September 2022

Prioritising the elective care waiting list in Coventry and Warwickshire

Findings from a public deliberation

Final report

Reema Patel, Devina Sanichar and Anna Beckett

Contents

Executive Summary

This report presents the findings from a project commissioned by NHS Midlands and Lancashire Commissioning Support Unit working closely with University Hospitals Coventry and Warwickshire (UHCW NHS Trust). The project was designed to feed into the development of a prioritisation system that will allow patients on elective care waiting lists to be prioritised, utilising a wider range of factors than have previously been considered. The driver for this work was existing research which demonstrates that existing approaches to waiting list prioritisation (based on waiting times alone) risks fuelling inequality. During the pandemic, prioritisation based on clinical urgency was introduced but the NHS trust wished to explore how waiting lists could further be developed in ways that reduced inequality, having seen inequality widen during COVID19.[1] This project explores the potential for prioritisation within the parameters of the existing NHS constitutional standards. These standards provide that patients have the right to access certain services commissioned by the NHS within maximum waiting times, or for the NHS to offer suitable alternatives if this is not possible. These constitutional standards are set out in the NHS Constitution for England.[2]

These findings report on a deliberative public engagement to understand people's views and perspectives on the use of different prioritisation factors with the intent to reduce inequality in the region of Coventry and Warwickshire. Deliberative public engagement is a process of 'long form' engagement and research which involves the public in consideration of complex and controversial topics. This project convened participants over 12 hours of deliberation through four three-hour virtual workshops that were held between 29 March 2022 and 7 April 2022. Around 50 participants were recruited from rural, market-town, and urban parts of Coventry and Warwickshire and participants attended all four workshops. In the workshops, participants were introduced to different evidence from specialists to support discussion and deliberation, as well as being given the time and space to consider the overarching question, in the deliberative process of research. They were also invited to consider the implications of these factors beyond their own individual circumstances, by thinking about a range of fictional 'personas' and their experiences of the prioritisation system.

Key cross-cutting themes

After going through the deliberative process, exploring waiting list factors in detail and listening to various perspectives, the majority of participants felt that if the collection of data about patients on the factors involved in the prioritisation could be done efficiently, and if the metrics could be made fair, an enhanced system of waiting list prioritisation would be preferable to the existing system. However, they did not underestimate the difficulties in doing this and encouraged the Trust to ensure sufficient monitoring and oversight to minimise the risk of any unintended consequences. Below are some of the cross-cutting themes that emerged.

Recognition of the complexity of the challenge in prioritising waiting lists and defining fair outcomes: Through deliberation, participants reflected that prioritising waiting lists is a difficult challenge with no easy answers. They were keen to achieve fairness and ensure everyone is treated but each person had a different interpretation of how this would be realised. Some wanted to prioritise fairness of access, with people waiting in line depending on the clinical urgency. Others thought it would be important to consider how to achieve fair health outcomes – for example by letting the people who may take longer to recover have their operation first.

Acknowledgement that waiting list prioritisation is no panacea for wider system issues – however, efficient and fair prioritisation could improve the system: Participants indicated that, beyond the prioritisation of the waiting lists, wider issues should not be overlooked and identified a number of 'whole system' priorities for tackling health inequalities. For instance, participants indicated the importance of the NHS focussing its attention on seeing

---

[1] HSJ (2022) – Can Addressing the Backlog Be a Means of Addressing Health Inequalities? https://www.hsj.co.uk/quality-and-performance/can-addressing-the-backlog-be-a-means-of-addressing-health-inequalities/7032716.article

[2] GOV.UK (2021). NHS Constitution for England. [online] GOV.UK. Available at: https://www.gov.uk/government/publications/the-nhs-constitution-for-england.

everybody as quickly as possible, drawing in more resources and using existing resources more efficiently to get through the backlog, as well as their knock-on impacts on health inequalities.

Factors involving individual health conditions were seen as acceptable for consideration in prioritising: Participants were introduced to a range of specific criteria or factors for consideration, on the basis of which waiting lists could be prioritised. The factors that received most support were popular largely because they were perceived to relate to 'clinical' considerations and were seen to be indicators of people's health and the urgency of their condition, as opposed to wider social circumstances. The factors which almost all groups agreed were important were:

- Previous admission or readmission because of the condition
- Other health conditions that have impact or previous diagnosis of the condition (here, there were questions about the interpretation of 'impact': most participants interpreted 'impact' as on the primary condition they were on the waiting list for, but some also extended 'impact' to detrimental impact on life)

There were also a set of wider factors which most participants found to be important. Again, these related to the mental and physical health and abilities of patients on the waiting list. Some participants expressed concern about the fair measurement and data collection challenges of some factors, such as disability and mental health. For instance, some people may neglect reporting a disability or mental health impact, for a variety of reasons further explored later on in the report, while others could possibly claim or over-claim a disability or impact on mental health, untruthfully, in order to speed up their treatment. These factors included the following:

- Disability (when it is related to the condition on the waiting list)
- Significant impact on mental health
- Needing to attend A&E or GP because of condition
- Other significant impact on quality of life
- Length of wait (who has been waiting the longest)

A number of factors were seen as more divisive and warrant careful consideration : A tranche of factors with some support, but which proved more divisive, included those relating to what some participants described as 'social' factors. Some people thought these were very important, but others were concerned that they could have unintended consequences for some groups of people. This included those who are:

- Unable to attend school/education while waiting
- Unable to work while waiting
- Carers for a relative, friend or neighbour
- NHS workers who are unable to work while waiting
- Older or younger than the general population (i.e based on age)

Finally, there were some factors which only few participants thought should play a part in waiting list prioritisation or should be attributed much weight for a variety of reasons. These included:

- Ethnic group (from a minority ethnic background)
- Lifestyle factors (e.g. diet, smoking, drinking)

- Those living in a more deprived area
- Those who are unable to volunteer or work in local community while waiting

Participants felt the consideration of priority, once on the waiting list, should be about the individual and their health (and, possibly, a few other factors for that individual, which are discussed further on). In workshops, participants explored individual fairness versus group fairness, exploring advantages and drawbacks of each. Making assumptions about people on waiting lists based on their membership of a particular group (for instance, using their location as a proxy for their income levels, or their ethnicity) was not supported for various reasons, addressed in detail later on in this report. There were concerns about the effects of deprioritisation, which might result in participants never being seen by clinicians (although in practice NHS constitutional rights would prevent this from happening). There was also concern that people could be effectively “penalised” for self-care or self-management of a condition, and there was also some concern about the risk of ‘double counting’ – for instance, double prioritising someone for the related characteristics of being from a deprived area and being out of work. Participants emphasised that they wanted health inequalities experienced by different groups such as those on low incomes and from minority ethnic backgrounds to be addressed but felt these interventions needed to take place upstream to the waiting list – for example, in considering the way resources were allocated and distributed across the NHS, and by improving service design. As a consequence, they wanted to be realistic about which problems the NHS waiting list was there to address or was able to solve.

Where these factors are introduced into waiting list prioritisation system, NHS Trusts should be mindful that these factors are likely to divide public opinion and invite some scrutiny. As a consequence, if Trusts choose to deploy these factors, a strong justification for deployment, full transparency about their deployment, as well as active scrutiny and monitoring is recommended.

