



NICE Listens: Public dialogue on health inequalities

Final Report

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1. Executive summary

## Background and methodology

[Health inequalities are defined by The King’s Fund](https://www.kingsfund.org.uk/publications/what-are-health-inequalities) as ‘avoidable, unfair and systematic differences in health between different groups of people’. Health inequalities are a result of a complex interaction between external factors known as the ‘wider determinants of health’, and a person’s biological, protected, and other individual-level characteristics leading to varying health outcomes. For example, people living in deprived communities in England often have worse life expectancies than those living in wealthier areas (see [the Marmot Review Fair Society, Healthy Lives](https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf) for more information).

[A report by the Institute of Health Equity](https://www.instituteofhealthequity.org/resources-reports/build-back-fairer-in-greater-manchester-health-equity-and-dignified-lives/build-back-fairer-in-greater-manchester-main-report.pdf) highlighted that health inequalities are widespread in England and have been worsened by the COVID-19 pandemic.

The National Institute for Health and Care Excellence (NICE) has made a renewed commitment to addressing health inequalities in its 2021 to 2026 strategy. It was therefore timely to engage the public on this issue, through its new programme of public engagement: NICE Listens. Basis Social was commissioned by NICE to engage members of the public in a dialogue to understand their views on health inequalities in England and how they believe these should be addressed by NICE. Specific objectives were to understand:

1. How would the public like NICE to act in regard to health inequalities?
2. What value do the public place on different types of health inequalities? Are some more important for NICE to consider than others?
3. What other factors should inform committee deliberation when they are considering health inequalities?

The NICE Listens public dialogue involved 28 participants who completed several tasks and attended four online workshops each lasting two hours, conducted between 16th September 2021 and 16th November 2021.

Participants were recruited to reflect a range of age ranges, ethnicities, income levels, life stages, locations, and disability status. The sample was weighted more toward those groups who are most affected by health inequalities. Specifically, ethnic minority communities and those living in deprived areas were purposively overweighted in the sample.

The workshops were designed to enable people to engage with the topic of health inequalities by exploring different perspectives and evidence. Alongside plenary and small group discussions, structured analytical tools, such as trade-off exercises were used to do this. Earlier workshops focused on providing participants with information and allowing exploration on the topic. Later workshops allowed for deeper debates and, at times, consensus to be reached.

## What do people understand by ‘health inequalities’?

Before delving into the topic of health inequalities, participants first discussed the topic of health and ‘good health’ more generally. They then explored what influences health before going on to discuss health inequalities and the issues surrounding the topic.

Participants understood ‘good health’ in terms of the absence of conditions that restrict people’s independence, happiness and ability to live life in the way they desire. While there was recognition that ‘good health’ is subjective and varies greatly from person to person, most participants placed greater value on quality of life than length of life. Participants identified three broad factors influencing health:

* individual behaviours (including diet, exercise and life experiences)
* social and environmental factors (including housing, outside space, air pollution, disposable income, and social networks)
* access to healthcare and medicine

Individual characteristics such as biological or protected characteristics (e.g. gender and ethnicity) were not discussed without prompting. Participants were largely uncomfortable with NICE prioritising groups in tackling health inequalities using these factors in isolation. Instead, participants thought health (and social) inequalities were mostly linked to social and environmental factors.

It should be noted that NICE has a legal duty to consider protected characteristics under the Equality Act; participant views toward the relationship between protected characteristics on health inequalities will not influence these duties.

Resulting from a combination of materials designed to prompt discussions, and input from experts, there was discussion on intersectionality and the wider determinants of health, which prompted participants to reflect on the systemic, often cyclical nature of inequalities. Health inequalities were seen by participants to represent unfair differences in health outcomes between groups that are determined by circumstances largely beyond an individual’s control.

## What value do people place on addressing health inequalities?

As with [the findings from the 2006 Citizens Council meeting on health inequalities run by NICE](https://www.ncbi.nlm.nih.gov/books/NBK401723/pdf/Bookshelf_NBK401723.pdf), within this public dialogue, there was again consensus that health inequalities in England should be addressed. Most participants supported actions to achieve greater equality in health outcomes and to reduce health inequalities, even when the gains to the overall health of the population were reduced by prioritising those with poorer health outcomes.

Common throughout these discussions was a desire to improve healthy life expectancy, not simply life expectancy.

When tasked with allocating resources to address health inequalities in various hypothetical scenarios, participants tended to use one or more of four ‘lenses’ through which to assess and prioritise needs/actions. For details on priority scenarios addressed by participants please see the methodology annex.

1. **‘Ethics’** in terms of what could be considered as ethically or morally the right thing to do.
2. **‘Fairness’** as it relates to perceived level of control over health outcomes and/or determinants of health. When using a fairness lens, participants would make a personal judgement as to how ‘fair’ they considered it would be to prioritise an individual or group over another individual or group based on a certain determinant of health (as identified in a given scenario).
3. **‘Relatedness’** in how much one relates to the individuals or groups in question, based either on wider determinants, biological and protected characteristics, or conditions/illnesses impacting them. Some participants intentionally resisted using this lens to enable a greater degree of objectivity to their decisions.
4. **‘Health optimisation’** in terms of achieving the greatest impact on health outcomes (particularly healthy life years) for the most people.

## How NICE should act regarding health inequalities?

Members of the public taking part in this research were clear that health inequalities were a priority to address and should be embedded as a core consideration in all guidance and advice produced by NICE.

NICE was seen as having an important role in addressing health inequalities by adopting an objective and where possible, evidence-based stance to the assessment of economic, scientific and social value judgements when making recommendations. This includes considering actions to address health inequalities using both health optimisation and ethics lenses. The consensus among participants was that NICE should both:

* prioritise recommendations for action that will have the greatest (positive) impact on quality life years for the greatest number of people (health optimisation); and
* account for health inequalities in decisions, including recommending actions to mitigate negative impacts on health outcomes which would be recognised as unfair within social value judgements.

It is important to note that participants believed that by improving living conditions and outcomes for most people, standards would gradually improve for all (including those who were more disadvantaged).

Participants expected NICE to prioritise addressing health inequalities where there were significant differences in healthy life expectancy between certain groups and these were related to circumstances beyond an individual’s control. Beyond this, participants expected NICE to account for health inequalities in the guidance it produces (i.e. understanding who could be disproportionately impacted for better/worse, and how to mitigate against this).

When prioritising recommendations that benefit the overall population at the expense of reducing health inequalities there was still a desire:

* to ensure there was no loss of life years for the more disadvantaged groups; and
* that alternative actions were taken to try to improve their health outcomes and mitigate against widening inequalities.

There was acknowledgement of the complexity involved in these decisions and that there is no ‘one-size-fits-all’ way to approach these prioritisation decisions. Participants did not want NICE to adopt a blanket approach in which actions to reduce differences in health outcomes between groups were prioritised over those that would benefit a larger proportion of the population, or vice versa. There was a desire for a ‘case-by-case’ approach to addressing health inequalities, using judgements about scientific, economic and social values, informed using qualitative and quantitative data. Research on health inequalities was believed to be important to build a strong evidence base from which to address it.

There was a consensus that, where possible, NICE should prioritise guidance looking at preventative actions to improve health outcomes and tackle health inequalities. There was a common view that prevention rather than treatment was better in the longer term and could also reduce pressure on the NHS and NICE, in turn freeing up resources to focus on further reducing health inequalities.

For NICE to be able to address health inequalities through its guidance, participants felt it must be in the strongest possible position to make objective, transparent and evidence-based recommendations.

In considering health inequalities it was also seen to be important for NICE to consider how it could draw on evidence from those directly impacted by inequalities, to ensure that decisions were grounded in the lived experience of those affected. This could help NICE further its understanding of the causes of health inequalities and the interventions that could help improve people's health outcomes.

Another important priority was to ensure that NICE staff were trained effectively on the topic of health inequalities and NICE’s role in addressing them.

There was some support for NICE working collaboratively with other organisations to ensure that its guidance was successful at reducing health inequalities. There was a desire for NICE to be more active in this role, which could come in the form of more directly supporting implementation of activities to address health inequalities.

## Key considerations

This research provides some considerations for NICE regarding its role in addressing health inequalities as follows:

* A definition for health inequalities (both at a conceptual and operational level) could help to ensure clarity across the organisation on what NICE defines health inequalities as encompassing.
* Internal guidance and training for NICE staff could increase awareness and understanding of what health inequalities constitute, the complex factors that contribute to health inequalities, and the importance of and potential for, accounting for (and where possible addressing) health inequalities in NICE’s work.
* Embedding health inequalities within guideline development and health technology evaluation methods using a transparent process (such as a framework) could help to ensure consistency in how health inequalities are considered when making recommendations.
* In looking to understand and address health inequalities it is important to ensure meaningful involvement of groups affected by health inequalities.
* It is important to promote diversity in staffing to encourage representation of those who are or have been affected by health inequalities across all levels of an organisation.
* Members of the public are more supportive of actions to address health inequalities where a clearer connection is made between the inequalities experienced and the wider determinants that impact those more disadvantaged groups. National organisations driving the quality and effectiveness of health and care (including NICE and NHS England) could look to raise the profile of health inequalities to promote public support for actions that prioritise those groups currently most disadvantaged.
* By actively supporting the adoption and implementation of NICE guidance recommendations that address health inequalities – for example through provision of or signposting to useful tools and resources, monitoring impact and through partnership working – there is a greater likelihood of NICE driving actions that tackle health inequalities.

## Key word definitions

**Equality** – equal distribution (of health or healthcare) across individuals of a population.

**Equity** – fair distribution (of health or healthcare) across individuals of a population, with the implication that it may not always be fair to be equal. For example, healthcare resources may be distributed according to need.

[**Intersectionality** – as defined by the online dictionary Lexico](https://www.lexico.com/en/definition/intersectionality), is the interconnected nature of social categorisations such as ethnicity, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.

[**Wider determinants of health** – as defined by Public Health England](https://www.gov.uk/government/publications/health-profile-for-england-2018/chapter-6-wider-determinants-of-health) area diverse range of social, economic and environmental factors such as education, employment and housing, which influence people’s mental and physical health. Systematic variation in these factors constitutes social inequality, an important driver of health inequalities.

1. Background and methodology
   1. What are health inequalities?

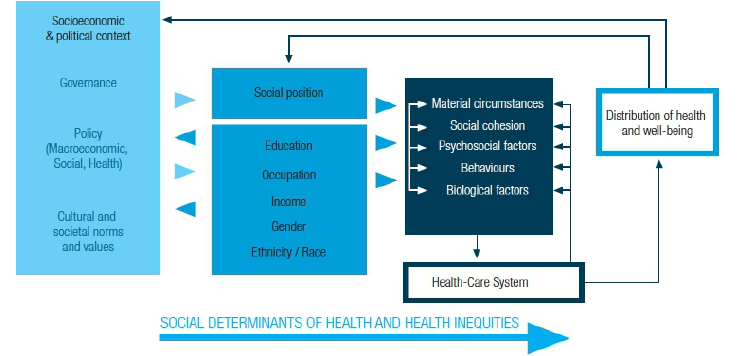
[Health inequalities are defined by The King’s Fund](https://www.kingsfund.org.uk/publications/what-are-health-inequalities) as avoidable and unfairly distributed differences in health between groups of people.

