National Institute for Health and Care Excellence

NICE Listens health inequalities project findings

This report gives details of findings and recommendations from the NICE Listens health inequalities project. It also provides a summary of evaluation findings to inform future NICE Listens projects.

The Board is asked to review the report.

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March 2022

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Introduction

NICE Listens provides a mechanism to undertake deliberative public engagement when NICE encounters moral, ethical, or social value challenges that cannot be resolved by scientific evidence alone.

On 18 May 2021 the NICE Executive Team approved health inequalities as the first NICE Listens topic, with the objective of answering the following questions:

* 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?

Health inequalities are defined by NHS England as ‘avoidable, unfair and systematic differences in health between different groups of people’. Health inequalities arise because of the conditions in which we are born, grow, live, work and age.

The Health and Social Care Act (2012) stipulates 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’. In reflection of this duty, NICE’s [principles](https://www.nice.org.uk/about/who-we-are/our-principles), which guide the development of guidance and standards, include a specific aim to ‘reduce health inequalities’.

NICE’s 2021-2026 strategy pledged a ‘renewed determination to prioritise our work to reduce those health inequalities that have been highlighted during the pandemic’.

NICE already had a significant programme of work underway to strengthen its approach to addressing health inequalities. This programme of work is overseen by the internal Health Inequalities Oversight Group.

The NICE Listens health inequalities project is one of several pieces of stakeholder engagement work undertaken to inform the work of the Health Inequalities Oversight Group.

Background

NICE Listens was developed to build on deliberative public engagement previously undertaken through the NICE Citizens Council. Using online methods and recruiting new participants for each project, NICE Listens aims to be a more flexible model for engagement.

1. An external contractor, Basis Research, was commissioned to help deliver this piece of work alongside colleagues in the Science Policy and Research programme (SP&R).
2. In October and November 2021, four iterative online workshops were held fortnightly with 28 members of the public. Participants also completed pre and post workshop tasks via an online platform.
3. The workshops and tasks were designed to enable participants 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. An example of the type of trade-off activity presented to participants can be found in Appendix 1.
4. The 28 members of the public were purposively sampled to broadly represent the demographics of England, with weighting towards people who are more likely to be affected by health inequalities i.e., those living in more deprived areas and from ethnic minority backgrounds.
5. Basis Research conducted the analysis of the workshops and associated tasks, and have produced a written report with conclusions and considerations for NICE based on the objectives. Draft versions of the report were reviewed by NICE staff.
6. The conclusions and considerations compiled by Basis Research have been used by SP&R to create internal recommendations for actions NICE could take in relation to health inequalities. The decision to formulate the recommendations internally was taken to ensure they were actionable within NICE’s remit and principles.
7. A NICE Listens health inequalities steering group was established in September 2021, comprising representatives from the NICE Health Inequalities Oversight Group and from the SEA, CHTE, CfG and H&SC directorates. This group provided input into the design of the workshops, observed the workshops, reviewed the report drafts, and helped form the recommendations.

Report conclusions and considerations

1. The executive summary of the NICE Listens health inequalities report, which contains the conclusions and considerations written by Basis Research, can be found in Appendix 2 of this paper.
2. Overall, the report concludes that the public supports NICE taking action to address health inequalities, though to varying degrees depending on the circumstances.
3. Encouragingly, the conclusions and considerations from the NICE Listens health inequalities report affirm the programme of cross-institute activities already underway to strengthen NICE’s approach to consider health inequalities, and its role in providing system support in this area. Furthermore, the findings align with those from other work aimed at reviewing NICE’s role in addressing health inequalities, including an internal survey of the approaches taken to address health inequalities across NICE programmes, a review conducted by external experts (Dr Ann Hoskins and Dr Lois Murray), and the Arms-Length Bodies survey conducted in collaboration with the CQC.
4. The findings also highlight two main areas where NICE could go further: the first in strengthening its approach to addressing health inequalities, and the second in strengthening its role in supporting the health and care system to address health inequalities.