Ensuring that the waiting list prioritisation approach had adequate human and clinician involvement, and clinicians were supported to use the tools well: Participants discussed the challenge of ensuring that there is still human input into the prioritisation system, while maintaining a system free of bias. Few participants were comfortable with a computer allocating scores and finalising the order of a waiting list without human intervention. A number of reasons were given but the main reason was recognising the risk of overlapping conditions – participants highlighted the importance of clinicians recognising that interconnected factors may result in possible double-counting of patients who may fall under multiple factors. Thus, clinicians would need to exercise oversight of the system, and exercise contextual judgement in certain instances. However, participants also felt that clinicians needed rules to follow and clear guidelines to ensure that the process is standardised so that the human element would not introduce too much bias. They also wanted systems in place to monitor for unintended consequences of the system, including bias or discrimination.

Participants expressed significant initial concern about gamification, but on balance and following deliberation, felt that the benefits of improving the system outweighed these concerns: the range of responses and degree of concern expressed by participants at first around gamification illustrates the importance of developing waiting list prioritisation policies and procedures with clear transparency and public engagement at the outset. Whilst many participants expressed concerns about gamification at early stages in the deliberation (Workshop 1), as the conversation progressed (Workshop 3) participants increasingly felt that whilst a minority may attempt to game the system, most people would not. At later stages, many participants stressed that the minority of people who would inevitably be playing the system should not impact the majority adversely. Therefore, for many participants, following considered discussion and dialogue, the risks presented by failing to improve the health system outweighed concerns about gamification, although participants stressed the need to ensure monitoring for gamification was in place.

1 Introduction

1.1 Background and objectives

This report presents the findings from a project commissioned by NHS Midlands and Lancashire Commissioning Support Unit working closely with University Hospitals Coventry and Warwickshire (UHCW NHS Trust). Prior to the COVID-19 pandemic, waits for elective care treatment were gradually increasing, with the 18-week waiting time target not having been met since 2016. As a result of the pandemic, the numbers of patients waiting on elective care waiting lists across the NHS have increased significantly. These longer waits raise the question of how patients on the waiting lists should be prioritised and invite consideration of the value judgements that underpin that question (Spilsbury, 2022).[3]

The current prioritisation system deployed across the NHS considers the Clinical Priority Code of the patient's condition (a recent intervention as, prior to the pandemic, the NHS would consider the length of time waited) and how long they have been waiting. However, many other patient variables could also be considered in this prioritisation – and prior research conducted for NHS England (London region)[4] shows that the public think other variables might be considered, such as whether or not the patient works, has dependents, or the extent to which the condition affects the patient day to day. This project adds to this prior work in London by undertaking in-depth deliberation on the question of which, if any, variables might be appropriate for waiting list prioritisation.

This report presents the findings from a deliberative public engagement project designed to explore public experience and expectations of waiting on elective care waiting lists across the NHS in the United Kingdom region of Coventry and Warwickshire. The aim was to support public health decision makers in Coventry and Warwickshire to engage members of the public on some of the potential prioritisation factors for NHS Waiting Lists, enabling the public to feed into the development of a prioritisation system in Coventry and Warwickshire. The aim of the prioritisation system is to allow elective care waiting lists to be prioritised which can then be taken forward to inform regional planning, local implementation and further engagement activity for the NHS in Coventry and Warwickshire. A particular interest and aim is to ensure that such an approach takes account of, and helps address, health and social inequalities. For example, if there are 1,000 patients on a waiting list for a hip replacement allocated as P4, what prioritisation system should be applied to determine the order in which these patients should be treated? The Trust wanted to understand the views of its public on how, and whether, the factors they generated in determining who gets called ahead of whom should be changed. This was done by supporting public health decision makers to engage members of the public, enabling the public to feed into the development of a prioritisation system.

The approach taken was deliberative – convening a demographically diverse group and 'mini public' of 49 participants over a period of 12 hours in total. During this process, they learned about Coventry and Warwickshire's approach to managing elective care waiting lists and potential factors that could be considered in a new prioritisation system (see Figure 1), they then deliberated about the potential for future use of the factors, as well as how they might apply to some fictional patients through case studies. A series of four workshops took place, in which design principles for the Coventry and Warwickshire NHS Trust on prioritising the elective care waiting list in Coventry and Warwickshire were developed. The complexity of the issue, as well as the proposed prioritisation system, meant that deliberative public engagement, which allows time for the consideration of evidence and different viewpoints, was a particularly suitable method.

The sample (Appendix A) was recruited to reflect the demographic diversity and makeup of the Coventry and Warwickshire region, including urban/rural split, a diversity of socio-economic backgrounds, ethnicities and ages. Efforts were made to recruit individuals who may not generally engage in research or act as advocates for their

---

[3] The Strategy Unit. (2022). Treating people on waiting lists: who decides what is fair? [online] Available at: https://www.strategyunitwm.nhs.uk/news/treating-people-waiting-lists-who-decides-what-fair.

[4] www.england.nhs.uk. (n.d.). NHS England and NHS Improvement London» London COVID-19 Deliberation Report. [online] Available at: https://www.england.nhs.uk/london/our-work/patient-and-public-involvement-reports/london-covid-19-deliberation-report/.

community, i.e. those whose voices are less likely to be heard. Participants were recruited through a specialist recruitment agency, with networks in Coventry and Warwickshire, and with particular expertise in reaching and engaging both urban and rural locations.

Figure 1.1: Prioritisation factors introduced during the workshops

Factor
Needing to attend A&E or GP because of condition
Previous admission or readmission because of condition
Other health conditions that have impact or previous diagnosis of condition
Length of wait (been waiting the longest)
Significant impact on mental health
Age
Ethnic group (from a minority ethnic background)
Disability
Live in a more deprived area
Lifestyle factors (e.g. diet, smoking, drinking)
Carer for a relative, friend or neighbour
Unable to work while waiting
Unable to attend school/education while waiting
Unable to volunteer or work in local community while waiting
Other significant impact on quality of life

1.2 Methodology

The method of deliberation was used to generate the evidence for this report. Deliberation is a progressive form of public engagement that can help to shape public policy due to its ability to provide informed and considered public opinion. It convenes 'mini publics' reflective of a broader population over an extended period of time. Participants are informed by experts and supporting stimulus about the topic/s in question and then invited to explore and deliberate trade-offs associated with this. This method creates an opportunity for decision-makers to understand public views that are carefully considered and rooted in real-life context, thus leading to more trusted and supported policy in the longer term. Numerous countries have implemented deliberation as a strategy for health policy making. For instance, Canada, the United States of America, Australia and Denmark, in addition to the United Kingdom have all utilised deliberative techniques to get public considerations on health reform initiatives. The OECD has reported on the rise of the 'deliberative wave' in engagement and research, whilst there is an established history and track record of engaging people in complex decisions about health data, as evidenced by recent initiatives such as the Wellcome Trust, Ada Lovelace Institute and Understanding Patient Data's juries on health data access, in addition to the OneLondon public deliberation on health data.[5][6][7][8]

This project took the form of a deliberative mini public – it was broken up into four three-hour virtual workshops that were held with the public (29 and 31 March 2022 and 5 and 7 April 2022). Participants were recruited by an external recruitment agency to reflect the broad diversity of Coventry and Warwickshire as an area. The research agency recruited to the sample specified in the Annex using a range of on the street and off the street approaches.