Every person possesses various biological risk factors that influence their health. Health inequalities are caused in part by the interaction of these risk factors with external factors, or ‘wider determinants of health’, which disproportionately impact certain groups of people.

Wider determinants typically lie outside of the health and social care system and include education, working conditions, income, housing and the environment in which people live. They are driven by political, social, and economic factors, which in turn influence individual socio-economic status (or ‘social position’) and the way someone may engage with health and social care services.

Figure 1 is a commonly used illustration of the determinants of health inequalities and how these factors interact with one another and the healthcare system.

Figure 1: Determinants of health inequalities adapted from [Solar and Irwin (2007) A conceptual framework for action on the social determinants of health](https://www.who.int/social_determinants/resources/csdh_framework_action_05_07.pdf).



* 1. Health inequalities in England

In 2010, a seminal report on health inequalities was published by Professor Sir Michael Marmot ([the Marmot Review](https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf)). This shone a light on the well-established evidence base documenting the unfair and unjust inequalities in health between those with higher social and economic status and other members of society.

The Marmot Review highlighted how differences in health conditions and life expectancies of different groups were widening, with poor and deprived communities and certain demographics, such as people with an African, Caribbean or Asian family background, experiencing the worst health outcomes and life expectancies. Importantly the Marmot Review called for health inequalities to be addressed by creating the conditions within which people could take control of their own lives. Key to this was recognising and tackling the wider determinants of health that start to create disadvantage before birth and continue influencing choice and behaviours throughout people’s lives.

The Health and Social Care Act 2012 states that ‘policy makers and commissioners must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service’. Despite this legislation, health inequalities continue to rise. In 2010 the difference in life expectancy between those living in the poorest neighbourhoods in England and those living in the richest neighbourhoods was seven years. In 2020 [the Institute of Health Equity published a follow-up report](https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on) co-authored by Professor Sir Michael Marmot, which made for sombre reading. Over a period in which government spending had reduced, health inequalities had grown. Most worryingly, life expectancy for both women and men living in the most deprived areas outside London have dropped.

In England, the COVID-19 pandemic has increased health inequalities and exposed how low income and poor housing are linked to ethnicity and location.

People with an African, Caribbean or Asian family background have been more likely to be infected with, diagnosed with, and die from, COVID-19 than people in white ethnic groups, and have experienced above-average increases in mental distress. Young people have also been disproportionately impacted by the pandemic, as public lockdowns and restrictions have reduced development and education, as well as training and employment, all of which impact future health equality.

* 1. Current understanding of the public’s view of health inequalities

In developing public policy and public services, decision-makers draw on both ‘hard’ scientific and statistical data (including data around economic cost-benefit), and social value judgements. Social value judgements relate to society and the value that members of the public, both individually and collectively, place on a given issue.

In the context of the work of NICE, decisions made around recommendations encompass not only objective assessments of clinical effectiveness and cost-effectiveness but also social value judgements, which come from assessing the relative social (and ethical) acceptability and desirability of different recommendations.

NICE first sought to understand public perceptions of health inequalities in 2006. Its Citizens Council, comprising 26 members of the public, met to discuss whether:

* NICE should prioritise actions to improve the health of the most disadvantaged members of society – narrowing health inequalities – even if this had only a modest impact on the rest of society; or
* NICE should prioritise actions to improve the health of the whole population even where this risked widening health inequalities

During three days of deliberation, including opportunities to hear from health experts, the members were largely unanimous in the need to address health inequalities in some way, though there was no unanimity in how this should be achieved. What followed was a stalemate when they voted on the two options, where relatively similar proportions of participants expressed a preference for each option. What was clear was that decision-making was complicated, that participants were conflicted in their choices, and this was evident in the contradictions that emerged in the decisions taken at different stages of the process of deliberation.

There also emerged views on how and why participants would like this issue to be addressed: the importance of a holistic approach reaching beyond the healthcare system; the idea of being proactive rather than reactive in responding to need; and to potentially prioritise those most susceptible to a condition/illness or those who are most disadvantaged. [A report of the full findings from the Citizens Council on health inequalities was published](https://www.ncbi.nlm.nih.gov/books/NBK401723/pdf/Bookshelf_NBK401723.pdf).

Over the past 15 years, there have been a wide variety of studies undertaken with members of the public about health inequalities. One common finding is that the public is uncomfortable with health inequalities in the UK and believes action should be taken to address health inequalities. This was evidenced in [a recent systematic review, which identified a strong aversion to health inequalities](https://link.springer.com/article/10.1007/s10198-019-01126-2) found between socioeconomic groups, and that people are typically willing to sacrifice overall population gain in quality life years in order to address inequalities.

In approaching the topic of health inequalities, members of the public are often quick to identify factors influencing health outcomes that relate to individual choice. For example, [a public dialogue conducted in 2014 by TNS-BMRB](https://www.gov.uk/government/collections/national-conversation-on-health-inequalities) found that people typically start by identifying individual behaviours (such as physical activity, alcohol and drug use, and eating habits) as the reason for health inequalities but go on to recognise the role of wider determinants. These wider determinants include income and employment, as well as environmental factors such as where people live, and access to services.

[The Institute for Fiscal Studies (IFS) and the Nuffield Foundation recently launched a review into inequalities within the UK](https://ifs.org.uk/inequality/attitudes-to-inequalities/), including a survey of over 2,000 members of the public to examine their views on inequalities (not just health inequalities). This survey highlighted that people can be split relatively evenly into three segments based on their views toward the causes of inequalities:

* individualists (29% of the sample) primarily consider factors within an individual’s control, such as personal choices and behaviours;
* structuralists (32%) mainly recognise factors outside an individual’s control, such as socioeconomic factors; and
* those ‘in the middle’ (39%) recognise both elements.

Most recently, [Kantar Public conducted online deliberative research as part of the Health Foundation’s COVID-19 impact inquiry](https://www.health.org.uk/publications/reports/unequal-pandemic-fairer-recovery) with over 70 members of the public. This study explored public attitudes to health inequalities and what actions, if any, people wanted to see taken to address them. Here again, participants were seen to acknowledge the role of wide determinants in inequalities, but they largely focused on the role of individual choice in determining health outcomes. As a result, actions to address health inequalities were largely seen as ones that should focus on enabling people to make changes to their own circumstances.

Through these projects, it has become clear that the public is in favour of addressing health inequalities, although how they feel that they should be addressed is less understood.

* 1. Research objectives

While addressing wider determinants of health is key to tackling health inequalities, there is also much that the NHS and other public health and social care services can do to address the influence of health inequalities. NICE is responsible for providing national guidance and advice on promoting high-quality health, public health and social care. Its role is to improve outcomes for people using the NHS and other public health and social care services.

Reducing health inequalities is enshrined in [NICE’s principles](https://www.nice.org.uk/about/who-we-are/our-principles); however, it has been 15 years since NICE considered health inequalities via the Citizens Council. With the impact of COVID exacerbating inequalities, along with the government pledging to improve and ‘level up’ the health of the nation, there is a strong rationale for a renewed focus on health inequalities. This has been formalised in [NICE’s 2021 to 2026 strategy](https://www.nice.org.uk/about/who-we-are/corporate-publications/the-nice-strategy-2021-to-2026) which sets out ‘a renewed determination to prioritise its work to reduce those health inequalities that have been highlighted during the pandemic'.

Basis Social was commissioned by NICE to engage members of the public in an online dialogue to understand their views on health inequalities in England and how they believe these should be addressed by NICE. Specific objectives were to understand:

1. How would the public like NICE to act regarding health inequalities?
2. What value does the public place on different types of health inequalities? Are some more important for NICE to consider than others?
3. What other factors should inform committee deliberation when they are considering health inequalities?

This was the first public dialogue using NICE’s new process for public engagement: NICE Listens. [Information about NICE Listens can be found on the NICE website](https://www.nice.org.uk/get-involved/nice-listens).

* 1. Research approach

Public dialogue is a form of deliberative group discussion that recognises the value that members of the public can add to decision-making around policy, legislation, and regulation. It is a particularly useful way of understanding public attitudes, views, and priorities around complex issues or controversial topics. It is characterised by:

* the involvement of people from a large cross-section of society selected to reflect a diversity of characteristics and views;
* the exploration of views through a process of deliberation, where participants are given information that helps them consider and debate issues in more depth;
* extended and/or reconvened sessions involving plenary and small group discussions (and supporting activities);
* the involvement of experts on relevant topics to inform people’s views, and the opportunity for participants to ask direct questions of experts in the field; and
* time for participants to reflect on what they have heard and discussed, and to develop their views in relation to others’ views.

Public dialogue is also a means by which those in power can engage meaningfully with citizens to find solutions to societal challenges. Further information on public dialogue approaches, principles and good practice can be found on the [Sciencewise website](https://sciencewise.org.uk/about-sciencewise/our-guiding-principles/) and the [OECD report ‘Good Practice Principles for Deliberative Processes for Public Decision Making’](https://www.oecd.org/gov/open-government/good-practice-principles-for-deliberative-processes-for-public-decision-making.pdf).

The NICE Listens dialogue involved 28 participants, recruited to reflect a range of backgrounds. Participants completed several tasks and attended four, two-hour long online workshops between 16th September 2021 and 16th November 2021.

* + 1. Sample

The sample design accounted for standard socio-demographics of England but, importantly, was weighted toward those groups that are most affected by health inequalities. Specifically, ethnic minority communities and those living in deprived areas were purposively overweighted in the sample. Table 1 shows the characteristics of sample who participated.

Note that the aim was not for the sample to be statistically representative of the English population, but instead to enable a breadth of views to be captured, including from individuals with lived experience of health inequalities.

All participants were recruited using free-find methods by Roots Research, qualitative recruitment specialists. This included using [the website ‘Take Part In Research’](https://takepartinresearch.co.uk/) to achieve organic targeting, and targeted emails to existing panel members to focus on the most relevant profile types. The project was advertised on social media to bring in people not currently registered on the website.

Participants were provided with detailed information about the project and a consent form outlining the purpose of the public dialogue, what their participation would involve, and how their data would be managed and used. Participants were recruited to meet a set of pre-agreed quotas – on a ‘first come, first served’ basis – which enabled a range of socio-demographic characteristics to be covered within this research. Participants each received an incentive of up to £250, depending on their attendance at the workshops and participation in offline tasks. This was clearly communicated at the point of recruitment. Incentives were paid following each workshop. 25 of 28 participants received the full incentive amount.

Table 1: Sample characteristics and achieved quotas

| Participant characteristics | Achieved quotas |
| --- | --- |
| Gender | Male (15)  Female (13) |
| Age | 18 to 24 (6)  25 to 44 (7)  45 to 64 (8)  65+ (7) |
| Ethnicity  Including first generation migrants (8) | Indian (2)  Bangladeshi (1)  Pakistani (3)  Other Asian (2)  Black African (4)  Black Caribbean (3) |
| Household income | Less than £25,000 (11)  £25,000 to £35,000 (6)  £35,001 to £60,000 (11) |
| Disability | Participants identifying as disabled (5) |
| Life stages | Students (2)  Working, no children (12)  Raising young children (4)  Empty nesters/Retired (10) |
| Location    Including participants from the 20%  most deprived areas on the Health  Deprivation and Disability Domain  Decile according to [the Government’s most recent](https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019)  [English Indices of Deprivation 2019](https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019)  (8) | East of England (2)  East Midlands (2)  London (4)  North East (3)  North West (4)  South East (4)  South West (2)  West Midlands (3)  Yorkshire and the Humber (4) |

* + 1. Overview of the process

This dialogue was run from 16th September 2021 until 16th November 2021. This involved four individual workshops taking place two weeks apart, supported by asynchronous, online engagement tasks between workshops. The dialogue was supported by [Incling, an online community platform designed for running research projects](https://incling.com/). Basis Social used Incling to manage engagement with participants and enable tasks asynchronous to workshops. Figure 2 provides a visual overview of the process.

