaire

The full questionnaire which was available on Citizen Space between the 11th of March 2022 and the 7th of April 2022 is set out below.

Question 1. Are you submitting feedback as an individual or on behalf of an organisation?

Answer format: 2 options.

1. Individual
2. Organisation

Question 2. Do you want to provide background information about yourself? This will help us understand who has participated in the consultation.

Answer format: 2 options.

1. Yes
2. No

Question 3. Gender

Answer format: 6 options.

1. Male
2. Female
3. Intersex
4. Non-binary
5. Other
6. Prefer not to say

Question 4. Is the gender you identify with the same as your gender registered at birth?

Answer format: 3 options.

1. Yes
2. No
3. Prefer not to say

Question 5. Age

Answer format: 12 options.

1. Under 16
2. 16 – 24
3. 24 – 29
4. 30 – 34
5. 35 – 39
6. 40 – 44
7. 45 – 49
8. 50 – 54
9. 55 – 59

10. 60 – 64
11. 65+
12. Prefer not to say

Question 6. Ethnicity

Answer format: 5 options with various sub-options and a free-text field for ethnicities which weren't covered by the options lists.

1. Asian or Asian British
    a. Indian
    b. Pakistani
    c. Bangladeshi
    d. Chinese
    e. Any other Asian background
    f. Prefer not to say
2. Black, African, Caribbean or Black British
    a. African
    b. Caribbean
    c. Any other Black, Black British, or Caribbean background
    d. Prefer not to say
3. Mixed of Multiple ethnic groups
    a. White and Black Caribbean
    b. White and Black British
    c. White and Asian
    d. Any other Mixed or Multiple ethnic background
    e. Prefer not to say
4. White
    a. English
    b. Welsh
    c. Scottish
    d. Northern Irish
    e. Irish
    f. British
    g. Gypsy or Irish Traveller
    h. Roma
    i. Other
    j. Prefer not to say
5. Other ethnic group
    a. Arab
    b. Any other ethnic group
6. If none of the options cover the ethnicity you belong to, please let us know here (free text)

Question 7. Where do you live?

Answer format: 5 options with county level sub-options.

1. England
2. Northern Ireland
3. Scotland
4. Wales
5. Other Country[5]

Question 8. Do you consider yourself to have a disability or health condition?

Answer format: 3 options and a free-text field.

1. Yes
2. No
3. Prefer not to say

What is the effect or impact of your disability or health condition? (free text)

Question 9. What is your sexual orientation?

Answer format: 9 options.

1. Heterosexual
2. Gay
3. Lesbian
4. Bisexual
5. Asexual
6. Pansexual
7. Undecided
8. Prefer not to say
9. If you prefer to use your own identity, please write it (free text)

Question 10. What is your religion or belief?

Answer format: 9 options.

1. No religion or belief
2. Buddhist
3. Christian
4. Hindu
5. Jewish
6. Muslim
7. Sikh
8. Prefer not to say
9. If other religion or belief, please write it: (free text)

---

[5] Provides country level sub-options rather than county level sub-options.

Question 11. Do you have any caring responsibilities?

Answer format: 7 options.

1. None
2. Primary carer of a child/children (under 18)
3. Primary carer of disabled child/children
4. Primary carer of disabled adult (18 and over)
5. Primary carer of older person
6. Secondary carer (another person carries out the main caring role)
7. Prefer not to say

Question 12. Do the Inquiry's draft Terms of Reference cover all the areas that you think should be covered by the Inquiry?

Answer format: 2 options.

1. Yes
2. No

Question 13. Please explain why you think the draft Terms of Reference do not cover all the areas that the Inquiry should address.

Answer format: Free text.

Question 14. Which issues or topics do you think the Inquiry should look at first?

Answer format: Free text.

Question 15. Do you think the Inquiry should set a planned end-date for its public hearings, so as to help ensure timely findings and recommendations?

Answer format: 2 options.

1. Yes
2. No

Question 16. How should the Inquiry be designed and run to ensure that bereaved people or those who have suffered serious harm or hardship as a result of the pandemic have their voices heard?

Answer format: Free text.

Annex B – Consultation events

Location	Theme(s)	Date
Cardiff	a) Disability b) Ethnic minorities, asylum and immigration c) Gender and LGBTQI+	15.03.22
Exeter	Post-16 education	16.03.22
Winchester	Social care	17.03.22
Virtual	Health	18.03.22
London	Justice	21.03.22
Belfast	Travel and tourism	22.03.22
Edinburgh	Business	24.03.22
Newcastle	Children and young people	25.03.22
Cambridge	Scientific community	28.03.22
Leicester	Long Covid	29.03.22
Leeds	Key workers	30.03.22
Liverpool	Arts, heritage, sport and leisure	31.03.22
Virtual	Local government	01.04.22
Virtual	Various	06.04.22