---

[5] www.oecd.org. (n.d.). Innovative Citizen Participation and New Democratic Institutions: Catching the Deliberative Wave | en | OECD. [online] Available at: https://www.oecd.org/gov/innovative-citizen-participation-and-new-democratic-institutions-339306da-en.htm.

[6] Public deliberation in the use of health and care data. (n.d.). [online] Available at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf [Accessed 28 May 2022].

[7] Mackie, M. (2020). Deliberative engagement with Londoners to steer the pandemic response. [online] Ipsos. Available at: https://www.ipsos.com/en-uk/deliberative-engagement-londoners-steer-pandemic-response.

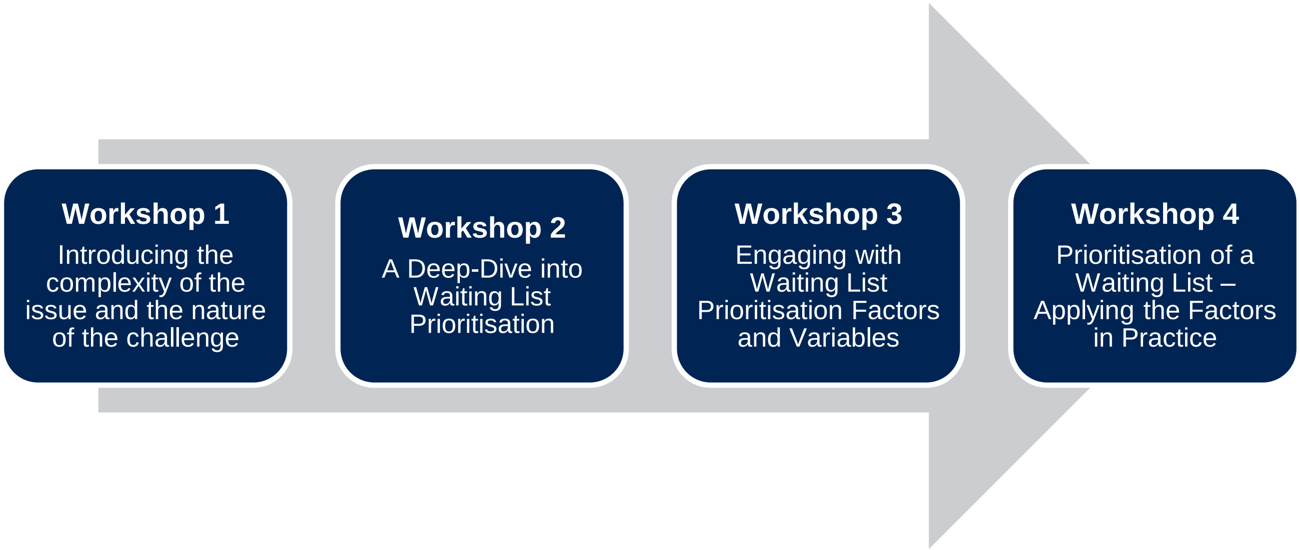
[8] Duxbury, K. (2018). Bringing the public along on the health tech revolution. [online] Ipsos. Available at: https://www.ipsos.com/en-uk/bringing-public-along-health-tech-revolution.

Quotas (target numbers of participants) were set by age, gender, ethnicity, social grade, area (Coventry or Warwickshire) and whether the area in which they live is urban, rural or a market town, in order to ensure the deliberative participants were broadly demographically reflective of the population of Coventry and Warwickshire. Quotas were also set to ensure some participants had a long-term health condition and some did not, and that some had experience of being on a waiting list for a health service (current or previously) and some had not, all to ensure a range of perspectives were included within the deliberation. Please see Appendix A for further details on the demographic composition of participants.

Participants were recruited by a specialist recruitment agency, working with their existing panel supplemented with targeted social media advertising. Many participants signed up to the existing panel via the agency's website, having seen advertisements in places such as social media, magazines, print and digital editions of newspapers, and postcards/flyers. The remainder were recruited to the panel via stands at face-to-face events using paper sign-up forms. The social media advertising was conducted via Facebook, targeted at anyone aged 18 and over. The advertising did not specify the nature of the research to avoid biasing the sample to those with a particular interest in the topic. Participants were remunerated for their time participating in the workshops.

1.2.1 Structure of the workshops and approach to deliberations

Figure 1.2: Workshop design



The workshops comprised a combination of smaller discussion groups (sometimes referred to as 'break-out groups') to understand and explore views and values, and whole group plenary sessions in which information was provided to the participants or where moderators would summarise findings from the smaller groups for all participants to hear. Stimulus material included presentations from experts and case studies illustrating fictional patients and how they would be scored using the prioritisation tool based on the UHCW's list of factors (this tool was created for the purposes of deliberation to aid and assist dialogue).

The smaller discussion groups comprised of five to six people. These groups were kept constant for the first three workshops and then changed for the fourth; they aimed to represent a mix of participant characteristics.

The deliberative workshops aimed to facilitate discussion around patient and public expectations, waiting lists generally, how the COVID-19 pandemic affected the waiting list processes, funnelling down into more specific discussions about the waiting list prioritisation tool, its factors, how it may be applied and other factors that should be taken into consideration.

Individual workshops were structured as follows (see Appendix B for more information on this):

- **Workshop 1: Introducing the complexity of the issue and the nature of the challenge**

Workshop 1 introduced the challenge to participants, in that the pandemic has amplified waiting times and there is a large backlog of people waiting for procedures and operations. Participants learnt how waiting list prioritisation worked historically and has had to change throughout the pandemic, and how this might be adapted even further going forward. The workshop comprised plenary discussions with specialists discussing the trends that occurred during the Covid-19 pandemic that have contributed to NHS pressures, explaining what elective care is and what kinds of operations and procedures it includes, an overview of how UHCW and its waiting lists were impacted by the pandemic and how many people were on waiting lists both pre-COVID-19 and presently. Specialists also gave an analysis of how the management of waiting lists fuel inequality, which may exacerbate it, and how this challenge can be addressed. This was then followed by smaller break-out group discussions that encouraged participants to consider their own thoughts and feelings around waiting lists. In addition to the presentations, stimulus included exercises involving fictional patients, their medical needs and an overview of their lives and working conditions (for instance, caring responsibilities, working patterns, age, and where they lived in Coventry and Warwickshire, as well as any other considerations, such as language barriers. In these exercises, participants were asked to evaluate each patient's experience and discuss how they should be prioritised, including if any other information was needed. In the last plenary, break-out group moderators were invited to summarise the key points derived from their discussions. The first workshop explored the following questions with subsequent workshops revisiting the questions: these questions:

  - What are their immediate reactions to the backlog and waiting times?
  - What are their experiences or expectations of waiting lists?
  - What are the potential risks/issues to consider in developing the tool?
  - What are some of the potential advantages?
  - How would they prioritise different patients with varying needs and why?