The dialogue was designed to be iterative and exploratory. Each workshop was designed to be responsive to the discussion in the previous workshops, the online discussion board, and responses to the online tasks. The ‘shape’ of the public dialogue aimed to focus initial engagement on exploration and information provision, then to allow time and space for reflection, with deeper debate and, potentially, consensus-building towards the end of the dialogue.

Figure 2: Overview of methodology A timeline of the NICE Listens methodology with key stages of the process marked out including the rapid evidence assessment, expert interviews, workshops and pre and post workshop tasks.


All materials used during the dialogue can be found in the methodology annex. This includes details on tasks participants completed outside of the workshops. It also includes the topic guides and stimulus used during the workshops. Stimuli are materials used to prompt participants and encourage responses and discussions. These can be in many formats such as photos, videos, or audio.

* + 1. Preparation stage

During the preparation stage a rapid evidence review was conducted on health inequalities in the UK and the public’s views on the topic. This was used to help develop the approach and materials used during the project, as well as inform the [background section of this report](#_Background_and_methodology). Five interviews were also conducted with experts and stakeholders across the fields of health, policy, and health inequalities (see table 2). Interviewees were identified by Basis Social and NICE, to ensure views on health inequalities from different perspectives including academics, charitable organisations and those with lived experience were taken. The interviews were used to help inform the design of the project and clips of recordings from the interviews were used to introduce the topic to participants during the workshops. See the ‘expert interview topic guide’ in the methodology annex for the more information on the content of these interviews.

Table 2: Expert contributors

| Name | Organisation |
| --- | --- |
| Dr Ann Hoskins | Independent public health consultant |
| Clenton Farquharson MBE | Think Local Act Personal |
| Ethan Williams | King’s Fund |
| Professor Richard Cookson | University of York |
| Professor Sir Michael Marmot | University College London |

Before the first workshop, participants were asked to record one video and take six pictures and post them on Incling. The purpose was to understand participants’ views on what good health means to them, and what factors influence health. See ‘Workshop One pre-task’ in the methodology annex for more details on this activity.

Participants were able to engage with each other online via a discussion board hosted on the Incling platform. This enabled participants to grapple with difficult topics and decisions over time rather than only during the live workshops.

* + 1. Workshop one

Workshop one was held on Zoom on Tuesday, 5th October from 6 to 8 pm and was attended by all 28 participants. This session involved five moderated breakout discussions, each consisting of five to six participants. The discussions were designed to enable participants to begin to understand and engage with health inequalities as a topic, and to begin gathering evidence of how participants were framing the issues around health inequalities. For more details on materials used in this workshop please see ‘workshop one topic guide and stimulus’ in the methodology annex.

Participants then completed a post-workshop task via the Incling platform. They were asked to provide two to three takeaways from the workshop and to engage with others’ posts on the topic. For more details on this task see ‘workshop one post-task’ in the methodology annex. The submissions for this task helped to inform the next workshop and were used in the analysis in the main report.

* + 1. Workshop two

Workshop two was held on Zoom on Tuesday, 19th October from 6 to 8 pm and was attended by all 28 participants. This session involved five moderated breakout sessions, followed by a panel discussion between four experts (see table 3) and all participants, and was concluded with five breakout sessions each involving five to six participants. The experts were identified in collaboration with NICE as those who could speak to, and facilitate discussions about NICE’s role across health, public health, and social care.

The session aimed to allow participants to further grapple with the topic of health and to help participants to see themselves/others reflected in inequalities data. It also sought to understand the factors that influence participant views on the prioritisation of health services and resources, including when it is justifiable to prioritise one group over another. Lastly, the workshop aimed to introduce NICE and its role in the health and care system to the participants. For more details on this workshop see ‘workshop two topic guide and stimulus’ in the methodology annex.

Table 3: Workshop two panellists

| Name | Role and organisation |
| --- | --- |
| Charlotte Goulding | Social care policy and practice support manager at NICE |
| Muna Abdel Aziz | Director of public health for Salford |
| Stephen O'Brien | Professor of Haematology at Newcastle University and chair of NICE technology appraisal committee |
| Deb O’Callaghan | Associate director at NICE |

* + 1. Workshop three

Before workshop three participants were asked to look at some hypothetical trade-off scenarios where they had to pick between two programmes, costing the same amount. This task involved trade-offs between prioritising individuals with less life expectancy over those with longer life expectancy. For details on these trade-off exercises, see ‘workshop three pre-task’ in the methodology annex.

Workshop three was held on Zoom on Tuesday, 2nd November from 6 to 8 pm and was attended by 26 of the 28 participants (with two not able to attend due to illness). This session involved five moderated breakout discussions each consisting of five to six participants where they discussed more trade-off scenarios. The scenarios addressed various ways in which health inequalities exist and participants were asked to discuss and debate the justification for their choices. For more details on this workshop and the trade-off scenarios used in during workshop three, see ‘workshop three topic guide and stimulus’ in the methodology annex.

* + 1. Workshop four

Workshop four was held on Zoom on Tuesday, 16th November from 6 to 8 pm and was attended by 27 of the 28 participants (with one not able to attend due to illness). This session again involved five moderated breakout discussions each consisting of five to six participants where they discussed various actions NICE could take to address health inequalities, including within guideline topic selection and scoping. In the second half of this final workshop, each group had a representative from NICE to answer participants’ questions about NICE’s actions. Up until this point, NICE representatives were present in the workshops as silent observers and did not engage with participants.

The participants discussed scenarios that addressed various ways in which health inequalities exist and were asked to choose where they would prioritise addressing health inequalities. They also discussed ways in which NICE can address health inequalities and their prioritisation for different approaches. For more details on the topics and priority decisions made during workshop four, see ‘workshop four topic guide and stimulus’ in the methodology annex.

* + 1. Analysis approach

Each discussion group was moderated by a researcher from Basis Social and the audio, video, and chats were recorded. Permission to record the sessions was taken in the consent form before beginning the project as well as verbally at the beginning of each workshop.

Following each workshop, the researcher would complete an analysis ‘pro-forma’. This was a document that was developed by the project lead following each workshop. The researcher was responsible for listening back to the recordings, reviewing the chats, and completing the pro-forma with findings from their session along with relevant quotes. The pro-formas were then combined to identify key themes. All pre and post-workshop tasks and discussion board responses were also recorded and grouped by theme.

Selected members of NICE staff were able to view the workshops live as silent observers, and following each workshop, an analysis session was held between these NICE representatives and the lead researchers from Basis Social. These sessions helped inform the next workshop and any associated tasks, as well as any analysis and reporting.

The lead researchers from Basis Social also held an internal analysis session at the end of the final workshop to further analyse the emerging themes and develop the structure for the report.

An initial report outline was developed to allow all researcher and NICE workshop observers to review and provide feedback. The full report was then written using the outline as a guide with continuous reference back to the findings and quotes.

* 1. Participant evaluative feedback

Following each workshop participants were asked to complete a survey to gather information on their views of the dialogue and ways in which the process could be improved.

The overall feedback was positive, with most participants reporting that they enjoyed the sessions (using a 0 to 10 scale; mean score: 9.1 out of 10; median score: 9 out of 10) and that they were run efficiently and effectively. These scores and those in table 4 are taken from the final survey, completed by 23 participants, covering views of all the workshops together.

**Question:** Please say how much you agree or disagree with the following statements

**Scale:** 0 Disagree - 5 Agree

Table 4: Participants' evaluative survey feedback

| Statement | Mean score | Median score |
| --- | --- | --- |
| I felt able to participate and express my views | 4.6 | 5 |
| The events were well organised and facilitated | 4.7 | 5 |
| The information provided was useful and well designed | 4.3 | 4 |
| The information was fair and balanced | 4.3 | 4 |
| The workshops gave me a clear understanding of the aims of the dialogue and how it will be delivered | 4.2 | 4 |
| Overall, I thought the events were useful and enjoyable | 4.6 | 5 |

Overall, participants reported that researchers effectively managed the discussions with patience and empathy, which allowed participants to feel comfortable engaging with a difficult topic.

‘I have to mention that [researcher] (who led 3 out of 4 of the sessions I was in) was absolutely fantastic. She gave everyone a fair chance to speak without putting pressure on anyone, explained everything well and was so friendly and supportive throughout.’

Participants believed that the small discussion groups were effective for engaging with others on the topics. While some believed that there were instances in which certain participants dominated the conversations, generally it was felt that everyone was able to have a chance to speak and share their opinions. One recommendation to encourage a more proportionate representation of views was to encourage quieter participants to use the chat function more during discussions.

Some participants felt that because of the large quantity of information that needed to be absorbed, it would be beneficial to share materials to be used during the workshops before the session. This practice was adopted part-way through the dialogue and seemed to support participants in engaging with the content during the sessions.

The workshops addressed health and health inequalities very broadly, before going on to decisions over addressing health inequalities. Some participants felt the overall goals of the dialogue could have been set out more clearly from the start, together with the participants’ roles in each workshop to meet these goals. This is something that would need to be balanced with the iterative design of the dialogue process.

‘I think giving us a greater idea/less vague explanation of the overall aims of this event and our specific role during the initial sessions would have been helpful.’

Workshop two involved a panel of experts engaged in dialogue with all the participants. This discussion was reported to be useful, but at times how the experts discussed the topics was felt to be very technical and not very accessible. Some people also felt that there were too many experts, which meant less could be covered. It was suggested to have fewer experts per session and that the experts should be briefed/encouraged to use plain, non-technical language.

In the final workshop a NICE representative was specifically placed in each breakout room to be able to answer questions about NICE’s processes and practices, which the researchers would not be able to personally answer. This was found to be extremely beneficial.

‘I thought the break-out sessions was well moderated with everyone given the chance to express their views. Having someone from NICE to provide context when required worked well. Cannot think of how the process could be improved.’

* 1. Strengths and limitations of this project

This public dialogue involved online qualitative research, using an iterative design that was responsive to the priorities of those participating based on the discussions and feedback gathered following each workshop. These elements are both strengths and limitations.

Qualitative research offers depth of insight and is fully appropriate for complex subject matter such as health inequalities. Furthermore, deliberative methods, in which participants are gradually exposed to new information and perspectives over time, with opportunities to pause and reflect, is an enabling approach. Participants are supported to build up the confidence to articulate their views on sensitive subject matter in a way that is meaningful and attempts to address power imbalances.

Traditional qualitative approaches such as focus groups or quantitative surveys are much less likely to achieve the depth of insights into people’s priorities and the reasons behind these. The level of nuance achieved through the presentation of such a variety of scenarios would be hard to achieve via alternative methods.