Recommendations

Based on the findings from the NICE Listens health inequalities project it is recommended that NICE should continue with its work to:

* 1. Create a vision for its approach to health inequalities which lays out the meaning of health inequalities within its work and how this aligns with and differs from the approaches of other system partners. This vision should specify the models and frameworks that underpin NICE’s approach and be widely communicated within and outside the organisation.
  2. Embed systematic consideration of health inequalities across guidance development and processes, for example, within defining the scope of guidance, topic prioritisation, contents of topic suites and implementation support. To achieve this NICE should:
     1. Develop, pilot and evaluate methods for transparent and consistent consideration of health inequalities and use learnings from the pilots/evaluations to review and update relevant policies and processes
     2. Ensure methods seek to consider the intersectionality of health inequalities, i.e., how different factors overlay and interact to increase health inequalities, with a particular focus on the impact of socioeconomic status
     3. Continue research on modifiers and trade-offs that relate to health inequalities, especially in health technology appraisal methods, to develop policies on how health inequalities should be accounted for.
  3. Conduct a broad and detailed review of who is involved and participates in its work, including guidance, implementation, quality standards, communications and support functions. The review should examine staff, committee members, experts, lay members and other partners to understand the extent to which we are recruiting and working with people with diverse lived experience of health inequalities (taking into account protected characteristics, wider determinants of health such as socio-economic status, and inclusion health groups). The review should identify areas of good recruitment and retainment practices, areas that need improvement and areas where there are opportunities for new ways of working.
  4. Embed involvement of groups affected by health inequalities (taking into account protected characteristics, wider determinants of health such as socio-economic status, and inclusion health groups) as a standard practice as early as possible in the guidance development process. In embedding involvement NICE should also:
     1. work with patient groups at the local rather than national level to encourage involvement from those with direct experience rather than those just representing people with direct experience
     2. ensure practices for recruiting lay members/experts by experience to be involved in NICE’s work are equitable rather than just equal, i.e., they need to be tailored based on the people/groups being involved and their specific needs
     3. assess and address the increased resources, in terms of both time and funding, required to support the involvement of people with lived experiences of health inequalities.
  5. Routinely consider how implementation of its recommendations will impact on health inequalities (either positively by reducing them, or negatively by worsening them). Partnership working and implementation advice and support should be directed to situations where there is a potential to significantly reduce health inequalities and/or avoid worsening of health inequalities.
  6. Actively work to identify and address evidence gaps in health inequalities by continuing to work with partners such as the NIHR to promote research recommendations on health inequalities, and by encouraging health and social care providers and others to collect health inequalities data. Monitoring and tracking research on health inequalities is important so that we can address issues in guidance updates when research findings become available.
  7. Improve and increase frequency of communications about health inequalities to actively promote an understanding of:
     1. why health inequalities exist and how wider determinants of health are key drivers of health inequalities
     2. what NICE is doing to address health inequalities
     3. where all existing NICE guidance and advice on health inequalities can be found, e.g., via a dedicated section on the NICE website
     4. how recommendations around health inequalities have arisen in guidance and why the recommendations are being made.
  8. Ensure its work is more accessible for members of the public and service providers outside of the health and care sector. The navigability and accessibility of the website could be improved to enable information on NICE's vision and approach to health inequalities to be more easily found.

1. In addition, it is recommended that NICE should commence work to:
   * 1. Drive a culture that recognises the importance and benefits of addressing health inequalities by developing and rolling out general training for all NICE staff that provides an overview of what health inequalities are, how they arise, the impact they have, and how NICE’s processes and methods can consider health inequalities. ​
     2. Develop specialist guidance and training for all NICE staff, committee members and partners (e.g., academic centres, suppliers) who are involved in guidance development and implementation, to make them aware of:
     3. the definitions of equality, equity, intersectionality and health inequalities
     4. what health inequalities constitute
     5. the complex factors that contribute to health inequalities, and the importance of wider determinants of health as key drivers of health inequalities
     6. the importance of accounting for health inequalities in NICE’s work, framed within its legal duty
     7. different approaches to tackling health inequalities
     8. how and where to find evidence on health inequalities
     9. how to complete and use Equality Impact Assessments.

Training and guidance on health inequalities should be viewed as dynamic resources that require updating on a regular basis to reflect current needs and evidence.

* + 1. Ensure that the importance of prevention is reflected in its work, for example, when defining the scope of guidance, topic prioritisation, the contents of guidance topic suites and support for implementation, and explore opportunities to further its work is this area, for example through its environmental sustainability work which has the potential for positively impacting on wider determinants of health.

1. NICE should further consider the resource requirements needed to deliver this programme of work, in light of the public support for addressing health inequalities.