alma economics

Annex C – Overview of respondents' demographic breakdowns

Figure 9. Share of respondents by gender

Gender
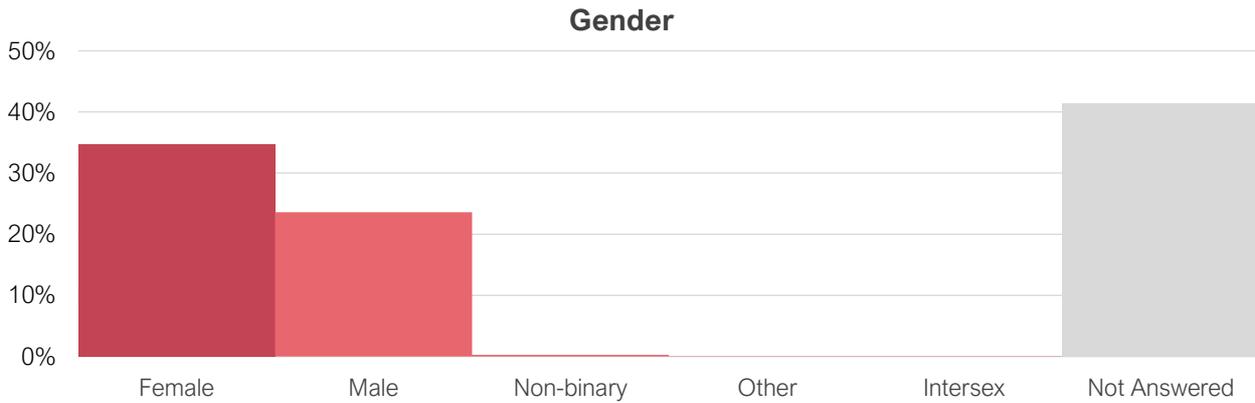
Figure 10. Share of respondents by sexual orientation

Sexual orientation
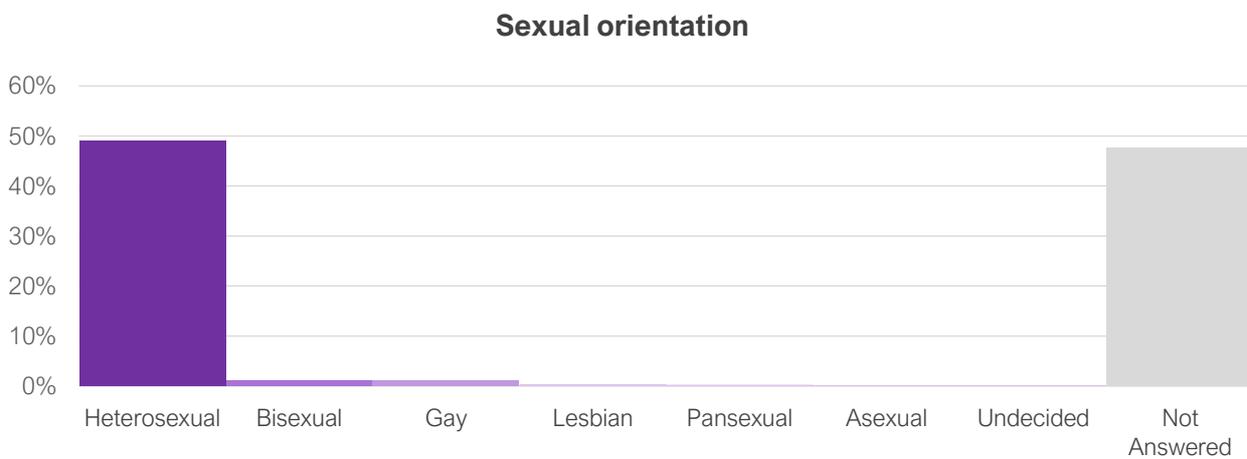
Figure 11. Share of respondents by religion

Religion
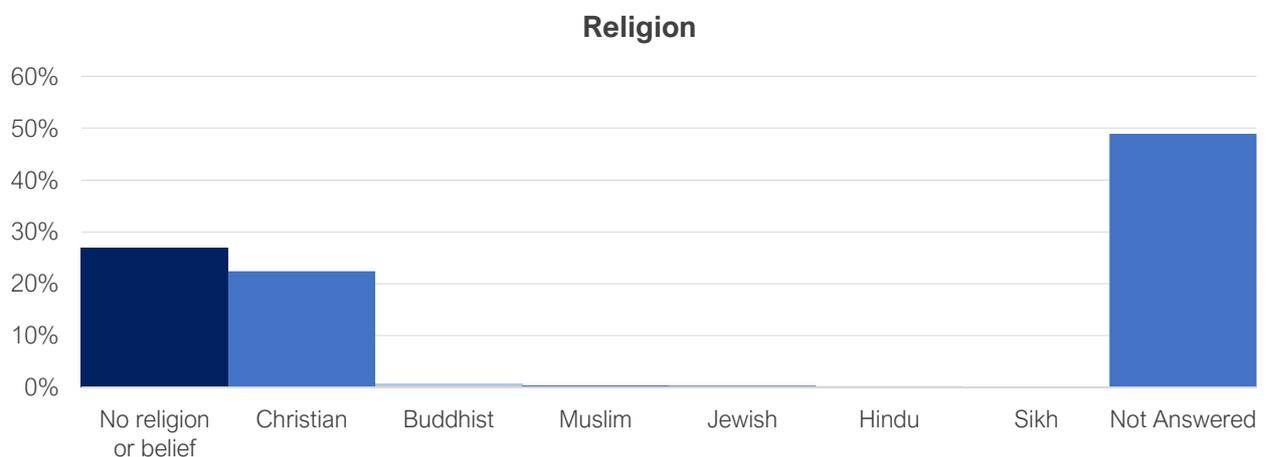
Figure 12.   Share of respondents by country