- **Workshop 2: A deep-dive into waiting list prioritisation:** Workshop 2 aimed to enable the participants to understand more about the proposed waiting list prioritisation tool and how it works and begin a discussion about the scoring/prioritisation data points and criteria. The workshop comprised plenary discussions with experts discussing the tool's key factors and variables. These factors include:
  - previous admission or readmission with condition
  - needing to attend A&E because of their condition
  - other health conditions that have an impact, or a previous diagnosis of cancer
  - length of wait
  - significant impact on mental health,
  - age, ethnic group
  - disability
  - living in a more deprived area
  - lifestyle factors e.g. diet, smoking, drinking, carer for relative, friend or neighbour
  - being unable to work while waiting
  - being unable to attend school / education while waiting

  - being unable to volunteer or work in local community while waiting
  - being an NHS worker who is unable to work while waiting
  - any other significant impact on quality of life

Emphasis was placed on communicating the need for the public's input on the use of the tool and the relative weight each factor should be given. This was then followed by smaller break-out group discussions where participants were asked in this workshop to identify a list of important factors for prioritisation and/or deprioritisation. This was done via a process of elimination and their relative weight; factors were weighted in a waiting list prioritisation grid. Break-out group moderators were then invited to summarise the key points from discussions, offering an overview of participants' choices regarding the factors, including how the factors were weighted and the rationale behind different choices. The workshop explored the following questions:

  - What are the key issues in fairly prioritising waiting lists?
  - Which factors seem most important to consider in the waiting list tool?
  - Which factors seem problematic/difficult to consider in the tool and why?
  - Which waiting list tool factors are participants most on the fence about?
  - What additional information is required to rank waiting list tool factors?

- **Workshop 3: Engaging with waiting list prioritisation factors and variables:** Workshop 3 encouraged participants to reflect on the introduced waiting list prioritisation tool factors and think about how to ensure perverse outcomes of the prioritisation system are avoided, such as gamification (a key issue that was explored throughout the workshop but especially in Workshop 1 and 2) which directed the discussion on further exploring its weight on the waiting list prioritisation tool in Workshop 3. The workshop comprised of plenary discussions with experts explaining to participants how waiting lists are currently prioritised, why each of the proposed waiting list prioritisation tool factors might need to be considered and/or any issues with any of those factors, and gamification and inequalities amongst the factors. This was then followed by smaller break-out group discussions that allowed participants to reflect on how they ranked factors and think about gamification and how it can be dealt with; the waiting list prioritisation grid was used throughout to aid reflection and to allow participants to make changes to their rankings. Moderators of each group were then invited to share what emerged from break-out discussions. This workshop explored the following questions:
  - Do participants have further or contrasting reflections on the waiting list prioritisation tool factors?
  - What factors are participants still unsure about?
  - What further information for consideration of factors may be required?
  - Do participants have additional factors/thoughts to add to the list of factors?
  - How do we ensure that these systems cannot be gamed, or create perverse outcomes?

- **Workshop 4: Prioritisation of a waiting list – applying the factors in practice:** Workshop 4 directed participants in discussing, within smaller break-out groups, the prioritisation score of fictional case studies, based on their prioritisation of factors in the past workshops. In this workshop, participants were largely engaged in thinking about the fairness of scores and uncertainty in prioritising patients. They were also asked to examine a specific factor. This encompassed:
  - evaluating the key principles that should govern how the NHS uses this factor

- what information is required before using the factor
- the opportunities and risks of the factor
- conditions and safeguards that need to be in place
- unintended consequences of the factor
- thinking about its application and use in a given instance or context.

Finally, participants returned to a final plenary discussion where representatives from each group had a chance to present the factor they were assigned and three key points on proposals for informing how the NHS might use the factor (key principles, conditions and safeguards). The workshop concluded with representatives (public health specialists and clinicians) from NHS Coventry and Warwickshire.

Overall people were positive about the opportunity to input their views on such an important issue and enjoyed the process as a whole:

- They reported finding the speakers clear and engaging, though occasionally it felt as though they had an agenda that they were trying to push (particularly in relation to the importance of factors such as deprivation and ethnicity in prioritisation); so the views and perspectives were engaged with critically.
- Participants felt that having discussions with people who have different views to themselves helped broaden their thinking and views
- They found it interesting and, to some, the information was described as surprising, novel or new.
- The topic was complex and demanding from participants – the nature of the issues and topics being discussed (issues of health and inequality in particular) meant that for some, it was a personally challenging ask to deliberate about this topic and some highlighted that there was a lot of information to take in.

1.2.2 Analysis of deliberation

The workshop discussions, both in break-out rooms and plenary, were transcribed and systematically inputted into a master document, allowing for more in-depth analysis of findings, and the waiting list prioritisation grids from each group were collected for examination. A thematic analysis approach was implemented in order to identify, analyse and interpret patterns of meaning (or ‘themes’) within the qualitative data, which allowed the researchers to explore similarities and differences in perceptions and views. Thematic analysis is a qualitative research method that discerns patterns across data, such as from focus groups, interviews and transcripts. In total, there were two people involved in the thematic analysis. They independently wrote up various chapters of the report, with one person going back and reviewing the report to ensure stylistic consistency. A third person independently reviewed the report to review the themes.

1.2.3 Participants

The public participants for the deliberative workshops were recruited to represent a spread of residents across Coventry and Warwickshire, with different demographic criteria (e.g. gender, age, socioeconomic status etc.) to represent a broad range of views.