Evaluation and lessons learnt

1. This was the first project in the new NICE Listens programme of deliberative public engagement.
2. The project was delivered successfully within the time frame and budget specified by ET and the business objectives.
3. An internal evaluation of the NICE Listens process has identified a number of findings that are useful to consider for future projects:
   1. NICE Listens provides a useful opportunity for cross-centre working to address key issues, and to enhance understanding of how these issues affect directorates in different ways.
   2. Embedding involvement of relevant staff from across NICE is important to ensure the needs of different directorates are accounted for in the project design. A project steering and/or advisory group with cross-directorate representation, set up early in the project process, is a useful way of doing this.
   3. Objectives for NICE Listens projects should not be too broad. The greater the focus, the more likely the project is to produce actionable findings.
      1. Objectives should be set by the project steering group to give a greater sense of ownership.
      2. The current budget allows approximately 10-12 hours of online contact time with around 25 people. Within this time, there are limits to the amount of technical and specialist knowledge that can be imparted whilst still providing adequate time for in-depth debate and discussion. This should be considered carefully when setting objectives.
      3. NICE Listens should not be used to try to answer questions about technical processes and methods that we are finding difficult to answer internally.
   4. Online deliberative engagement methods provided a useful alternative to face-to-face methods. They allow not only high-quality deliberations and results, but also the involvement of a more diverse group of people than there otherwise would have been, due to increased convenience (i.e., no travel required, can take part in evenings, can take part when isolating).
   5. This project suggests online engagement methods are able to maintain participant attendance across a period of time. Only 3 of the 28 participants did not attend all the workshops, and these absences were all due to illness.
   6. Though online engagement methods risk being impacted by technological limitations e.g., poor internet connections, these issues only occurred a small number of times, and did not impact the overall quality of the discussions and results. Ensuring the research agency had staff in place to provide technical support minimised this risk.
   7. Given the complex nature of the topic and need to recap information provided in previous workshops, more time with participants would have been valuable. Factors such as participant fatigue and scheduling restrictions would need to be considered in deciding how to increase the time available.
   8. The timeline for the project (8 months between ET approval for procurement and obtaining the final draft of the report) was feasible. However, extending it slightly would have several benefits:
      1. it would allow the commissioned research agency more time in the design and preparation stages of the project to understand NICE’s role and remit. This is useful context for both project design and report writing.
      2. it would allow more time to be dedicated to upfront project design which is useful when working in an iterative manner as the focus between workshops is then on making amends to already developed materials.
      3. it would allow more time for involvement of NICE staff across directorates. Staff do not always have dedicated time allocated to work on NICE Listens. However, their involvement is essential to ensure project materials such as workshops stimuli reflect the nature and breadth of NICE’s work.

Overall:

* 1. staff involved fed back that NICE Listens offers a unique opportunity for them to hear directly from and, where appropriate, interact with members of the public about important topics impacting NICE’s work.
  2. though the online engagement method has some limitations, it provided access to a broad group of people, in a way that was appropriate given current COVID-19 restrictions and concerns.
  3. the method is suitable for future projects, though additional time with participants would be useful, especially if the topics are particularly technical.