Country
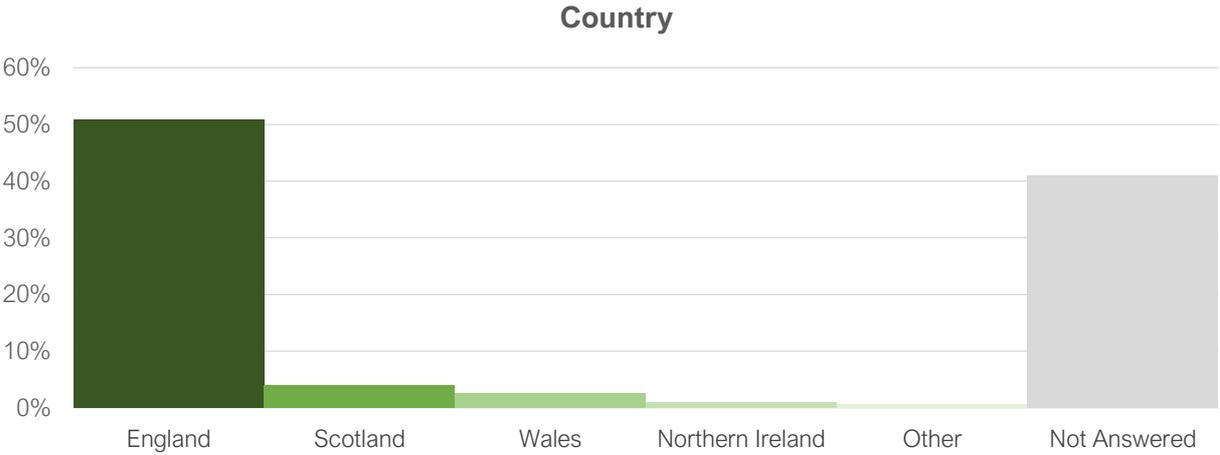
Figure 13.   Share of respondents by ethnicity

Ethnicity
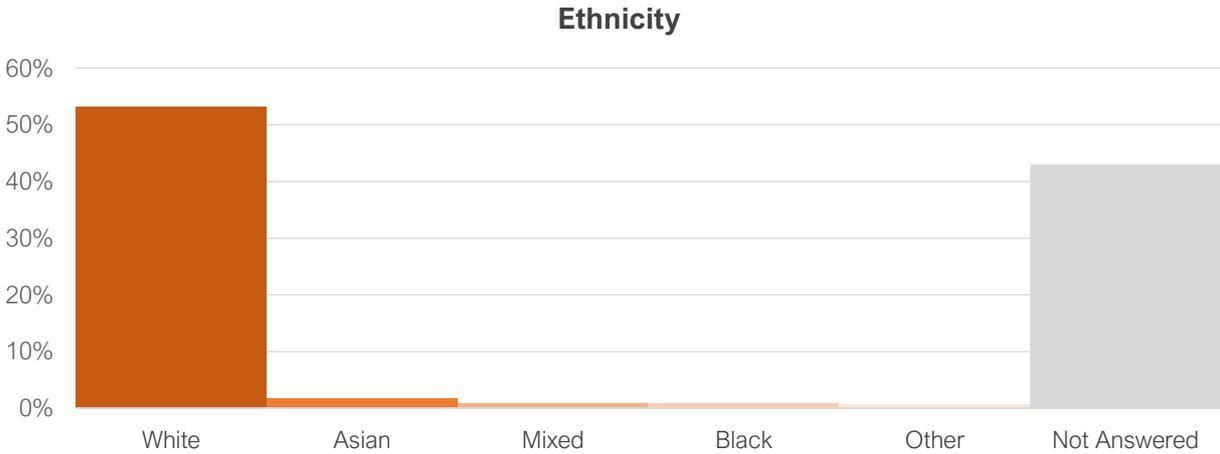
Figure 14.   Share of respondents with and without disability

Disability
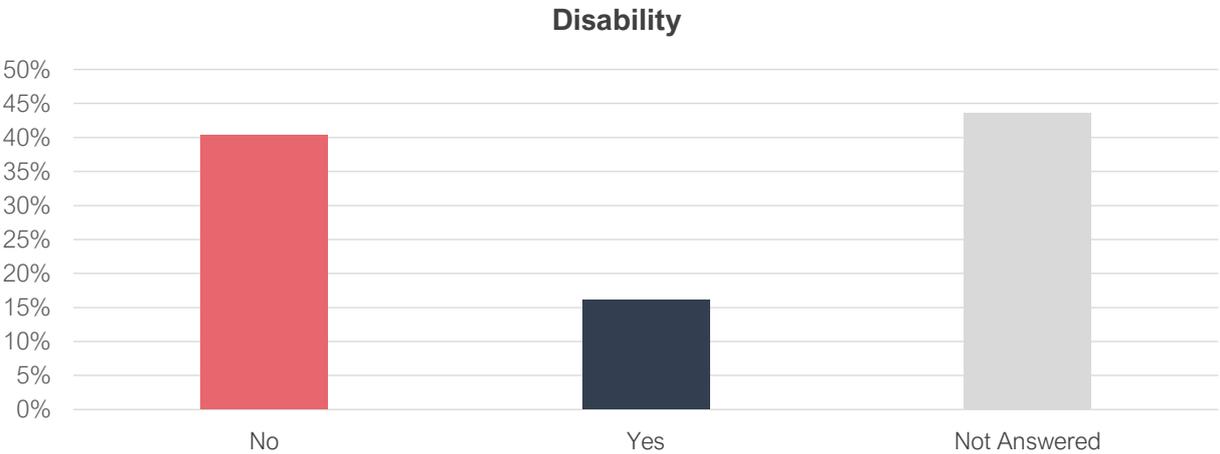
Figure 15. Share of respondents by caring responsibilities