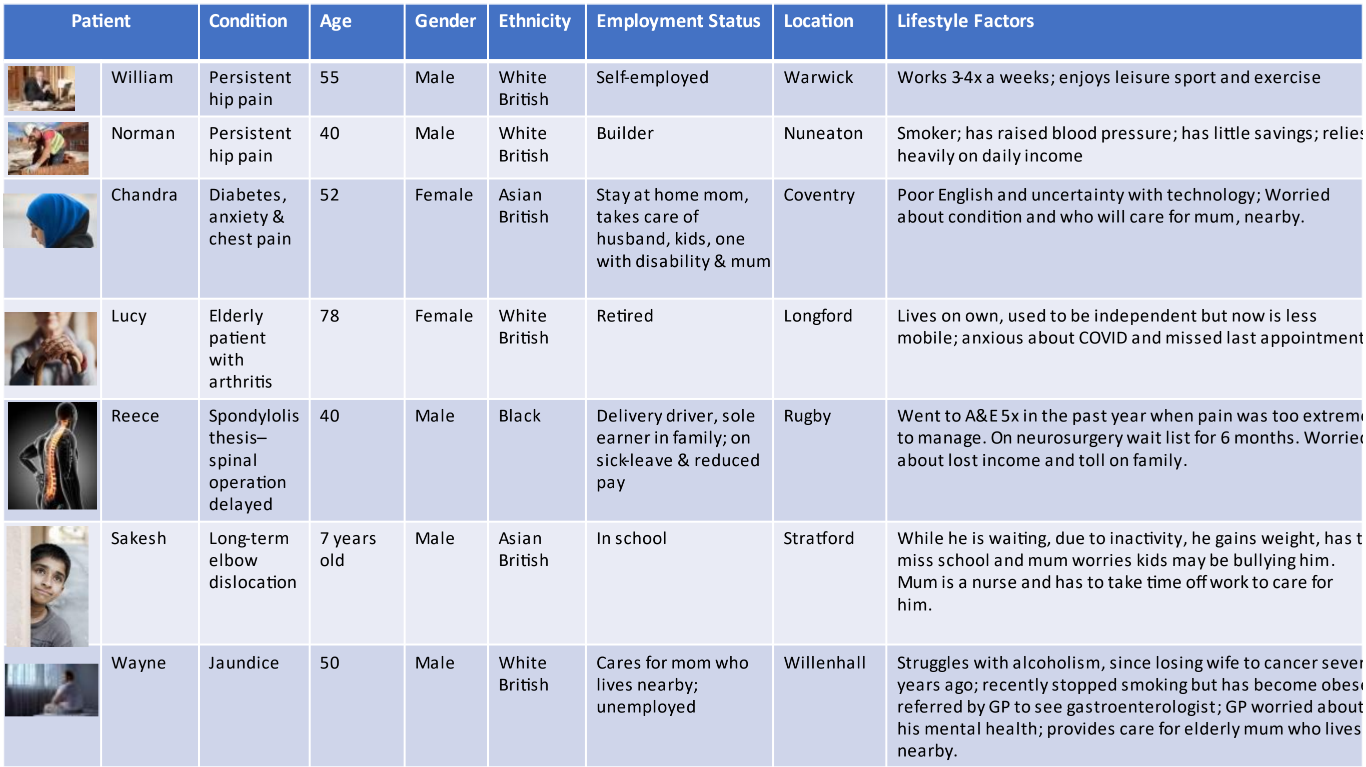
A full profile for both the public and staff workshops as well as the depth interviews can be found in the Appendix.

1.2.4 Stimulus materials

In the workshops, the groups used different stimulus materials to support their discussions in addition to presentations from different stakeholders (see Appendix B). The main stimulus were:

- **Seven case studies,** illustrating the stories of a range of fictional patients who might be on the waiting list (see Figure 2 for a summary). The case studies aimed to demonstrate the range of situations people on a waiting list might experience, highlighting potential issues for consideration. These case studies were introduced in the first workshop and were returned to in the final workshop to help ‘stress test’ a version of the prioritisation tool.

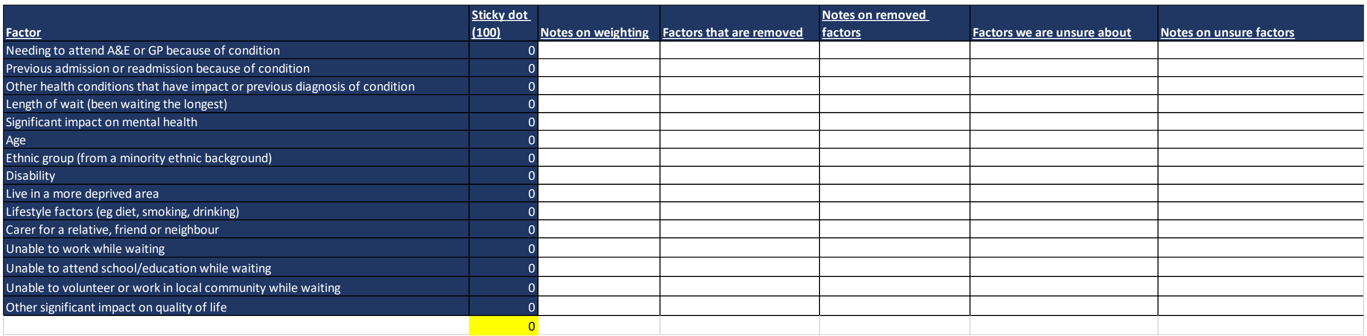
Figure 1.3: Figure 2: Case study summary



Patient		Condition	Age	Gender	Ethnicity	Employment Status	Location	Lifestyle Factors
	William	Persistent hip pain	55	Male	White British	Self-employed	Warwick	Works 3-4x a weeks; enjoys leisure sport and exercise
	Norman	Persistent hip pain	40	Male	White British	Builder	Nuneaton	Smoker; has raised blood pressure; has little savings; relie heavily on daily income
	Chandra	Diabetes, anxiety & chest pain	52	Female	Asian British	Stay at home mom, takes care of husband, kids, one with disability & mum	Coventry	Poor English and uncertainty with technology; Worried about condition and who will care for mum, nearby.
	Lucy	Elderly patient with arthritis	78	Female	White British	Retired	Longford	Lives on own, used to be independent but now is less mobile; anxious about COVID and missed last appointment
	Reece	Spondylolisthesis– spinal operation delayed	40	Male	Black	Delivery driver, sole earner in family; on sick leave & reduced pay	Rugby	Went to A&E 5x in the past year when pain was too extrem to manage. On neurosurgery wait list for 6 months. Worrie about lost income and toll on family.
	Sakesh	Long-term elbow dislocation	7 years old	Male	Asian British	In school	Stratford	While he is waiting, due to inactivity, he gains weight, has t miss school and mum worries kids may be bullying him. Mum is a nurse and has to take time off work to care for him.
	Wayne	Jaundice	50	Male	White British	Cares for mom who lives nearby; unemployed	Willenhall	Struggles with alcoholism, since losing wife to cancer sever years ago; recently stopped smoking but has become obes referred by GP to see gastroenterologist; GP worried about his mental health; provides care for elderly mum who lives nearby.

- A fictional prioritisation algorithm was presented as a spreadsheet to encourage participants to consider the relative importance of different factors (see Figure 3). They were able to adapt this and add or remove factors to reflect their position. This grid was introduced in the second workshop and the groups returned to it in the third workshop after a further presentation about the factors participants found more difficult to understand.

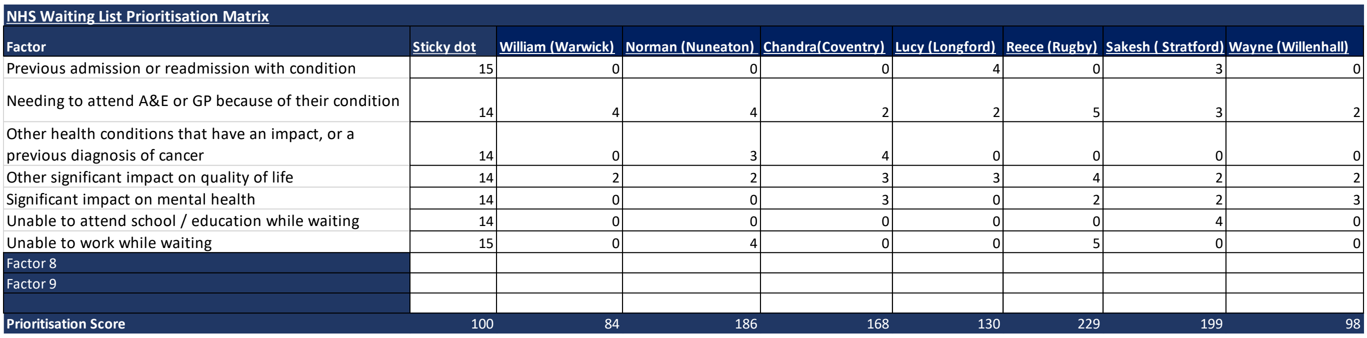
Figure 1.4: Fictional model for prioritisation factors