While a qualitative approach was appropriate given the exploratory focus of the dialogue, it is not possible to generalise from the findings in the same way that would be possible if the research involved more of a quantitative approach. This dialogue had a small sample size of 28 participants which is suitable for this form of deliberative engagement but meant that it was not possible to include participants from all groups of society (for example, the sample did not contain any white non-British individuals).

The online approach enabled the research team to reach a wide representation of people from across England; this would have been less feasible with a face-to-face approach. It also enabled participants to take part in pre-workshop tasks and discussions that extended the dialogue beyond the four workshops. An online approach was also more convenient for participants to attend as there was no need to consider time to travel. This made it easier for individuals to fit the workshops around work schedules and other commitments. This also meant there was no need to consider budget for travel and accommodation.

However, an online approach does mean that the dialogue did not include those participants considered to be digitally excluded. There were also some participants whose internet connections were weak and disrupted the discussions for them. These participants were given alternative means to engage such as through the chat function and the discussion board. An offline approach involving in-person workshops would not have been recommended during the COVID-19 pandemic due to risks to participants and researchers.

An iterative approach to the dialogue was adopted, to ensure that the topics for discussion were aligned with participant priorities and interests, while still accounting for the overall objectives. The benefit of this was that the materials developed and areas for discussion were tailored to the needs of participants and helped to steer the dialogue in a very natural manner. There are, however, limitations to an iterative approach, namely it makes it more difficult to replicate the research (nevertheless, all research tools including stimulus and topic guides can be found in the annex).

The iterative approach to this dialogue presented notable challenges for NICE and the Basis Social research team. Within the two-week window between each workshop, research materials had to be developed very quickly, leaving limited opportunity for rounds of input. This isn’t to devalue the quality of the stimulus but rather to highlight the importance of effective communication between NICE, the Basis Social research team, and supporting stakeholders. Spacing the workshops between two-week periods allowed participants time to reflect on what they heard during the sessions and consider their perspective based on what others shared.

1. What do people understand by ‘health inequalities'?
   1. What is good health?

To understand participants’ awareness, understanding and attitudes towards health inequalities and in turn, what this means for NICE, it was important to explore what they understood by ‘good health’.

‘Good health’ was seen as relating to both physical and mental health, with recognition of the two being fundamentally connected. Within some of the smaller group discussions, mental health tended to be top of mind (notably coping with stress and depression). This was seen to impact people regardless of their age and was felt to be more prevalent because of COVID-19 and the impact of the pandemic. Physical health was often linked to diet and exercise, with issues of ill health mentioned more often by older participants.

“Health can also relate to having peace of mind.”

“Good health, to me is keeping at a decent weight being able to exercise.”

“Mental and physical health go hand in hand. A while ago I tore my Achilles and couldn’t be active. That made me feel really low as I’m naturally very active and play lots of sports.”

In many ways, ‘good health’ was discussed in terms of absence of conditions that restrict people’s happiness, independence and ability to live life in the way they desire. It was also discussed in the context of absence of pain or conditions that need recurring contact with health services (or in some cases, the use of medicines to treat longer-term conditions).

“In short, it means being able to enjoy life.”

“Free from obstruction, things that may impede your life or stop you spending time with the people you love.”

“A worry is being dependent on someone else to look after you.”

There was recognition that ‘good health’ is subjective and varies greatly from person to person. What may be considered ‘good health’ for one individual may be considered poor health from someone else’s perspective. Older participants were more likely to reflect that ‘good health’ is something that is often taken for granted and only truly valued when it is taken away.

“If you have a disability or mental health condition, what is good health for you, then someone else might look and think that is not so good.”

“Everyone has different avenues through which good health can be achieved.”

“Health is something that I had a better quality of when I was younger.”

Throughout the course of this public dialogue, most participants placed greater value on quality of life than length of life. This can be seen to directly relate to concepts of ‘good health’, namely the absence of conditions that cause pain or restrict independence. Where this was less clear-cut was when considering others (such as loved ones), and here participants identified a tension between wanting to extend life but also not wanting people to live in pain or discomfort. This was a tension that could be seen to run throughout the dialogue process and influence participants’ views toward actions that impacted different groups in society (e.g. extending the lives of people living in particularly challenging circumstances).

“Quality of life is important; a longer life is no good if you have poor health.”

“Quality of life is important, there’s no point having a really long life if you’re not happy. Quality of life is more important than having a long life.”

“I’d rather live my life to the fullest and die knowing that I’ve done that even if I die at 70. We’ve got to live our lives everyday as if it’s the last.”

* 1. What influences health?

Having described ‘good health’ participants were also asked – as part of a pre-workshop task and within small group discussions – what factors they felt influenced people’s health. Participants identified three broad factors:

* social and environmental factors (including housing, outside space, air pollution, disposable income, and social networks)
* individual behaviours (including diet, exercise and life experiences)
* access to healthcare and medicine

The range of factors identified and discussed by participants is illustrated by the following quotes. Some reference the photos and images participants provided to convey their views. It is important to note that the quotes included are designed to illustrate the breadth of submissions of the pre-task, not to analyse the importance of any factors or discuss consensus or disagreement among participants. This was not intended to be an objective assessment of the range of factors or intersectionality of factors identified by participants, but rather to get an indication of those factors that were top of mind, to facilitate discussions in the first workshop.

* social and environmental factors including:
  + housing

“I would say that the people live too many in a house too close together, they work hard and do not get much money – but the people who live 10 miles again, live in a big house, with horses and those people have less to worry about”

* + outside space

“Whether you live next to a railway line or a park, all these things contribute to your lifestyle. With the park comes easy opportunities to walk and be active, and outside in the fresh air”

“Councils don’t invest much in these lower income areas. I’ve been to some of them and you can just tell. For example, the streets are just not as clean. There is a vast difference in areas even less than half a mile apart.”

* + air pollution

“When I go abroad my inhaler goes to one side and the minute I land at Heathrow I am reaching for my inhaler straight away. I live in a wonderful city with terrible pollution”

* + disposable income/money

“If I need mental health support if I had money I would pay for therapy, if I can’t afford it, I get put on a 2 year waiting list”

“Money. This probably has one of the biggest impacts on people’s health. To have more money is to have better access to good quality food, time for leisure activities, better access to healthcare. Working too hard for money or to achieve plans can cause people to burn out. I worry a lot about making enough money in the future”

* + social/support networks

“Support from your friends and family is really important. In fact, good health can be taken for granted. You could have a hereditary disease, and then you’ll really need your friends and family in order to manage it well”

“My wife is a good influence on me, she’ll always remind me to get to the gym or get on my bike. And my colleagues at school too, we do staff sports on a Friday afternoon when the kids go home”

“It’s the state that you are living in. Family, friends, it all has a part to play in your health.”

“Pets are good for our health as well as good company”

* individual behaviours including:
  + diet

“I consider a varied diet to be important. I have also included a bottle of wine [in the photos submitted] because I believe most things in moderation contributes, makes life enjoyable”

“Eating healthy helps you give your body the right energy needed”

* + exercise

“Roller skates. Exercise without feeling like you are exercising. Gets me out and about and meeting new people. Great for physical and mental health”

* + life experiences - many people shared that experiences such as travelling kept them in good mental health.

“These pictures influence my health positively. I love walking outdoors, I enjoy swimming and traveling”

* access to healthcare and medicine

“As someone with several conditions that heavily rely on patient-led treatment, having supportive healthcare professionals around me who listen to my perspective and respect my knowledge of my body is vital to my overall well-being”

“I am so lucky that I live in London with access to some of the best hospitals in the country. If you lived in Devon, you would not have access to care”

“My diabetes kit. My health largely relies on my ability to keep a very close eye on my blood sugar and insulin doses 24/7”

In this task, participants often focused on one of the broad factors identified in the pre-workshop task (and on a specific influence within these). Nevertheless, through discussions in workshop one, it was clear that participants appreciated the interconnectedness between the factors under discussion, even if this isn’t reflected in the pre-workshop task imagery.

Individual characteristics such as biological or protected characteristics (e.g. gender and ethnicity) were not discussed as factors influencing health outcomes without prompting from a researcher or expert, or the use of stimulus. It could be difficult for participants to make the connection between good or poor health and biological or protected characteristics at a group level (e.g. among specific ethnic minority groups).

* 1. What are health inequalities and what causes them?

This research did not seek to gather completely unprompted views on health inequalities or the differences in health outcomes between different parts of society in England.

Within workshop one, a range of materials were presented that introduced the concept of health inequalities, including examples illustrating differences in life expectancy between different groups and expert views about the causes of health inequalities. Concepts of fairness, avoidability, and the influence of wider determinants on health outcomes were raised. Views about health inequalities were then discussed at length within workshops one and two to explore how these were understood by participants.

Health inequalities were seen by participants to represent unfair differences in health outcomes between groups that are determined by circumstances that are largely beyond an individual’s control. These circumstances were primarily tied to socio-economic factors such as income, education, employment, and where someone lives.

“What I took away about the inequalities of health is that what happens can often be down to luck or mismanagement, and there’s just an unfairness to it, dependent on certain circumstances.”

Household income and the level of poverty of the area in which individuals live were seen as a primary driver of health inequalities (and wider social inequalities).This appears to be because participants could see a direct connection between these factors and other factors that directly or indirectly impact health: employment opportunities, suitable housing, air pollution, food choices, access to healthcare services, etc. Throughout the dialogue, health inequalities tied to income and area were often those which participants felt most strongly about. This is aligned with other work exploring the value people place on addressing different types of inequalities.

“It all boils down to your socio-economic standing. If you earn more, you can get more. I know people who have good salaries and private healthcare. One of the benefits of that is annual screening which will pick up illnesses earlier so that you have a better prognosis.”

“…someone died from pollution in the air. So, whether you live in the city or the countryside, that matters.”

“If you’ve got a lot of money you just have more doors that open for you, and on the other side of that door would be better health.”

“People in these areas are earning far less than the average wage earner. And I’d assume their standard of living is much lower as well. The amount of funding in these areas must be lower as well. And I’d assume quality of education is lower too.”

“You also need to make things affordable, healthy things affordable, otherwise how can those on an extremely low budget start to live and eat healthier.”

“It's not fair. Because we all work, we all work hard, but it's not fair on the people that don't have a lot of money.”

“If you can't afford something, you work a bit more, don't you? And that's probably the case with me and my family. But that won't be the case with everyone. So, if you if you can't go out to work because of mental health issues for example.”

“If you come from a lower-income background, from a background with a higher risk of getting these diseases, if your job's not as good as somebody who is in Hampshire or wherever, you can't afford to buy the best foods and what have you. It puts you at greater risk of all this.”

“if you're in a wealthier area you can afford to deal with any issues that may arise with health conditions, you know, you live in a better area, better schools, better way of life.”

In contrast, certain characteristics such as ethnicity and gender were not brought up spontaneously by participants, nor was it evident for many participants how these characteristics had any bearing on health outcomes. While participants were understanding in discussing these characteristics when tied to wider determinants, such as income or where someone lives, making generalisations about the health or socio-economic status of people based on biological or protected characteristics in isolation was not something they were comfortable with. While participants didn’t discuss it in these terms, what they were accounting for here was intersectionality, and the need to focus in on those characteristics that are drivers of inequality rather than ones that simply correlated with inequality.

“Race shouldn’t be a factor.”