Caring responsibilities
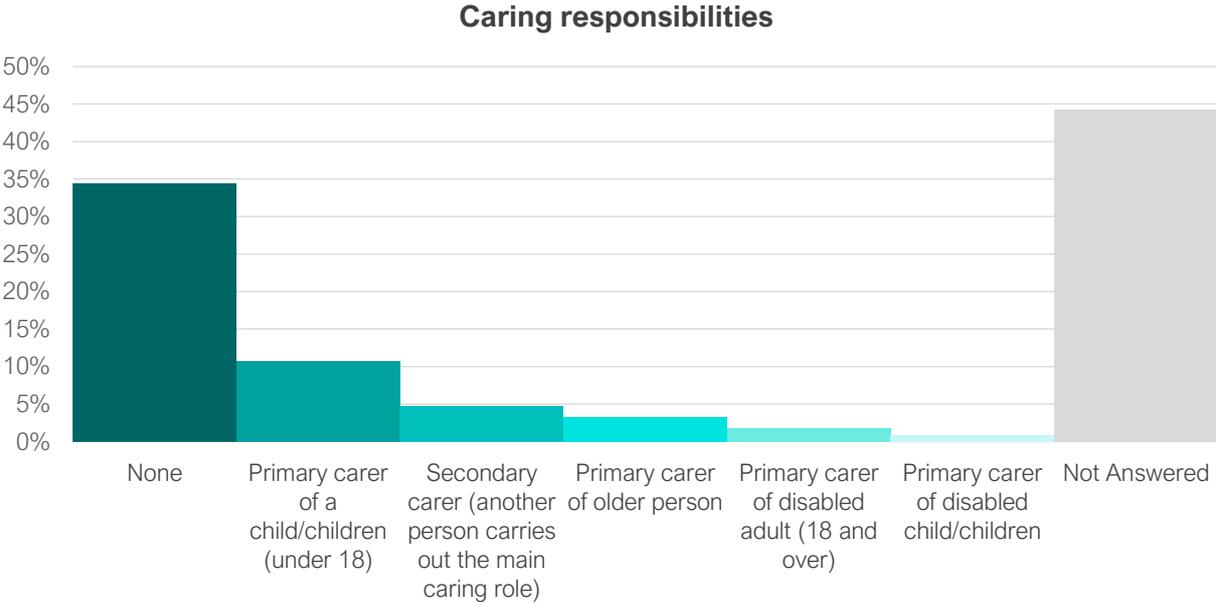
Annex D – Question 12 demographic breakdowns

**Figure 16.   Share of respondents who said "Yes" by gender**
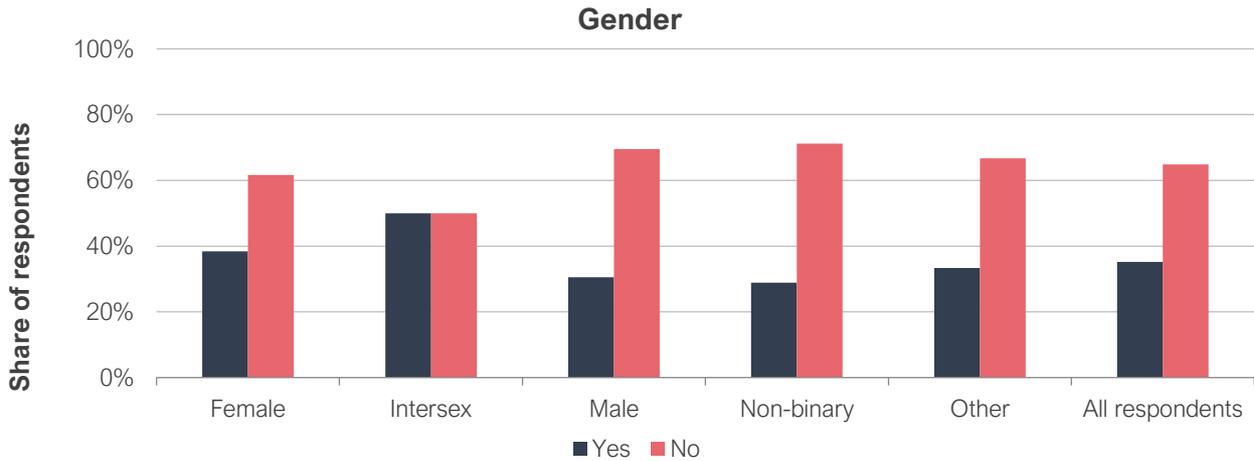
**Figure 17.   Share of respondents who said "Yes" by sexual orientation**
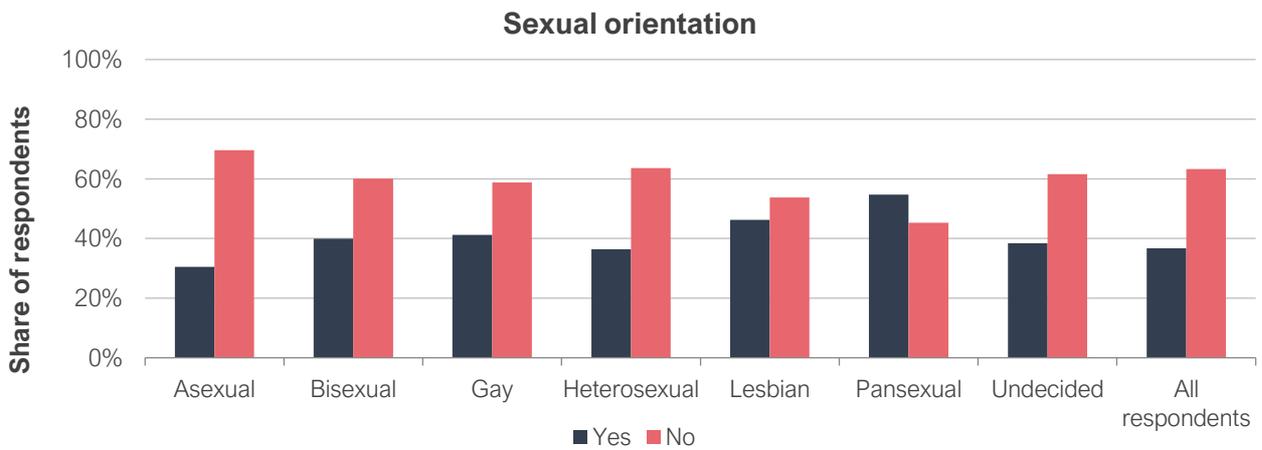
**Figure 18.   Share of respondents who said "Yes" by religion**
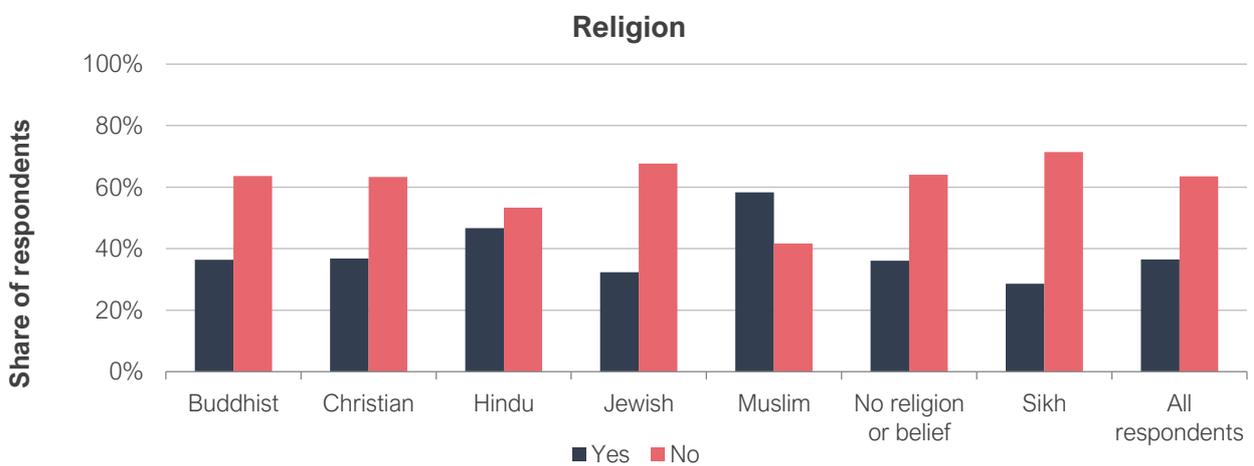
**Figure 19.   Share of respondents who said "Yes" by country**