Factor	Sticky dot (100)	Notes on weighting	Factors that are removed	Notes on removed factors	Factors we are unsure about	Notes on unsure factors
Needing to attend A&E or GP because of condition	0					
Previous admission or readmission because of condition	0					
Other health conditions that have impact or previous diagnosis of condition	0					
Length of wait (been waiting the longest)	0					
Significant impact on mental health	0					
Age	0					
Ethnic group (from a minority ethnic background)	0					
Disability	0					
Live in a more deprived area	0					
Lifestyle factors (eg diet, smoking, drinking)	0					
Carer for a relative, friend or neighbour	0					
Unable to work while waiting	0					
Unable to attend school/education while waiting	0					
Unable to volunteer or work in local community while waiting	0					
Other significant impact on quality of life	0					
	0					

- A pre-populated assigned risk score and solution informed by deliberations, roughly based on a high-level analysis of the emerging discussions, was used in the final workshop (see Figure 4). This brought together the more frequently selected factors and attributed each of the case study characters a score based on their story. Participants were encouraged to discuss the process and outcome of scoring the people in this way, to help illustrate how the tool could work in reality.

Figure 1.5: A spreadsheet exploring most common factors and the impact on each case study character



NHS Waiting List Prioritisation Matrix

Factor	Sticky dot	William (Warwick)	Norman (Nuneaton)	Chandra(Coventry)	Lucy (Longford)	Reece (Rugby)	Sakesh (Stratford)	Wayne (Willenhall)
Previous admission or readmission with condition	15	0	0	0	4	0	3	0
Needing to attend A&E or GP because of their condition	14	4	4	2	2	5	3	2
Other health conditions that have an impact, or a previous diagnosis of cancer	14	0	3	4	0	0	0	0
Other significant impact on quality of life	14	2	2	3	3	4	2	2
Significant impact on mental health	14	0	0	3	0	2	2	3
Unable to attend school / education while waiting	14	0	0	0	0	0	4	0
Unable to work while waiting	15	0	4	0	0	5	0	0
Factor 8								
Factor 9								
Prioritisation Score	100	84	186	168	130	229	199	98

1.3 Structure of the report

Below are the detailed findings derived from both the public workshops. Each section contains a top line summary followed by the results of the public deliberation workshops. Unless indicated otherwise, the findings below reflect the view of participants throughout the deliberations.

2 Overarching challenges and tensions

This chapter sets out the key tensions in the group discussions around prioritising waiting lists before going into the detail of each of the factors in the next chapter. It illustrates the cross-cutting themes which arose when participants tried to decide how to prioritise the factors.

> **"It is really a bit like playing 3-dimensional chess trying to take all the factors into account and then come out with a fair allocation of positions on the waiting list. You can see how complex the whole situation is. What is the most important factor? Is it someone being able to continue to work? Or someone's social engagement? So many different factors that affect individuals. It's going to be an interesting discussion…"**

Specifically, it covers some of the key points raised by participants such as:

- Prioritisation is complex and it is key to ensure that everyone is treated
- Appeal of focusing on clinical assessments and individual level information
- The importance of developing a fair approach
- Handling interconnected factors
- Minimising / monitoring the risk of gamification
- Developing a system with humans in the loop
- Unintended consequences
- Data collection and data quality

2.1 Prioritisation is complex and everyone must be treated

At the start of the workshops, some groups pushed back on the assumption that the waiting list should be prioritised by factors other than clinical urgency. As discussed further in chapter 6.1 below, there were participants who expressed that they would much prefer if patients could all be seen quickly so that prioritisation is not necessary – understanding that this would require more resource to allow this to happen.

> **"All of these people should have the same right to be assisted at the same time. None of them are more important than others. Their condition should be the only factor, not social aspects."**

There was strong agreement that the most important considerations are clinical urgency and ensuring nobody has an infinite wait, in line with the way lists are currently managed. As outlined below, some participants wanted only these criteria to be applied. However, on reflection, most participants felt that including additional factors to prioritise some people ahead of others could be worthwhile, if the factors can be demonstrated to be robust (i.e. so that whoever did the scoring, patients in the same situation would get the same score) and fair. For example, they rationalised that while chronic pain will never be life threatening and therefore would not make someone a clinical priority, the impact on someone's quality of life could be very significant.

> **"If people are suffering more than others, those people should go first. You are reducing suffering for those people. I certainly see advantages."**

2.2 Is it best to focus on clinical assessments alone?

Within many of the groups, a minority of participants felt that the prioritisation should be based solely on clinical assessments. These people typically believed any other criteria could potentially have a negative impact on fairness.

> **"I would say if you've got somebody who's suffering greater pain from an affluent area and someone in less pain from a deprived area that jumps ahead of the person in great pain, then that's wrong. It should go based on your clinical assessment."**

Some thought that a clinical assessment would be the only reliable information available to those involved in the prioritisation, as well as being the fairest way to make the decision. They were concerned that gaps in data could lead to people being mis-prioritised.

> **"They've got this idea in their heads that by putting all this information in they can find out more about people, but you can put as much information into the system as you like and it doesn't really tell you anything about their life or the impact on their life and their pain levels."**

Even in the absence of gaps in the data, some suggested that 'social' considerations, such as whether or not they had children, where they live or the type of work they do would be inherently unfair, as it would result in some people being prioritised above others based on factors outside their control. Any of these distinctions could lead to a 'second-class' service for people who do not have the characteristics which are given priority by the system. Rather than seeing it as some people being prioritised, they saw it as the people who drop down the list being 'penalised'.

> **"I would be annoyed if he beat me up the list because he has 6 kids and is an alcoholic. That isn't fair and I don't see how bringing in these extra questions would reduce the list."**

While these participants could empathise with evidence about different health outcomes for people from particular backgrounds, they did not believe the waiting list was the best way to resolve these concerns. Instead, they suggested that more should be done to support people to access the NHS sooner and to ensure they have a similar quality of experience once they are in the system so that their outcomes would improve.

> **"We're trying to solve problems that aren't medical ones in a way. We're looking at balancing out people who are living in deprived areas and things like that and is that for the NHS to do or is it for the government to do?"**

This view was by no means universal, however. The majority of participants did see the benefit of bringing in additional data (beyond the existing factors used) and felt that an updated system with more nuanced data could have the potential to be fairer. While clinical assessments were seen as vital, many participants preferred a more holistic approach to prioritising patients on the waiting list. They concluded that there were quality of life needs and barriers, such as income and mental health, that deserved to be taken into consideration too.

> **"We need a way of not just a medical assessment, we need to know about their day-to-day life, their dependants, their job, their wellbeing. We need factors to assess to compare them fairly."**

> **"I think Norman would be fairly high up. His condition is more severe and he also has the social aspect that he's not earning for his family as well, which is going to affect his mental health."**

2.3 Developing an approach that is fair

Throughout the workshops participants debated both implicitly and explicitly what they were optimising the waiting list to achieve. Considerations included minimising the overall burden on the NHS, maximising quality of life and ensuring fairness to those waiting.