“Just because you’re Black or Asian, doesn’t mean you’re necessarily disadvantaged. You could be a higher income earner, a professional, living in a nice home in the countryside… It’s complex and it depends on which factors are more pertinent to that person.”

“I don't think it should matter. Race or gender.”

“I didn't think of whether it was a minority or gender or wherever sexuality because it's irrelevant. There's just a gap, there's an inequality and it just needs to be addressed.”

When prompted with statistics and scenarios in which differences in health may be associated with these biological and protected characteristics, participants tended to be relatively uncomfortable in identifying themselves as being part of a group that may be disadvantaged. While not articulated in this way by participants, it is our view that this lack of identification with disadvantage could – at least for some participants – underplay the significance of wider determinants on health outcomes. Instead, participants looked at their own circumstancesand, depending on their gender, ethnicity or age, could make a case for how they had overcome the influence of these characteristics. In this way, health outcomes could be seen as being within an individual’s control to influence.

“I’m a black woman who smokes with diabetes. So, I’m part of this statistic, but I also live in Westminster which is one of the richest boroughs and I own my own home.”

“You’ve got to look at what's making their life expectancy shorter. And obviously, it's due to a lack of education, but I'll tell you now, it's going to get better over time. I'm from Bangladesh background. Classic example. I’m living a decent standard.”

Some protected characteristics such as religion, race, and sexual orientation were also discussed, though largely through the prompting of researchers, as they may relate to discrimination. These characteristics were seen to potentially lead to individuals facing prejudice and discrimination, which may impact both mental health directly as well as wider life opportunities.

“Religion and racism go hand in hand, a white person is more likely to get higher paid jobs, and this means that certain religious groups will be stuck in certain poorer areas.”

“That can be an extra factor that you have to deal with, you have to deal with racism and homophobia.”

“If you’re trying to suggest it’s their ethnicity that’s causing a shorter life expectancy, I don’t think that’s the case. But I suspect it could be because they haven’t had equitable conditions for a number of reasons, such as prejudice amongst the general population, leading to adversity and resistance and other issues.”

While a minority of participants returned to individual behaviours as the key driver of differences in health outcomes, most participant discussions were driven by an appreciation that individual choices were influenced by wider determinants. Further, a small number of participants, potentially influenced by the stimulus and input from experts, reflected on the **intersectionality** of different characteristics (biological, protected and socio-demographic) and how factors interact and can compound the influence of one another.

“My biggest takeaway was just how much of our lives and decisions don’t seem to be in our own hands, they’re based on factors outside of our control, which I think is a bit scary.”

“My wife always says the worst thing they did was to stop home economics at school. So not all young people have an opportunity to learn anymore unless they’re interested in food. They’re going to get into the car and go for the convenience food instead, like KFC or Burger King or whatever.”

“Low-income areas are more susceptible to things like alcoholism and drug dependency. And in the UK drug dependency is more criminalised than treated like a medical condition. Which won’t help with getting these people off the drugs. And being dependent on them will lower your life expectancy.”

Discussions around wider determinants also prompted participants to reflect on the systemic and often cyclical nature of inequalities. It was recognised that it can be hard to pinpoint a ‘starting point’ for the causes of health inequalities as they are often rooted in factors completely outside of people’s control (such as their upbringing) and influenced by wider determinants. As with other research undertaken with members of the public around health inequalities, the complexity surrounding the causes of health inequalities can result in people feeling relatively helpless and cynical toward the possibilities of addressing health inequalities.

“I think health inequalities are just a manifestation of all the other inequalities we have in society.”

“Does it start with education, which can give you a better income? Or does it start with income, which can give you a better education, and where you live and, you know, putting resources in?”

“Governments come in and recognise these differences between areas, but they do not improve things. Nothing is changing and these inequalities will keep existing.”

“We understand that it’s complex, there are many factors involved, and these factors will vary from person to person or group to group…I feel that health inequalities are just a manifestation or symptom of the general injustices and unfairnesses in society. And can you actually do anything about health inequalities?”

However, what was clear for participants is that a systemic issue such as inequality requires a systemic response and that actions by individual parts of the ‘system’ – in particular health and social care services – will only get so far in reducing the gap.

“I think when we approach these things in a sort of silo mentality of just tackling one area it isn't necessarily most beneficial.”

1. What value do people place on addressing health inequalities?
   1. Tackling health inequalities is a priority

As with the 2006 Citizens Council meeting on health inequalities run by NICE, within this public dialogue, there was again consensus that health inequalities in England should be addressed.

Health inequalities were generally seen as being unfair. While the terminology around ‘equality’ and ‘equity’ was often confused by participants it was also apparent, through the discussions, that most participants supported greater equity in actions to achieve greater equality in health outcomes. In principle, participants were supportive of reducing health inequalities and improving health outcomes for those who are more disadvantaged.

In abstract terms (i.e. without any defining characteristics differentiating groups), where there was a difference in something as important as life expectancy between one group and another, there was a general desire to reduce this difference.

“We want to get people as much on a level playing field as we possibly can!”

“You just have to try to be as fair as you can. If you work in that direction, eventually everyone will benefit.”

Participants were asked to discuss various hypothetical scenarios in which they were tasked with prioritising one group over another in allocating resources that could influence health outcomes. See the methodology annex for discussion guides and stimuli used in these scenarios.

Where the decision was made in the absence of any other information aside from a label to differentiate the groups, most participants prioritised reducing health inequalities, even where the increase in average population-level life expectancy was reduced by prioritising those with poorer health outcomes.

While these decisions largely remained the same when the groups to be considered were living in more or less-deprived areas, the decision-making process became more nuanced as participants were asked to consider different characteristics (e.g. protected characteristics, vulnerable populations). While some participants erred more toward maximising health gains or reducing health inequalities, very few remained consistent in their views across the differing scenarios. This reflected the relative weight that participants placed on different information/characteristics.

Common throughout these discussions was a desire to improve healthy life expectancy, not simply life expectancy. There was a view that extending lives for those living with conditions that brought pain, discomfort and dependence was not desirable, though participants recognised the tension in these decisions, particularly when faced with the potential of losing a loved one. While not commonplace, there was also some discussion as to the value of extending the life of individuals in very challenging circumstances – such as those who were homeless – without also improving their quality of life and therefore their healthy life expectancy.

“What's the point of increasing their life expectancy, if their quality of life is going to be the same?"

Another common theme throughout the discussions was a desire to avoid losses, also known as loss aversion. While there was a desire to reduce health inequalities and ‘level the playing field’, many participants felt that it was undesirable for decisions on prioritisation to result in any reduction in life expectancy or healthy life expectancy for any group regardless of their relative starting point.

“We’re trying to make people more equal; we’re not going to drag people down to do that, we need to bring people up, with more resources.”

“That would be a levelling down rather than a levelling up.” [in reference to scenario in which length of life would be subtracted from advantaged group and length of life was added to disadvantaged group]

“You shouldn’t be able to restrict one group’s life expectancy over another. No one has a right to make that kind of decision, I think that’s crossing the line.”

There were a few participants who took an opposing view to this and felt it acceptable for more advantaged groups to experience a loss of life expectancy to address health inequalities. This occurred in the trade-off scenario in which reducing health inequalities between wealthy areas and deprived areas required reducing life expectancy for the wealthiest (see ‘workshop three topic guide and stimulus’ in the methodology annex for details on these scenarios). Some of this seemed to stem from negative feelings toward those seen as more privileged while others believed it was important to maintain the principle of equity, regardless of how that was achieved.

“The more affluent don’t give a damn about us, so why should I care about them?”

“The reason why I still stick with choice B [reduce inequalities at the expense of life expectancy for wealthiest], at least is equal; everyone gets the opportunity to do something.”

Many themes emerged on the value judgements undertaken by participants about how and when to address health inequalities. As previously reported, participants were able to discuss the complexities and nuances surrounding the different influences on health outcomes. However, as participants responded to various hypothetical scenarios on resource allocation it was often more of a challenge to consider the wider complexities and determinants of health. These scenarios typically involved decisions about whether to prioritise addressing health inequalities or optimising population health. The topic guides and stimuli used to present these scenarios can be found in the methodology annex.

Under time pressure and within a small group setting participants tended to use one or more of four different ‘lenses’ through which to assess a given scenario and take a value judgement on the relative priority to be given to addressing health inequalities. These lenses overlap, as illustrated in figure 3, and include:

1. **‘Ethics’** in terms of what could be considered as ethically or morally the right thing to do
2. **‘Fairness’** as it relates to perceived level of control over health outcomes and/or determinants of health
3. **‘Relatedness’** in how much the participant felt the individual or groups under consideration were like themselves or someone they were close with
4. **‘Health optimisation’** in terms of achieving the greatest impact on health outcomes for the most people

Figure 3: Four lenses on health inequalities

Figure 3 shows a venn diagram illustrating that the four lenses on health inequalities, ethics, fairness, relatedness and health optimisation all overlap with each other.


The use of these four lenses has not been quantified. The lenses are each discussed individually in [sections 4.1 to 4.5](#Section_4_1), but in practice, participants tended to use a combination of each to make their decisions.

While, in principle, there was a desire to reduce health inequalities as this felt like the fair and responsible thing to do, context is critically important in practice as it influences which lenses were used in assessing a given scenario. This helps to explain why there was such a high degree of variation at the individual level when participants prioritised tackling health inequalities.

* 1. Lens one: ethics

Participants’ starting position was often to consider those who were most disadvantaged and marginalised. Narrowing the difference in health outcomes felt like the right thing to do, and in some cases was seen to be the most responsible thing to do as tackling health inequalities would lead to benefits for everyone in society in the longer term, not just those who were currently least well-off. This lens involved less weighing up of evidence, and more of an emotive reaction to a presenting situation based on levels of inequality (and perceived inequity). This lens is closely related to concepts of fairness and deservedness (detailed in [section 4.3](#Section_4_3)) which are also judgements of what is right but based more on evidence or assumptions relating to a given population or situation.

“If you live in a civilised society you do want to help those with most need who are most vulnerable first, so that’s a good starting point.”

“When you get to the stage of having to sleep in doorways, you can’t brush your teeth and have to wear the same clothes every day, it’s unbearable to think about what that must be like. So, it’s still a no-brainer to help the most needy.”

“You help these people who don’t have as much hope as others.”

“To make sure that the people that are in dire straits and in need get seen first.”

“It felt very instinctive for me to vote for the underdog.”

“I think we need to stick with helping the underdog, the resources still need to go to the neediest, as currently, their life expectancy is still 10 years less.”

“You should always walk to the slowest paced person in the group, to achieve more together.”

* 1. Lens two: fairness

When using a ‘fairness’ lens, participants would make a personal judgement as to how ‘fair’ they considered it would be to prioritise an individual or group over another individual or group based on a certain determinant of health (as identified in a given scenario). In the scenarios we presented, this could include differences in income, location, ethnicity, gender, housing situation, or wider circumstances (such as being impacted by homelessness). The primary contributing factor through which participants judged ‘fairness’ wastheperceived level of control an individual or group was felt to have on those factors seen to be influencing their health outcomes. In other literature on inequalities, this is also related to levels of perceived ‘deservedness’.xii

Certain factors that contribute to health outcomes were considered to be more or less in an individual’s control. Individuals were seen to have the least control over their biological and protected characteristics and most control over their behaviours. Social and environmental factors – while influenced by policy, legislation and other external forces (such as market conditions) – were seen by participants as something people could exert some control over. For example, participants felt people could move where they lived, change jobs etc. where they had the will to do so. When using the fairness lens, the complexities and intersectional ties between factors were less focused on and sometimes completely ignored.