Country
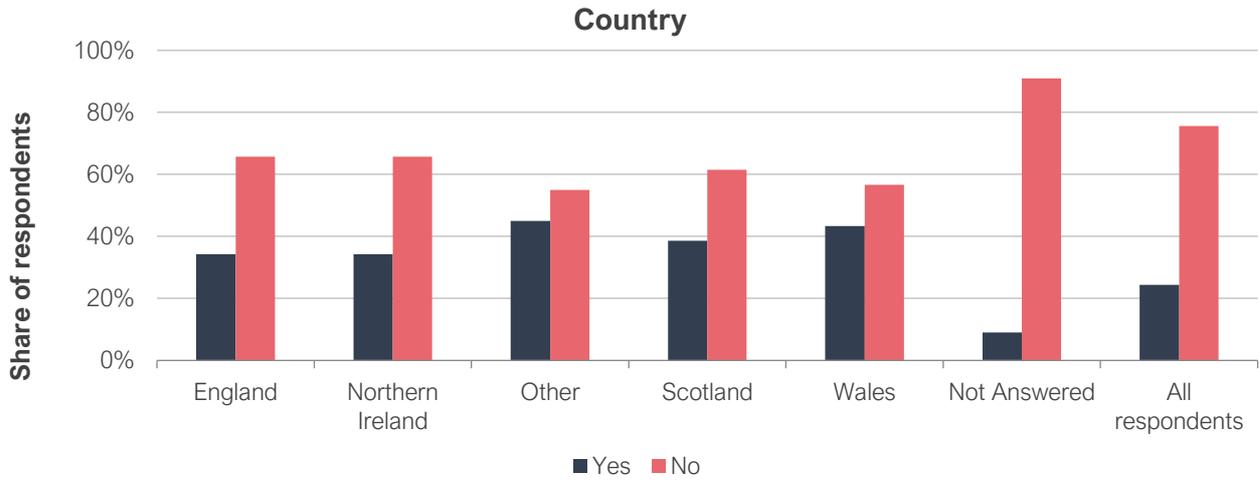
Figure 20.   Share of respondents who said "Yes" by Ethnicity

Ethnicity
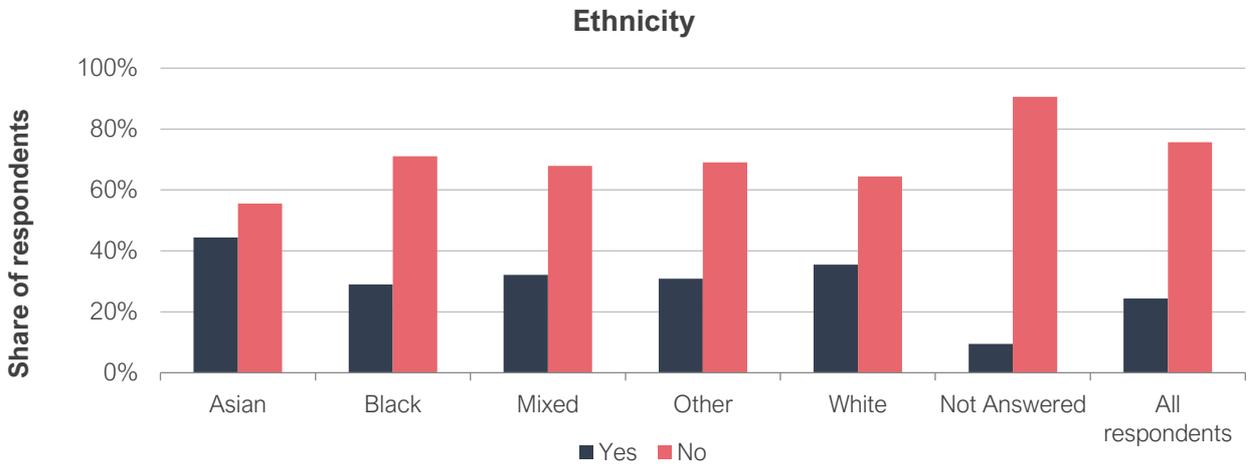
Figure 21.   Share of respondents who said "Yes" with and without disabilities