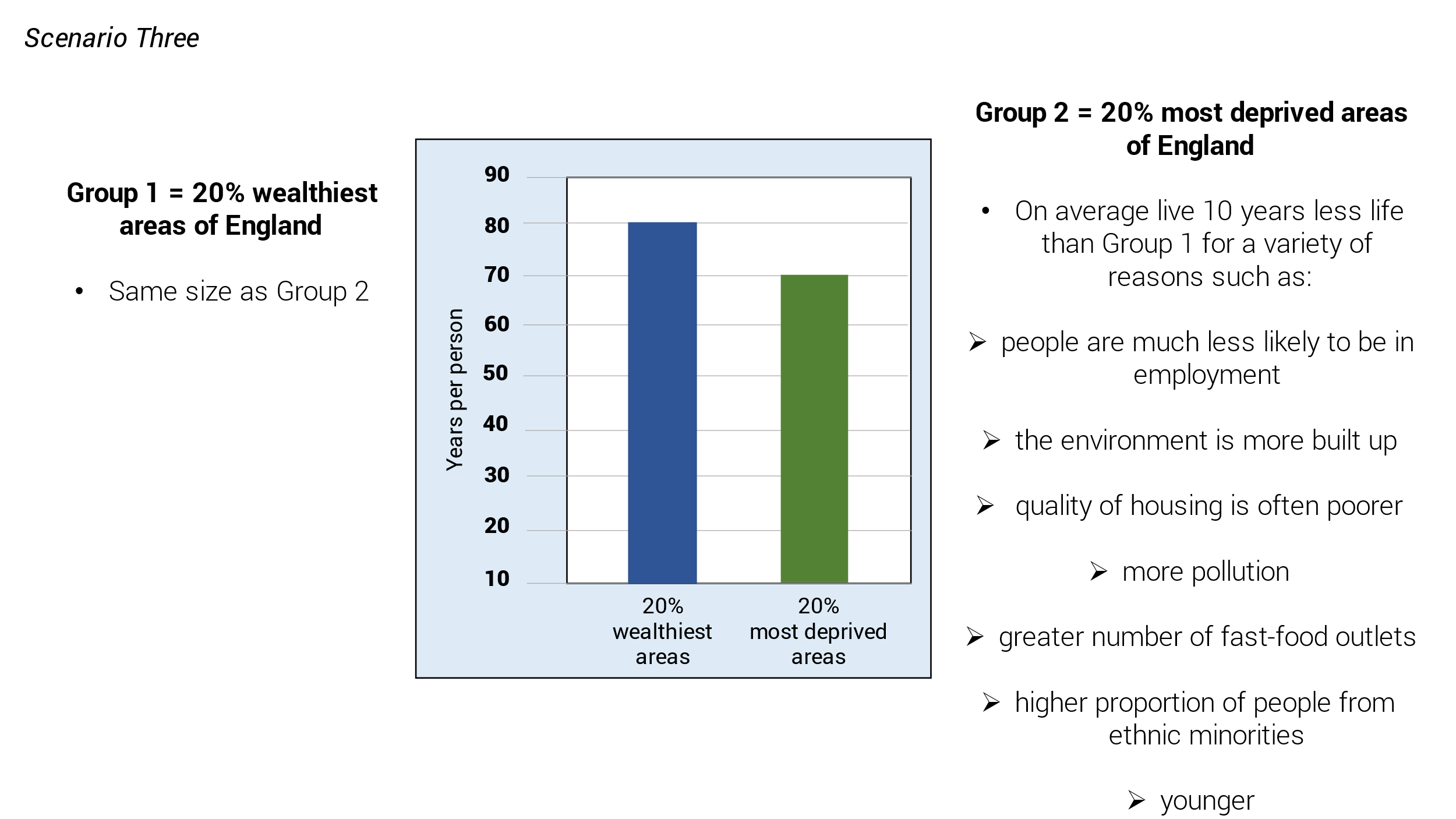
Conclusion

1. The findings from the NICE Listens health inequalities project affirm the programme of activities already in NICE’s approach to considering health inequalities in all we do. They also suggest two areas for further work.
2. The first NICE Listens project was delivered to time and budget and has produced valuable lessons which will inform future NICE Listens projects.
3. SP&R will continue to work closely with the Health Inequalities Oversight Group to ensure the findings of the NICE Listens work are considered as part of the prioritisation and resourcing for the 2022-2023 health inequalities programme of work.
4. SP&R will share the findings with relevant groups such as NICE’s equality and diversity group (NEDG), methods and processes group, and the Public Involvement Programme to explore how relevant recommendations, e.g., on committee make-up and public involvement, can be addressed.

Issues for consideration

The Board is asked to review and discuss the recommendations in the context of them feeding into the work plan and recommendations for the wider health inequalities work being conducted at NICE.