> **"If you look at the whole population, the people in greater need will have the longer-term impact get in sooner, and the people who can wait longer and not suffer so much wait longer. It's trying to make it fairer."**

As noted above, some groups thought there was a difference between clinical and social need, suggesting that some of the issues of inequality discussed in the workshop were not for the NHS to fix. However, for others in the workshop, in the absence of anyone else to address these issues, they could see a role for the health service.

> **"Life isn't fair, but I think it is a moral obligation as a human being to even out those odds where necessary, if possible."**

Participants discussed different aspects of fairness. Some thought that equality of access was the priority, under the banner of universal healthcare for all.

> **"The founding principle of the NHS is that access to healthcare should be based purely on clinical need… it's a valid point that you can't focus on the disadvantaged areas at the expense of the advantaged areas, but equally you can't just let the advantaged areas have all the healthcare."**

Others thought that equality of outcome was more important, ensuring the system would advocate for those who were unable or unwilling to push themselves to the front of the queue but who were most clinically in need. Some noted that certain combinations of factors could unintentionally exacerbate inequalities, for example by not placing as much value on caring as on paid employment.

> **"With the waiting list, it shouldn't just be about time. It's about equality of time to recover and how they may recover. I can see so many of the people who cannot access the healthcare they need because financially they can't do it. That's making it unequal. It isn't just about the weeks or months for them to be treated."**

Some participants were concerned there was a risk that new factors could inadvertently exacerbate inequalities, with one suggesting a detailed equality impact assessment would be vital before the system was changed. For example, certain lifestyle factors, employment choices or caring responsibilities could be associated with particular demographic groups so prioritising them could result in priority being given to some demographic groups above others.

> **"But I'm worried that you'll find out a year down the line that there's an unintended bias. It might be deciding on drinking, smoking, where you live, but it might end up favouring men or a different ethnic group."**

2.4 Handling interconnected factors

Participants noted that the factors could often be interconnected and as such it would be possible for one person with a particular set of circumstances to get a high score on a range of prioritisation factors as a result of one underlying factor. This would result in them being placed higher on the waiting list than some people were comfortable with.

> **"I'm still worried that these factors overlap. What about someone in a deprived area, and we bump them up, and then we bump them up again because they have a low income? I think someone can tick so many of those boxes which would bump them up way too high."**

Examples of scenarios participants suggested might be correlated due to an underlying factor, thus leading to a higher score, include an overlap between

- Impact on employment and quality of life
- Having a long-term condition and a disability
- Age and being unable to attend school (or work)
- Mental health and quality of life
- Underlying condition and needing to attend A&E or admission to hospital
- Living in a deprived area and being from an ethnic minority

However, others commented that the additional weight could be appropriate, given the challenges that the factors represent.

> **"Maybe you deserve it…. You might need it."**

2.5 Minimising / monitoring the risk of gamification

Throughout the workshops, some participants raised concerns for the potential for patients to play the system with the intent of being treated more quickly. Some factors were identified as being easier to use to do this than others – typically those described as 'subjective' such as mental health or pain – and these factors tended to receive less support throughout the discussions accordingly.

> **"I work in complaints. The amount of times people who want a refund mention that they are disabled or are depressed, it doesn't affect my condition. Some of those people might be struggling but some of them might be playing that card trying to get a better deal."**

In the penultimate workshop, groups reflected further on how the potential for patients to game the system would work in practice, and whether it was realistic to suggest that somebody might move house to move up a waiting list or the extent to which people might lie or exaggerate their symptoms. On balance, most groups decided that the majority of people would not manipulate the system in this way, and that perceptions that it was a significant issue were likely to be the result of the media. Parallels were drawn with exaggerated concerns about benefit fraud. Although they thought that some people would seek to play the system, they decided that this was a risk worth taking in order to have a more sophisticated approach to managing waiting lists. However, they stipulated that it would be important to monitor this, to ensure that people were not taking advantage.

> **"In the grand scheme of things, it's for the good of the vast majority then it's a couple of people playing silly games."**

2.6 Developing systems with humans in the loop

For some people, the idea of an algorithm prioritising patients on the waiting list was unsettling. It felt much more reassuring to know that a clinician was making the decisions, drawing on their professional judgement of the individual patient and their condition. This was considered particularly important for patients who might not advocate for themselves, or who might find it difficult to admit they were struggling with the impact of their condition on their physical or mental health.

> **"Say it's a big point-based spreadsheet it then needs to be reviewed by someone who has met all of these people… Having that personal connection with someone is going to be incredibly important. The [case study] bloke is not going to tick that box that says I'm depressed but through that conversation with a GP and they start asking those questions, how he's doing."**

However, others preferred the idea of a well-designed automated system which could remove the potential for unconscious bias. One group talked about some patients having a 'sob story' or a charismatic personality so they could convince the consultant they were a priority - which might mean they moved up the list: they could not agree if this was a positive outcome or not.

On balance, most thought that a hybrid system using the automated tool alongside clinical judgement would work best.

> **"There could be an underlying reason why they should be treated as a priority, but the algorithm doesn't pick that up. Is there an override where a medical profession can say, this person should be a priority, but it doesn't tick our boxes?"**

2.7 Unintended consequences

Across the workshops, participants identified a range of potential unintended consequences of using a more advanced approach to prioritise the waiting lists. This included the impact of individual factors: for example, unintentionally rewarding people for visiting A&E or deprioritising people who do not have the relevant characteristics (such as having children) but who might still be important.

> **"[I'd prioritise] anyone who has dependants. Because if someone has a child who is relying on them, especially a disabled child, immediately, your mental health ill suffers so much more if you're helpless for someone who depends on you… I'm not saying put those with no family at the bottom of the list, but those are the ones which stick out to me."**

In other cases, people feared that unintended consequences could result from a combination of factors. Specifically, some suggested that people might choose which waiting list to join depending on which area would prioritise them the highest – thus unintentionally either attracting more patients to a particular hospital or Trust or resulting in them deciding to go elsewhere.

> **"You can choose where you have your surgery, so would you then find people are canvassing other NHS trusts to find shorter waiting lists to get bumped up the queue?"**

Finally, some groups suggested there is a risk that the chosen factors could be inherently biased towards or against certain groups. For example, the 'unable to work' factor could deprioritise older people and women disproportionately, which might be undesirable.

> **"I had a comment worrying about the unintended bias in the AI. You worry that a year down the line it might prioritise men."**

3 Response to specific factors

3.1 Overview

As outlined above, people found it difficult to prioritise factors, but there was agreement that clinical need should be the overriding consideration in all cases.

> **"Clinical need always has to be the number one factor."**

However, there was some consistency across the groups, in their rationale if not always their scoring.