Disability
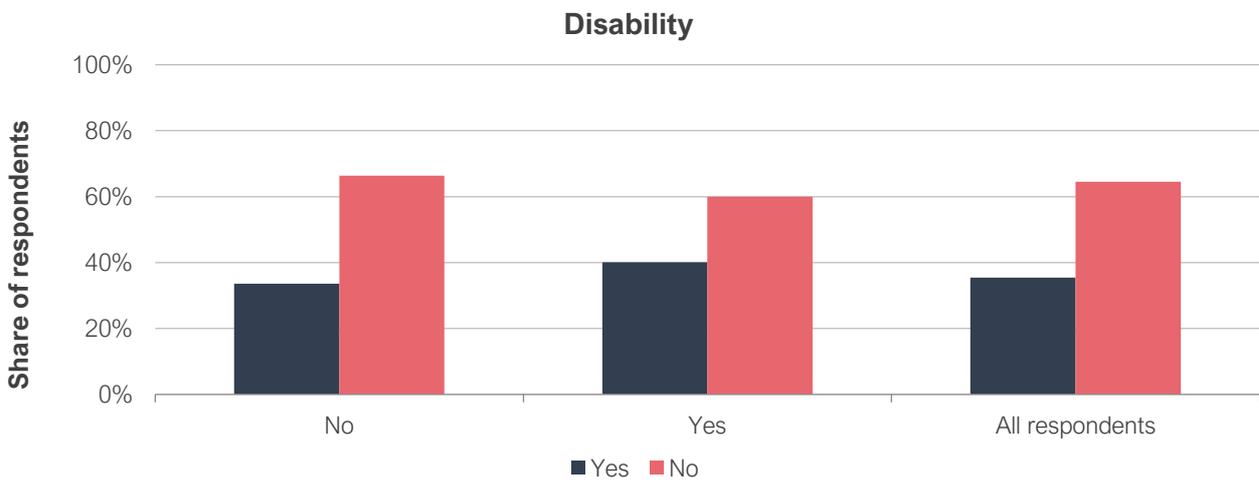
Figure 22.   Share of respondents who said "Yes" by caring responsibilities

Caring responsibilities
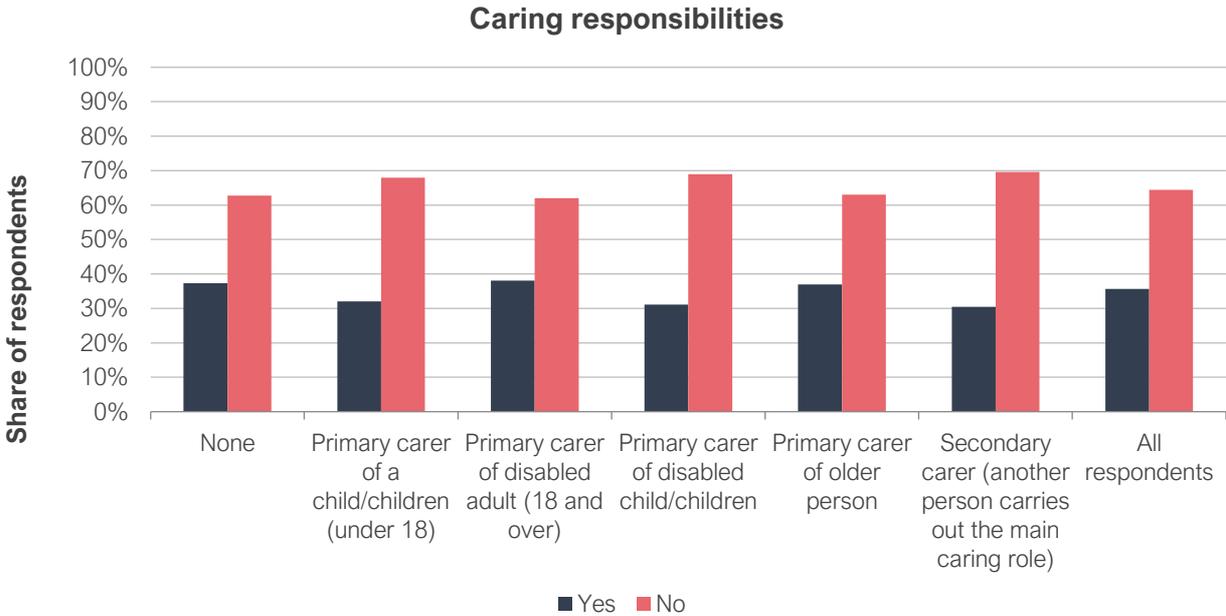
Annex E – Question 15 demographic breakdowns