When using this lens, individual behaviours were much more important factors to be considered. It was seen to be unfair to prioritise a group who were seen to be more ‘at fault’ for their relative health disadvantage or where it was felt that they could feasibly address those factors that were contributing to their worse health, over others who were seen to be less at fault.

Participants referenced examples relating to certain health conditions that may be caused or exacerbated by behaviours such as smoking, poor diet, or a sedentary lifestyle (for example chronic obstructive pulmonary disease (COPD) or type 2 diabetes).

“My mum's a type 2 [person with diabetes]. And you can easily change it. 90% of people can get themselves out of type 2 diabetes. So, they just need to do it.”

“I'm going to sound really harsh now. But if you smoke cigarettes, I mean, really, you should be paying the NHS to look after you.”

“I mean a lot of the time, it’s not their fault, poverty. But what are they doing to try and get themselves out of it? That’s what leads to social inequality. You need to try and move away from it yourself.”

When looking at scenarios through this lens, participants may not account for wider determinants of health that may influence these health outcomes and behaviours; or may underestimate the complexity of factors that lead to people's circumstances. As an example, some participants believed homelessness was the result of poor life choices and, in some cases, was within an individual’s control to influence. Likewise, the health inequalities experienced by Gypsy, Roma and Traveller communities (see [Cemlyn et al. (2009) Inequalities experienced by Gypsy and Traveller communities: A review](https://www.equalityhumanrights.com/sites/default/files/research_report_12inequalities_experienced_by_gypsy_and_traveller_communities_a_review.pdf) for more information) were seen by some participants as tied to these communities’ choices about how they lived. In these examples, participants felt that prioritising these groups over others would be unfair on the wider population unless there were very significant differences in life expectancy (i.e. 10 years plus).

“A lot of the reasons why they're homeless is because of their actions.”

“We were talking about 10 years, which is a big difference, which is why even though only 3,500 [Roma/Gypsy/Travellers in the priority scenario], but 10 years is a big, big number.”

“I mean, life as a homeless person. Some of them, you know, yes, it is their fault. But some of them, you know, they’ve a got mental illness and what have you, but there's always help available for them, which is why I'm quite surprised as to how they will actually stay on the street, I think a lot of them want to do that.”

“There is an element in my decision of acknowledging that MS [multiple sclerosis] is an auto-immune condition, out of a person’s control to get, it comes completely out the blue. But COPD is largely down to lifestyle choice.”

However, discussions often involved participants reflecting on the factors that may have led to individuals being in difficult circumstances or starting to unpick the complex web of connecting factors influencing differences in health outcomes between groups, through no fault of the individual. For example, some participants made the connection between mental health issues, life crises, and homelessness.

“A lot of homeless people are helpless people, they have a lot of issues, a lot of mental health issues. A lot of homeless people are not homeless by choice, so we need to really help them.”

“It's not their fault that they're on the streets, it really isn't. It's such a shame, when you hear the stories as well. And they just don’t have the right services.”

“I think it's only a very small percentage of self-inflicted [homelessness] through drugs or alcohol or whatever else. And a lot of that, in itself can be borne by mental health problems, which, you know, sometimes people have no control over, or it could be things that have happened in their life. I mean, it's quite a large proportion of ex-servicemen, which always shocks me.”

“It makes me want to lean towards choice C rather than choice A so that [ethnic minorities] can have a better quality of life because it could be those factors that influence their chance of having type 2 diabetes, so you want to counteract those effects.”

“If you come from a lower income background, from a background with a higher risk of getting these diseases, if your job's not as good as somebody who is in Hampshire or wherever, you can't afford to buy the best foods and what have you. It puts you at greater risk of all this.”

“COPD does seem more managed, so MS [multiple sclerosis] feels more deserving of supporting. However, I disagree with those talking about how lifestyle factors into the decision. Who are we to say that someone is less deserving of help, we don’t know what life they’ve had or the decisions they’ve had to make.”

Choices relating to smoking, diet and physical activity, or choices relating to vaccinations and screening – while behaviours performed by an individual – can also be seen to be influenced by wider determinants. Participants adopting more of this systemic and macro-level view of behaviours were more likely to consider it fair to prioritise groups where health inequalities were, in part at least, a result of choices taken by those affected.

While participants were willing and able to consider the influence of wider determinants of health, they felt it was unfair to prioritise groups based solely on biological or protected characteristics such as ethnicity, race or gender. Interestingly, this appeared to be a result of considering these factors both at a micro-level (e.g. ‘I’m Black African and I don’t feel at risk of health inequalities due to my ethnicity’) and a macro-level (i.e. in looking at the wider complexities and determinants of health for these groups). Participants did not see these characteristics to be determinants of health in and of themselves. Rather, factors such as income and location, that may be associated with these characteristics (at least at a population level), were considered more relevant. Therefore, instead of focusing on a biological or protected characteristic of a population (with the exception of genetic conditions which were more likely to impact different biological groups, for example, sickle cell disease which is more prevalent in people with African and African-Caribbean family backgrounds), considering populations with lower incomes, and living in deprived areas – factors which were considered to directly contribute to health inequalities – was felt to be fairer.

“I think you need to tackle areas like poverty, you may find a narrowing in the gap of health inequalities between various group.”

Quality life years was also considered in respect of decisions around the fairness of action (or inaction). For some groups (and for some conditions) there was a view it would not be fair to those experiencing health inequalities to extend their length of life without first addressing their quality of life. This included individuals where the level of suffering that they would experience in living was seen to be high, or the relative gains to be made in prioritising them over others were felt to be compromised by their anticipated future behaviours should the conditions in which they lived not be addressed. Examples of this were members of Gypsy, Roma and Traveller communities, and those who experienced homelessness.

“It may be a waste to spend money on improving their [people experiencing homelessness] life expectancy.”

“If we're just treating them [people experiencing homelessness] medically and just sending them back onto the streets, or they're living longer, is that really the best way to deal with this issue?”

“So, we've got to remember that if we are increasing the years by 4, they're [Gypsy/Roma/Travellers] still going to have no education participation, they're still going to have high levels of discrimination. We're still going to have a lot of mental illnesses. So, although we are increasing the quantity of life, are we really making an impact on the quality of life?”

It is important to note here that these views are counter to NICE’s stance on quality of life. NICE adopts the quality-adjusted life year (QALY) as its preferred measure of health outcome. The QALY model does allow the possibility of health states considered to be worse than being dead. However, this does not mean that any specific groups, such as people experiencing homelessness, have an average health status that is so poor that lengthening their lives would be considered to make them worse off. Evidence on the quality of life of these groups was not presented to participants.

* 1. Lens three: relatedness

The third lens used by participants in helping them make prioritisation decisions was ‘relatedness’. This was how much the participant felt the individuals or groups under consideration were like themselves or someone they were close to. This could include friends and family members but could also be a much larger group with shared protected or biological characteristics (such as their ethnicity), circumstances (such as where they lived) or health conditions.

When considering hypothetical scenarios, some participants would adopt a relatedness lens and prioritise those groups that they saw themselves as belonging to. This occurred most in scenarios where these groups were those impacted by health inequalities. It was also employed where gains in terms of average population-level life expectancy could be lost by prioritising a more disadvantaged group that participants didn’t self-identify with. This was often explained by participants in terms of self-preservation and being ‘selfish’.

“People are inherently selfish. If it affects them, or their family or yourself, yes, you're going to go for what affects you, gives you more benefit.”

“I'm a severe asthmatic with COPD overlap. Of course, I'm going to go for that group. Okay it's a difficult choice, but sometimes hard choices need to be made. And that is purely selfish.”

“I think pretty much the majority of us would say being in group 1 [an advantaged group] wouldn't change our decision. But like, historically, that's just not true. Like if you're used to being privileged than other people becoming more equal, from what I've seen, like tends to feel like you're being oppressed. Which makes it different to what you're used to.”

While the ‘relatedness’ lens was something that many participants employed when assessing a scenario, there were some individuals who (at times) did not let the extent to which they identified or shared similarities with different groups influence their decisions. Instead – quite purposefully – they opted to step back and use another lens through which to inform their decisions. This was the case even where there was an appreciation that this would lead to reductions in health gains for them or their loved ones (by virtue of being negatively impacted by how resources would be allocated). In these circumstances participants often reflected on their relative advantages – in health terms – and the importance of reducing health inequalities.

“If I was in group 1 [advantaged group], I would happily let group 2 [disadvantaged group] gain more life.”

“And if I was part of that wealthy group, it wouldn't make a difference because you know, you've enjoyed your life.”

“I pictured: ‘what if I was in group 1 [advantaged group]?’ You know. I would benefit from that, but it's not the right thing. It's not the fair thing.”

“If I was in group 1 [advantaged group], say group one was males and females, that still wouldn't have an impact on my choice because to benefit more, where I'm already in a good enough position. So, we should be helping bridging the inequality gap between the second group that's the right thing.”

* 1. Lens four: health optimisation

The final lens that was used by participants to make value judgements was ‘health optimisation’, which related to the perceived impact of prioritisation decisions on health outcomes, delivering the greatest value for money while also reducing burden on the NHS. Unlike the two previous lenses, this was independent of determinants of health and focused entirely on outcomes. Greatest impact typically meant having the most significant improvements to quality life years for the largest population but could also involve accounting for actions which sought to minimise health reduction (i.e. negative health outcomes resulting from decisions).

“You shouldn’t have to choose one group over another to improve their life expectancy. But if you introduce economics and say there is limited resources you have to strip the emotion out of it and say which option would have the most impact.”

“I was thinking about you know, the greatest good for the greatest number of people.”

Applying a health optimisation lens could lead to very different decisions by different participants depending on the situation under consideration and the factors seen to be involved (including the extent to which a group would be disadvantaged by a decision).

In some scenarios, participants looked at which groups would experience the greatest amount of change because of the intervention. This could relate to the number of additional years of life (or healthy life) gained/lost at an individual level or the number of additional years of life (or healthy life) gained/lost at a population level.

In other scenarios where there was a more explicit focus on a specific condition, participants were often assessing the treatability of different conditions and the severity of impact that conditions were believed to have on an individual’s quality of life. As an example, for some participants, this included choosing to prioritise type 2 diabetes over type 1 diabetes because type 2 diabetes was considered treatable, while type 1 diabetes was seen to be only manageable.

“I’m not overweight or inactive, but I also got type 2 diabetes. I presume its genetic. But it’s easily controlled through tablets and doesn’t have a huge impact on my life. But type 1 is far more serious, that’s why I think they’re more deserving of the funding.”

“I was diagnosed with type 2, but I managed to reverse the effects. My friend has type 1 and the impact on her life is phenomenal. Type 1 clearly has the greater need.”

Conditions that are rare (i.e. impacting smaller numbers of people) were seen to be less of a priority given the expectation that relatively small numbers of people would benefit. However, in scenarios involving rare conditions participants considered the severity of impact and distribution of the condition (including whether the conditions predominantly impact more disadvantaged groups).

“Certainly, certain illnesses are more urgent than others. Cancer, for example, and they really should be going to the top of the list.”