Appendix 1 – Example of stimuli used in workshops

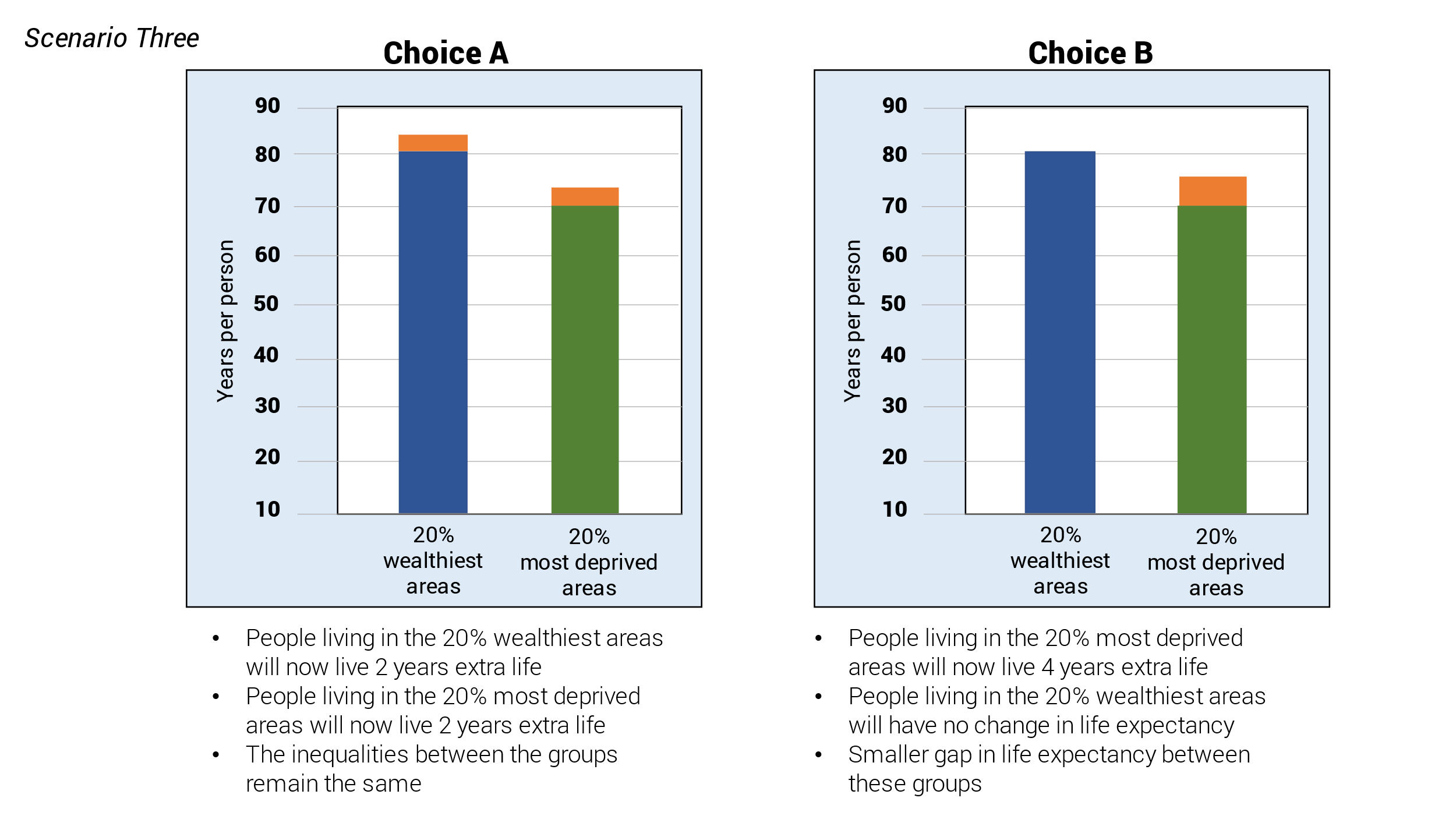


Group 1 = 20% wealthiest areas of England

* Same size as Group 2

Group 2 = 20% most deprived areas of England

* On average live 10 years less life than Group 1 for a variety of reasons such as:
  + people are much less likely to be in employment
  + the environment is more built up
  + quality of housing is often poorer
  + more pollution
  + greater number of fast-food outlets
  + higher proportion of people from ethnic minorities
  + younger



Choice A

* People living in the 20% wealthiest areas will now live 2 years extra life
* People living in the 20% most deprived areas will now live 2 years extra life
* The inequalities between the groups remain the same

Choice B

* People living in the 20% most deprived areas will now live 4 years extra life
* People living in the 20% wealthiest areas will have no change in life expectancy
* Smaller gap in life expectancy between these groups

Appendix 2 – Executive summary of the NICE Listens health inequalities project report

**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 2021-2026 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, location, 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 (see above).

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 the majority of 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)**,** isthe 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) are a 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.