Figure 23.   Share of respondents who said "Yes" by gender

Gender
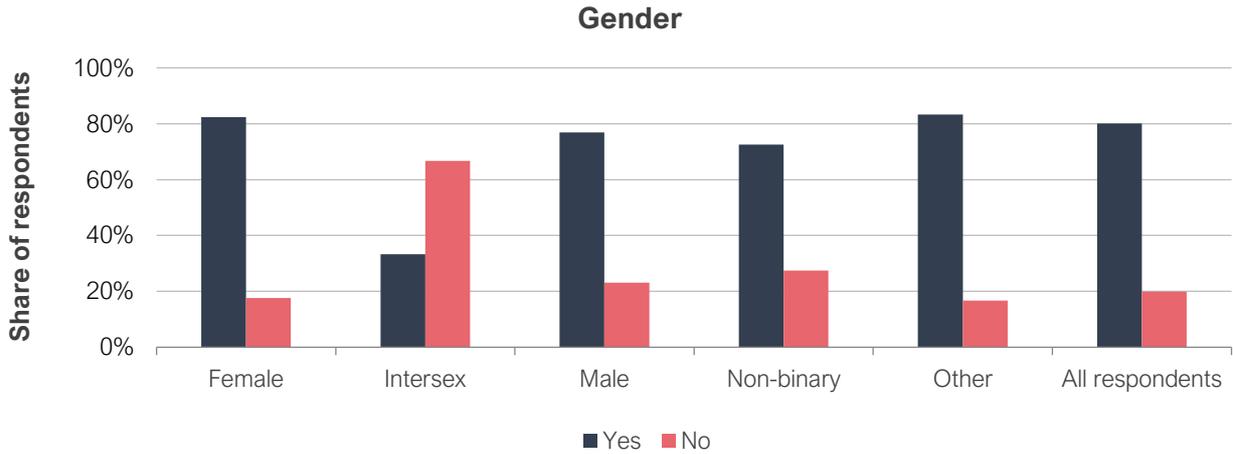
Figure 24.   Share of respondents who said "Yes" by sexual orientation

Sexual orientation
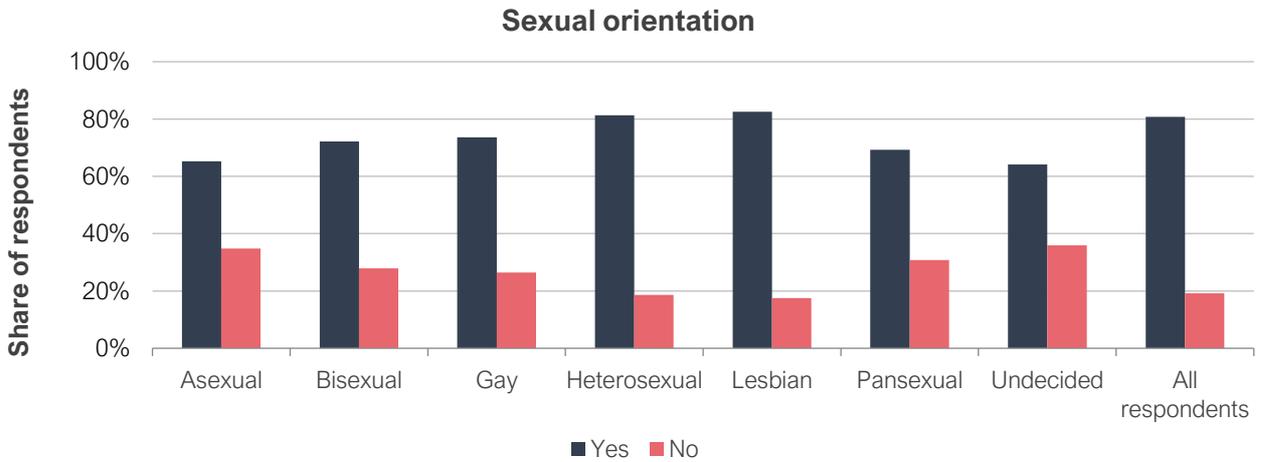
Figure 25.   Share of respondents who said "Yes" by religion

Religion
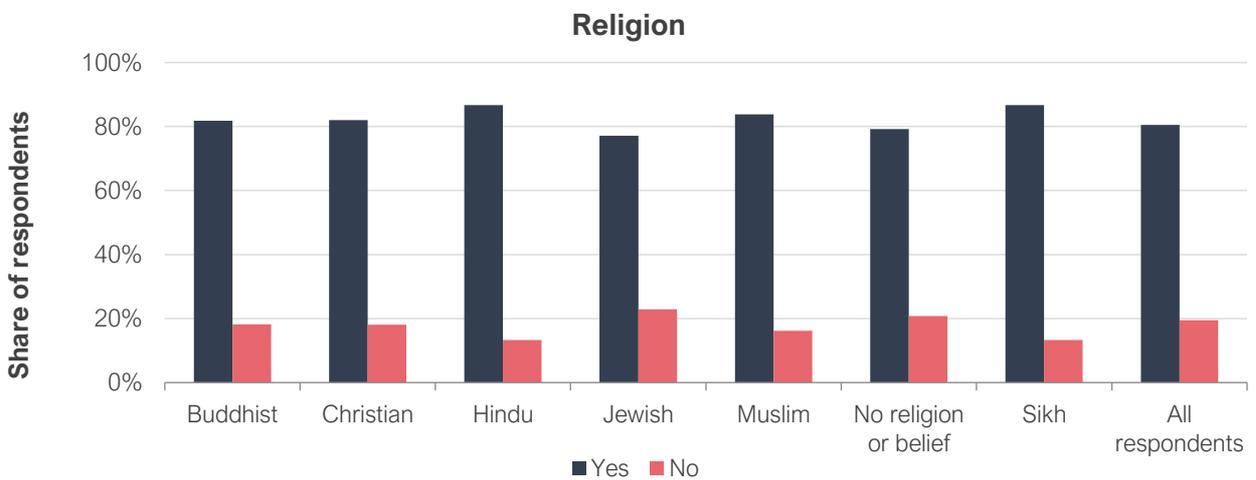
Figure 26. Share of respondents who said "Yes" by country