“If it's rare, then it's probably not something that's more important than something like cancer.”

“I think there's more risk of prejudice where the conditions are rare and not well understood. Looking historically, something like sickle cell disease was a rare condition in western culture, and it was only when it was identified, and it started to move up in priority and ceased to be less well understood.”

Some participants approached decisions by making a considered cost-benefit judgement based on assumptions around the cost of illnesses/conditions to society or the economy. This could include some assessment of the lifetime productivity of different groups (e.g. gains through employment), or in other cases estimating the likely impact of tackling health inequalities on the healthcare system in both the short and longer-term.

“I’m accounting for the potential for economic activity, the fact that this condition [Multiple Sclerosis] is hitting people younger, therefore, you're restricting the economically active years that they have.”

1. How people would like NICE to act regarding health inequalities
   1. What NICE should consider in addressing health inequalities

There was a desire for NICE to address health inequalities and to support the more disadvantaged and disempowered groups within society. Participants believed that NICE should represent the interests of the population as a whole and to consider the ‘bigger picture’ in making what were widely recognised as very difficult decisions. In performing this role there was an expectation that NICE would adopt objective and transparent decision-making processes.

“It’s been thought provoking these last few weeks, to see more clearly the challenges that NICE have to face in making their decisions, and the things they have to take into account. And how difficult it is to make decisions about where the money goes, and who benefits from it.”

“It's nice to know that there are people out there who are representing us, although it'd be interesting to see the demographic of the people making these decisions, because that does play a big part in it as well.”

“The point was made that NICE has a procedure to go through its decision-making, so I assume that’s to make it as impartial and balanced as possible. But if you’re somebody who is more inclined to empathise with situations then that could be difficult to arrive at a at a decision that you haven't really put more feeling to thinking about it rationally and realistically.”

Participants felt that NICE should make prioritisation decisions – for example in selecting and prioritising guidelines – based on an objective assessment of the evidence base (which includes scientific value, economic value and social value) and considering what is ethically right at a societal level. The desire was for NICE to reduce the risk of bias when reviewing evidence relating to the influence of wider determinants and biological or protected characteristics thereby accounting for both health optimisation and ethics lenses in guiding decision-making.

The general consensus among participants was that NICE should balance (i) prioritising actions that have the greatest (positive) impact on quality life years for the greatest number of people (health optimisation) and (ii) account for health inequalities in decisions, including addressing differences which would be recognised as unfair within social value judgements. It is important to note that participants believed that by improving conditions and outcomes for most people, standards would gradually improve for all (including those who were more disadvantaged).

“I think it’s important to cover a wider range of topics in the guidelines because there are always going to be inequalities that exist. And it’s only going to affect a certain percentage of the population, whereas going for wider population sizes you’ll have more impact.”

“No matter how hard you try there’s always going to be a group left out. So as long as we get the overwhelming majority of people in the guidelines. It would be advantageous in the long term to go for greater coverage.”

“Health inequalities suggests that certain people have a higher propensity to certain diseases. So, I would still be giving my resources towards them than the population as a whole.”

When prioritising actions that benefit the overall population at the expense of reducing health inequalities there was still a desire (i) to ensure there was no loss of life for the more disadvantaged groups, and (ii) that alternative actions were taken to try to improve their health outcomes and mitigate the widening of inequalities.

As an example, participants were presented with a scenario involving a fictional app that would enable patients to remotely monitor their diabetes condition via a smartphone (see ‘workshop four stimulus and topic guide’ in the methodology annex for more information on the scenario presented to participants). This was seen by participants to be a desirable option for NICE to recommend as it would improve quality life years for a large group of people with diabetes. Participants further rationalised this decision by highlighting how, in considering health inequalities within this scenario, resources could be redirected to ensure that additional (face-to-face) support was provided to those who were digitally excluded, i.e. using the cost and time savings made from deploying this hypothetical diabetes app.

It is important to acknowledge that although this was seen as an ideal option among participants, reallocation of budgets is not in NICE’s remit.

“So, if a lot of people can benefit from something and it doesn’t have a negative impact on people who won’t benefit from it then that’s ok. But if that programme takes away from people who need more help then that’s an issue.”

“To stop the majority of tech savvy people having this for the few who don't seems a strange sort of use of resources. Okay, there would be a greater inequality but there’s such a great number of people would benefit from this. It seems a sensible move forward.”

“There’s a high proportion of pensioners who have type 2 diabetes and many of them don’t have smart phones, just old-fashioned big button ones. They’re technophobic and I can’t imagine pensioners going out to buy an iPhone just for this. So, I don’t think this can be an option for everyone, but I’m not opposed to those who do have smartphones or access to one using it.”

“This is a device that doesn’t cost a lot of money and would help a lot of people.”

There was a desire to prioritise actions that reduce pressure on the NHS and the healthcare system. This was seen as critical for maximising health outcomes for the greatest number of people. One way in which participants felt this could best be achieved was through preventative action. Participants were able to make the connection between health inequalities and wider determinants. There was a strong desire to improve the conditions in which people are born, live, learn and work to tackle health inequalities at more of a systemic, macro level (i.e. across services and policy areas, rather than just within healthcare).

“If you have reduced demand on healthcare then more people will be positively impacted.”

“If you fix the demand on the health care system, you might then be able to fix the most issues for patients.”

“Prevention should be the focus, because in the long run, that will help you save money.”

“Important that prevention can focus on taking the pressure off the system.”

“Prevention obviously better than treatment. Hard to say something will be cut because someone in the service needs an annual health check.”

“If it’s been recognised that because of learning difficulties their life expectancy is shorter and quality of life is poorer, that’s grounds enough for me for the checks to be implemented. Early intervention will ultimately lead to better quality of life, and improving epilepsy and diabetic conditions in the long run that surely has to be a saving on the footfall for the health service.”

There was acknowledgement of the complexity involved in decisions around what qualifies as the greatest impact for the greatest number, and that there is no ‘one-size-fits-all’ way to approach these prioritisation decisions. There was a desire for a ‘case-by-case’ approach to addressing population health and health inequalities. In other words, the approach should not be set in stone, but rather it should be responsive to changes in evidence and circumstances (the COVID-19 pandemic is a good example of the need for this).

“One size doesn’t fit all. We’re all individuals and have individual needs. That should be taken into consideration.”

“In some areas, because of environmental conditions, it could mean some people are experiencing exceptional circumstances, so they needed to be treated as matter of urgency.”

“I think you have to take each decision on a case-by-case basis.”

In the view of the report authors, this means that judgements on health optimisation cannot be broken down into a simple equation in which weights are attributed to tackling health inequalities. Instead, judgements about scientific and economic values also need to account for social values which vary depending on context: the individual circumstances, needs and priorities of those impacted, and what is to be gained and what is to be lost (i.e. where might resources otherwise be spent). This involves making those judgements based on both qualitative and quantitative data.

“We’re all the same but have different needs, with the guidelines they should take the needs of everyone into consideration. So that no one is left out or left behind.”

“Inequality in general is only an issue when people aren’t getting the basic things that they need. So, it depends on the situation.”

“It’s always important to consider all of the attributes that factor in. To be so specific and focus in on just one thing can be an easy get out. It’s better to look at the whole scenario and give it the consideration and care it deserves.”

The importance of taking decisions on a case-by-case basis is clear when considering access to services. Equal access to services was seen as a desirable outcome; ensuring that no matter where people lived in the country, they had an equal access to and quality of health and care services. However, this only makes sense where population needs are equally distributed. Where people live, variations in wider determinants of health and manifestations of health conditions all influence the health and social care needs of individuals, as well as how healthcare services should reach and serve these populations. Where discussions enabled participants to make these connections between differences in needs, differences in services and therefore greater equality in outcomes, this was accepted as desirable.

“I think that is ultimately what we’re trying to achieve, making healthcare available to everyone. If it means spending more time and resource to reduce that [level of need], that would be the best overall for everybody.”

“…every area has its own problems from years ago. The area where we leave was all steel and mining. It’s gone now, but the effects when we were young…everybody had a cough or chest complaint. A lot of the kids had asthma. So different areas have different needs.”

“Inequality in health stems from lack of consistent coverage. So, we need to make sure there is consistent coverage.”

* 1. Prioritising actions to address health inequalities

Participants were presented with 10 high-level actions that NICE could take in tackling health inequalities and asked to prioritise them.

The 10 actions were grouped based on the focus of the actions: (i) internally-focused activities within NICE, and (ii) externally-focused activities with partners working to reduce health inequalities. Across each of the five break-out groups in which discussions took place, there was very limited consistency in results.

**Internal-focused activities** within NICE included the following actions:

* Prioritising NICE guidance on topics and areas that focus on health inequalities
* Recommending activities in NICE’s guidance to address health inequalities in specific disadvantaged groups
* Recommending that research is done to help NICE’s understand where there are health inequalities, who is most impacted and what are the likely causes
* Involving people from groups affected by health inequalities in NICE’s work
* Providing training to all NICE staff on what health inequalities are and what NICE’s role is in addressing them

These relate to internal efforts to address NICE’s responsibility for addressing health inequalities.

The first two activities (a and b) relate to whether NICE should directly address health inequalities. Participants who prioritised these highlighted that prioritising the disadvantaged would benefit the general population in the longer term (for example through improving levels of social cohesion and redirecting resources to other services).

“It’s like we need to ‘level up’ so that the group with the lower life expectancy and the lowest chances of progressing their futures, they’re the ones we should be targeting resources at to bring up their life expectancy.”

“It about trying to increase the life expectancy of those who are less likely to have a long lifetime. So, putting resources into areas that would increase life expectancy.”

“If there are certain communities being underserved, I don’t think that increasing things in general will automatically lead to an increase for those particular communities, so there needs to be a more specific outreach to them to bring them up in line with the rest of the country.”

“I think that if you address the health inequalities, then you're going to contribute to a broader coverage because there are dips, and if you focus on lifting up the dips, then you get a positive ripple effect across the spread. But if you just concentrate on trying to look at the spread without where the weaknesses are, the weaknesses will still be there.”

For NICE to be able to address health inequalities through its guidance, participants felt it must be in the strongest possible position to make objective, transparent and evidence-based decisions (activity c). For some participants, it was only through having a clear view of the evidence base surrounding the epidemiology of health inequalities in the population, the opportunities for intervention to address health inequalities, and the costs/benefits of these decisions that NICE could perform its role effectively. Research was believed to be important to build a strong evidence base. This would allow an understanding of current trends and where action should be taken.

“Decisions must be made on strong evidence.”

“[Research] will show us how to help these groups moving forward.”

While scientific and economic evidence was considered to be important, to develop a full picture it was also seen to be critically important that NICE engages with those impacted by health inequalities (activity d). A point was raised that some behaviours that contribute to negative health outcomes may be the result of an active choice or to socio-cultural influences that need to be understood and accounted for.

Many participants felt NICE needed to understand the nuances of an individual or population’s experience: to ‘walk in their shoes’. This could be done by involving groups impacted by health inequalities in the work NICE does (for example in selecting and prioritising guidelines). A small number of participants also highlighted that it is important that NICE staff involved in making decisions are representative of the wider population in terms of socio-demographics.

“It doesn't matter to what ethnic group what age you are. Basically, if people haven’t walked a mile in your shoes, they won't understand it. People have to speak for the shoes that they walk in.”

“An element of it might be choice, might be culture. It’s always dangerous to assume that people are not content in where they are. We have to get away from that focus and look at how you make positive outcomes for everyone and then we all benefit.”

“I believe NICE should continue having conversations with those directly affected by health inequalities on a regular basis to ensure their actions are having the desired impact.”

To have objective, transparent and evidence-based decisions it was felt necessary to ensure that NICE staff are trained effectively on the topic of health inequalities and NICE’s role in addressing them. This came with a desire for NICE to have ‘its own house in order’ in terms of a shared understanding of health inequalities from which a consistent and objective process for making decisions could be taken.

“Training seems to be the top of the pyramid, although it's often the bottom of the pyramid. In that if you're if your staff don't know what they're doing, then what hope has the organisation got?”

“You need to be able to speak the same language.”

External-focused activities with partners included the following actions:

* Actively working with partner organisations to ensure that NICE guidance is implemented in a way that will help reduce health inequalities
* Encouraging health and care organisations to address health inequalities
* Monitoring and evaluating how organisations are using NICE guidance to address health inequalities
* Encouraging other organisations outside of the health and care system (e.g. schools, local authorities) to address health inequalities
* Having clear and accessible information on how NICE can support efforts to reduce health inequalities

These actions related to working with other organisations, both within and outside of the health and care sector, to address health inequalities.

Over the course of the dialogue participants had been provided with information on the role and remit of NICE, the way in which NICE guidance was produced and how NICE interacts with other parts of the health and social care system. There was support for NICE working collaboratively with other organisations to ensure that NICE’s guidance is successful at reducing health inequalities. This included ensuring monitoring and evaluation of these organisations to track the success of addressing health inequalities and improve efforts going forward (activity h).

“The sole responsibility it should not be on NICE alone… you need other organisations to be involved.”

“Working together with other organisations seems more beneficial because you can also monitor and evaluate at the same time.”

“If you set a standard, you have to check that the standard is kept.”

While some participants prioritised NICE working within the health and care sector (activity g) as this was where NICE was seen to have the greatest influence, others prioritised services beyond health and social care (activity i). Firstly, there was an expectation that those working in health and social care would (or should) already be accounting for health inequalities in their actions. Secondly, participants reflecting on the influence of wider determinants of health and the importance of preventative action – and felt that supporting wider services (notably education and housing) would help in tackling some of the causes of health inequalities at a more systemic level.

“Going into schools and universities… we have a great example of COVID of NHS working in hand with schools and local authorities. It takes pressure off NHS and helps alleviate in other factors. So, joined up thinking can help.”

“B is a really important one, if you can teach children and teenagers, when it’s appropriate to go to the doctor rather than A&E so that they know the right place to go rather than burden the system. Important that prevention can focus on taking the pressure off the system.”

“Medication only targets a single individual who has that condition but focusing on prevention can help build awareness in the population.”

There was a general desire for NICE to be as active as possible in tackling health inequalities (activity f; as part of its broader remit of improving health outcomes amongst the population). As such, while NICE should be encouraging other organisations to address health inequalities, there was a desire for NICE to be more active in this role, which could come in the form of supporting implementation of guidance.

“It’s nice to have guidelines and info where people can go to, but implementing in a way that will actively reduce health inequalities is much more useful.”

The final area is relatedto raising awareness of NICE and its role in tackling health inequalities (activity j) which could be directed at partners, but equally members of the public.Very few participants had any awareness of NICE at the outset of this public dialogue. NICE plays quite a technical role within a complex system that in turn deals with complex subject matter, so despite communicating its role at various points of the dialogue participants found it difficult to fully grasp what NICE does and what changes it could affect.

For a couple of participants – who had attempted to find out more information about NICE online and visited NICE’s website – there was a view that its online presence, including its website, was unclear and did not effectively communicate NICE’s role to a lay audience. It should be acknowledged here that NICE primarily produces guidance for the health, public health, and social care system, rather than for members of the public.

For some groups, having clear and accessible information on how NICE can support efforts to reduce health inequalities, and providing information that empowers members of the public (and wider services) to take account of factors that influence health inequalities, were seen to be a key priority.

“If they put money towards giving people data that would be good.”

“NICE need to make themselves more visible and more tasty on their website. I have to say that as somebody who's sort of quite inquisitive, and quite reasonably intelligent, I almost gave up.”

“Encourage education and awareness of issues before they become issues.”

1. Key findings and considerations
   1. Key findings

NICE commissioned this public dialogue to understand people’s views on health inequalities in England and how they believe these should be addressed by NICE. This section sets out the key findings from this research, tied to the original objectives, and considerations for NICE based on these findings.

* + 1. Objective 1

**How would the public like NICE to act in regard to health inequalities?**

Members of the public participating in this research were clear in their view that organisations such as NICE should address health inequalities – which can be articulated as ‘unfair differences in health outcomes between groups which are determined by circumstances that are largely beyond an individual’s control’ –as they have a remit to consider the needs of all members of society. See [sections 3.3](#Section_3_3), [4.1](#Section_4_1) and [5.1](#Section_5_1).

Narrowing the gap in health outcomes felt like the right thing to do, and in some cases was seen to be the most responsible thing to do as tackling inequalities would lead to benefits for everyone in society in the longer term, not just those who were currently least well-off. As such, addressing health inequalities was seen as something that should be embedded as a core consideration in all of NICE’s work. See [sections 4.2](#Section_4_2), [4.3](#Section_4_3), [4.5](#Section_4_5) and [5.2](#Section_5_2).

NICE was seen as having an important role to play in addressing health inequalities by adopting an evidence-based stance to the assessment of economic, scientific and social value in judgements around prioritisation and resource allocation. This includes considering actions to address health inequalities using both health optimisation and ethics lenses. See [section 5.1](#Section_5_1).

Participants expected NICE to prioritise addressing health inequalities where there were significant differences in healthy life expectancy between different groups and/or where differences were clearly related to circumstances beyond an individual’s control. Beyond this, participants expected NICE to account for health inequalities in decision-making (i.e. understanding who could be disproportionately impacted for better/worse, and how to mitigate against actions that might exacerbate inequality). However, participants did not want NICE to adopt a blanket approach in which actions to reduce differences in health outcomes between groups were always prioritised over those which would benefit a larger proportion of the population. See [section 5.1](#Section_5_1).

Scientific and economic value judgements by NICE need to also account for social values which vary depending on the context: the individual circumstances, needs and priorities of those impacted, the severity of conditions, and what is to be gained and what is to be lost (i.e. where might resources otherwise be spent). This involves using both qualitative and quantitative data to make judgements taken on a case-by-case basis. Research was believed to be important to build a strong evidence base for addressing health inequalities. See [section 5.1. and 5.2](#Section_5_1).

* + 1. Objective 2

**What value do the public place on different types of health inequalities? Are some more important for NICE to consider than others?**

Individual characteristics such as biological or protected characteristics (e.g. gender and ethnicity) were not discussed as factors influencing health outcomes in the absence of specific prompting. While correlated with health inequalities, these characteristics were not seen to be determining factors and therefore participants were largely uncomfortable with NICE prioritising these groups in tackling health inequalities. Instead, health (and social) inequalities were most clearly tied to social and environmental factors such as people’s level of income and the level of material deprivation of the area in which they lived. See [section 3.3](#Section_3_3).

Where discussions enabled participants to adopt a more integrated approach to understanding health inequalities (i.e. accounting for intersectionality, the differences in needs, access to services and how this links to greater equality in outcomes), greater importance was placed on actions to tackle health inequalities (and the drivers of health inequalities). There was a general desire for NICE to enable greater equality in health outcomes and an understanding that this required greater equity in actions and the allocation of services. See [section 3.3](#Section_3_3) and [5.1](#Section_5_1).

In previous studies we have seen that members of the public adopt positions toward tackling health inequalities that are reported on a spectrum of individualist to structuralist, depending on the level of control that people are seen to have over their circumstances and health outcomes. This current research suggests that these views are not fixed and are capable of movement with those adopting more individualist perspectives liable to adopt more structuralist views when exposed to information or points of view which shine a light on wider determinants. See [section 3.3](#Section_3_3).

* + 1. Objective 3

**What other factors should inform committee deliberation when they are considering health inequalities?**

Participants felt it important that NICE considers how its actions and recommendations regarding health inequalities impact and intersect with other parts of the ‘system’. There was a general consensus that, where possible, NICE should be prioritising recommendations that relate to preventative and systemic actions in improving health outcomes and in tackling health inequalities. Given the influence of wider determinants and the expected greater expense of treating the symptoms of illnesses and conditions compared to their causes, there was a common view that prevention rather than treatment was better in the longer term. Preventative action was also seen as important for reducing pressure on the NHS, in turn freeing up resources to focus on further narrowing the differences in health outcomes. See [section 5.1 and 5.2](#Section_5_1).

When NICE’s committees make a recommendation that may widen health inequalities, they should consider whether there are any further actions or recommendations that could help to reduce the inequalities. See [section 5.1](#Section_5_1).

In considering health inequalities it was also seen to be important for NICE to consider how it could draw on evidence from those directly impacted by inequalities, to ensure that decisions were grounded in the lived experience of those affected. This could help NICE to both gather and interpret evidence on the social value of addressing health inequalities. See [section 5.2](#Section_5_2).

* 1. Key considerations for NICE

This research provides an evidence base against which we provide some considerations for NICE regarding its role in addressing health inequalities.

* A definition for health inequalities could help to ensure clarity across the organisation on what NICE defines health inequalities as encompassing. This definition should provide clarity on what health inequalities are at a conceptual level as well as how they should be understood for the purposes of developing guidelines and measurement.
* Based on the discussions with participants, this could reference unfair differences in health outcomes, the influence of wider determinants, and the ambition to achieve equality of outcomes. One possible starting point for a definition is provided at the start of this section. While the current definition used by NHS England already encompasses this it may be helpful to have a more concise and accessible definition.
* Internal guidance and training for NICE staff could help to increase awareness of what health inequalities constitute, the complex factors that contribute to health inequalities, and the importance of and potential for accounting for (and where possible addressing) health inequalities in NICE’s work.
* Embedding health inequalities within guideline development and technology appraisal processes using a transparent process (such as a framework) could help to ensure consistency in how health inequalities are accounted for when making recommendations.
* In looking to understand and address health inequalities it is important to ensure meaningful involvement of groups affected by health inequalities.
* A commitment to promoting diversity in staffing to encourage representation of those who are or have been affected by health inequalities across all levels of an organisation could help both promote a deeper understanding of health inequalities and signal a commitment to tackling health inequality.
* There is a meritocratic view amongst members of the public for addressing inequalities. The evidence from this research suggests that members of the public are more supportive of actions to address health inequalities where a clearer connection is made between the inequalities experienced and the wider determinants which impact those more disadvantaged groups. National organisations driving the quality and effectiveness of health and care (including NICE and NHS England) could look to raise the profile of health inequalities to promote public support for actions that prioritise those groups currently most disadvantaged. This may build support for the allocation of resources to address inequalities, taking more of a preventative and systemic approach.
* By actively supporting the implementation of guidelines which address health inequalities – for example through training, education, monitoring and evaluation, and partnership working – there is a greater likelihood of NICE driving actions that tackle health inequalities.