Country
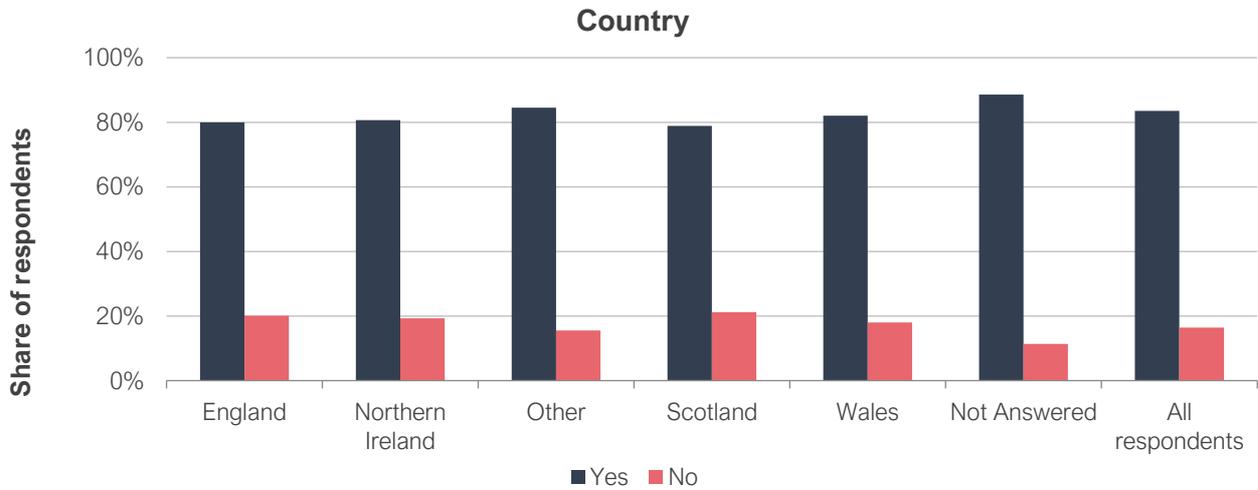
Figure 27. Share of respondents who said "Yes" by ethnicity

Ethnicity
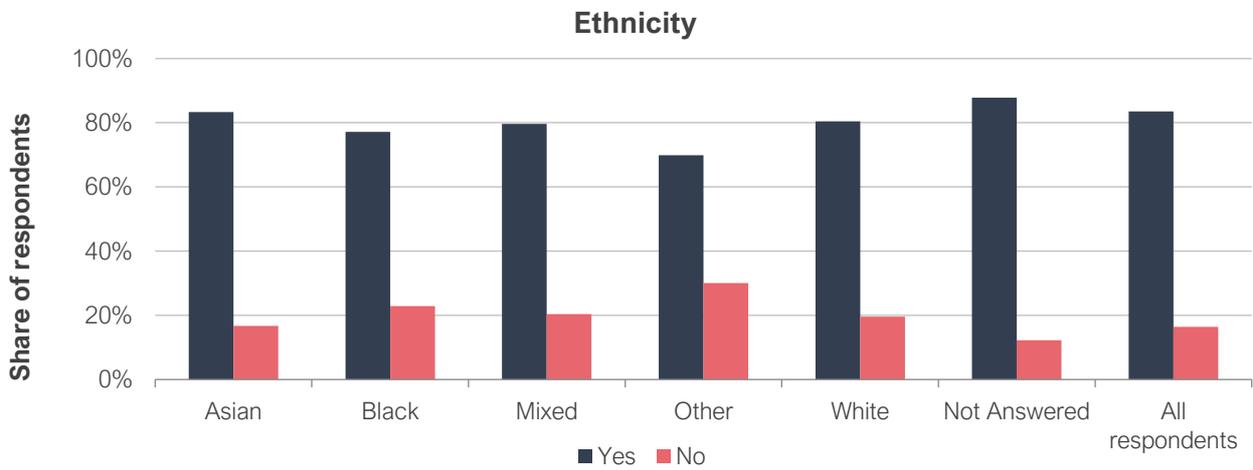
Figure 28. Share of respondents who said "Yes" by disability

Disability
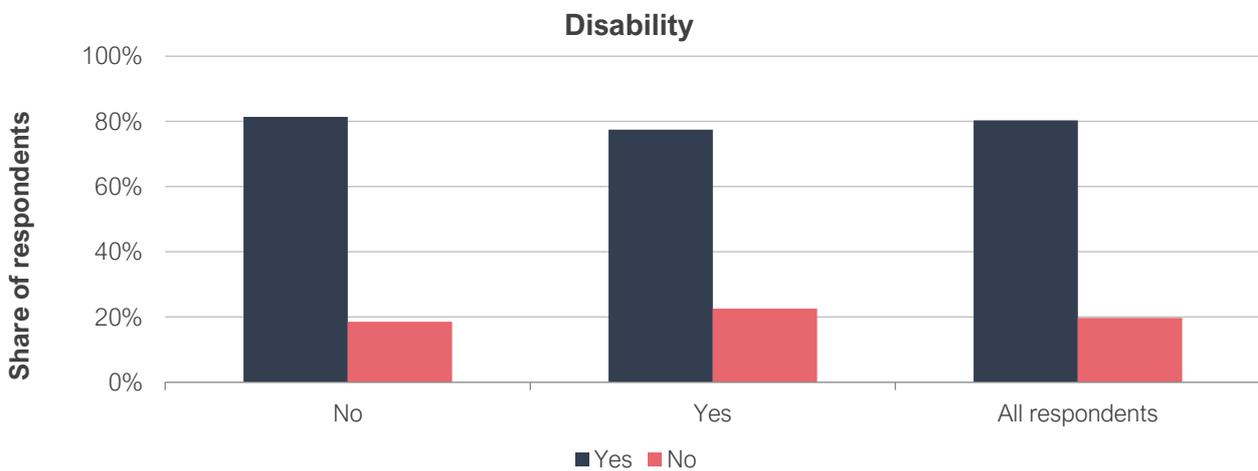
Figure 29. Share of respondents who said "Yes" by caring responsibilities

Caring responsibilities