The factors which almost all groups agreed were important were:

- Previous admission or readmission because of condition
- Other health conditions that have impact or previous diagnosis of condition

The factors which most groups thought were important also included the following:

- Disability
- Significant impact on mental health
- Needing to attend A&E or GP because of condition
- Other significant impact on quality of life
- Length of wait (been waiting the longest)

Factors with some support, but which proved more divisive included:

- Unable to attend school/education while waiting
- Unable to work while waiting
- Carer for a relative, friend or neighbour
- NHS worker who is unable to work while waiting
- Age

Finally, the factors which only few groups thought were important or were comfortable attributing weight to, included:

- Ethnicity (from a minority ethnic background)
- Lifestyle factors (e.g. diet, smoking, drinking)
- Live in a more deprived area
- Unable to volunteer or work in local community while waiting

The following section discusses why participants responded to these factors in different ways. It also discusses some additional factors which groups proposed including lack of support network, prognosis, pain level, access to services, financial impact and direct dependants. Finally, the section explores several factors which were suggested, but which the groups then dismissed.

3.2 Previous admission or readmission because of condition

Overview of measure

This was the most supported of all the factors proposed, with all the groups including a version of it in their final allocations, and nearly all groups considering it one of the most important factors in their weightings. The main reason for prioritising this factor was the perceived cost to the NHS of continuing to treat the condition while the patient is waiting, combined with the perceived robustness of the measure (i.e. because data comes directly from the NHS system, is inputted by clinicians and does not involve a judgement call). Some thought it could be combined with the other attendance factors (A&E and GP attendance, discussed in more detail in Section 3.6 below).

When checking this measure against the case studies, some noted that people's circumstances could impact on their ability to attend or be admitted, or that readmission might not necessarily indicate a condition was getting worse, compared with something like chronic pain which could not be addressed through admission. Therefore, the consideration of previous admissions was not ideal but overall was considered helpful.

> **"He [man in case study] has avoided going to find medical professional help because he doesn't want to let down his work. We are worried about income, jobs not being secure, not having sick pay. Giving him a zero because he hasn't attended because he has prioritised work over health, doesn't seem fair to me."**

Benefits

This measure was particularly valued due to its direct connection with a clinical decision that the condition is sufficiently serious to require admission to hospital. Unlike the A&E or GP attendance measure, participants did not feel that it was open to the potential for patients to play the system. Some suggested repeat admissions could be an indication that the condition is getting worse or that the current treatment is not working. They also suggested that this could be assessed while the patient was in hospital so that any worsening (or improvement) of their condition could be fed back into the prioritisation tool.

> **"Admissions is based on clinical assessment. It's a lot more important than A&E and GP. People get referred by the GP and sit back and wait, and some people attend repeatedly. Hospital admission is more important."**

Additionally, participants thought that inpatient stays would have resource implications for the NHS as well as quality of life implications for the patient. Therefore, particularly if the condition was resulting in multiple stays, it would be beneficial to the NHS to prioritise the patient.

> **"Also, the knock-on effect of resources. If they keep having to go in – if someone is not getting the treatment that is resolving the problem, and they have to keep going back, it's using up a resource."**

Some suggested also including information about hospital visits for adjacent conditions, which might be exacerbated by, or might exacerbate, the condition for which the patient is on the waiting list. However, others were clear that any admissions unrelated to the specific condition should be excluded as they are not relevant.

> **"It has to be relevant to the condition you're waiting for.**
>
> **"You might need a new hip and fall over and hurt your head, that should be counted as it wouldn't have happened without the condition."**

Drawbacks and concerns

Overall, the discussion of drawbacks of this measure was very limited. The few concerns which were expressed related to patients who might be down-weighted because they did not want to burden the NHS and therefore did not present to hospital when their condition worsened.

> **"There's the other side isn't there, there are lots of people who don't go into hospital as they don't want to be a burden. For example, older people who don't want to make a fuss. I'd hate to see that they're deprioritised for being in that generation."**

Equally, some suggested they rarely saw their consultant and were concerned their GP might therefore have the information about their worsening condition rather than the consultant.

> **"The GP may run a test and that test may show a deterioration. That needs to be highlighted straight away, you don't need to wait for a consultant to run the same test again to get the same verdict."**

Safeguards

As noted above, some groups thought there was a strong overlap with the factor relating to A&E and GP appointments and therefore proposed combining them to reduce the risk of double counting.

Overall, participants suggested that in addition to the number of admissions, the length of stay and the consultant's view on the severity of the condition would make people score higher on this metric. They also proposed ongoing monitoring as, if the frequency of readmissions were increasing, that could be a further indicator of a condition getting worse.

> **"It's worth looking at frequency and whether that's increasing. They may have been once in a year, then twice, and then once in a month, because that could be an indicator of how difficult things are getting."**

They also wanted some consideration of what happens after admission – whether patients are discharged successfully and likely frequency of readmission.

> **"And how likely are you to successfully discharge? If now every time you're going into hospital you need three different facilities and a six-week stay, is it easier and cheaper just to give you the operation?"**

Participants noted that sometimes when seeing a consultant the assessment might suggest that the condition has improved and, in this case, they were comfortable that a person might move down the list, although reflected that it is important that they are still treated in the end, if it is still deemed necessary.

3.3 Other health conditions that have impact or previous diagnosis of condition

Overview of measure

Again, this measure received support across almost all of the groups and was often weighted as one of the most important factors alongside previous admission. It attracted less discussion than many of the other factors, perhaps because few saw it as contentious. Unlike the 'social' factors, this is a 'clinical' factor which the system will be well placed to establish.

Benefits

Participants assumed that having other health conditions that are related to the reason patients are on a waiting list would mean that the problem could be exacerbated if not prioritised. As such, they thought it would make sense to prioritise the person for their own sake and to reduce the burden on the NHS.

> **"You're looking at, there could be more treatment necessary if they're not seen quickly."**

Similarly, a previous diagnosis could mean a recurring problem, which again would be a priority to treat to prevent further decline.

Some discussed the importance of considering related conditions which might not immediately be obvious.

> **"My dad needed a knee replacement, didn't get it, fell it and broke his hip. Has fallen again and broken his ribs. Has had pneumonia four times. If he had his knee done, it wouldn't have happened."**

In some groups, this factor was discussed with explicit reference to a cancer diagnosis. Views varied depending on whether people thought that the cancer was related to, or had an impact on, the condition for which the person was on the waiting list. If they saw a direct connection, they would be comfortable with priority being given.

> **"Depending on the complaint, if there is a high risk of a patient having secondary cancer or a recurrence, then they should be prioritised because obviously long term, that's life threatening. To me, it's more of a priority for saving life than a knee replacement."**

Drawbacks and concerns

Despite the broad support for this factor, people thought that it had to be fairly interpreted. Specifically, while they were concerned it could be too narrow as outlined above, they also feared it could be too wide and might include any condition, even if it was unrelated.

> **"I've got three underlying health conditions but if my tonsils need whipping out, they don't impact that. So, it doesn't always work."**

Similarly, for cancer, although it might be a related condition, some noted that it should not give someone automatic priority.

> **"I work with someone who had it [cancer] in her 20s, no days off sick, would you really then put that person forward compared to someone who is completely immobile?"**

Some raised concerns about undisclosed or undiscovered health conditions. Where these were present, they worried that a patient might be unhelpfully deprioritised due to lack of information.

> **"You might have one person who's been to hospital a few times with loads of conditions, and someone else might've never been near a doctor but with lots of things wrong with them. Does that mean they're not as important?"**

Safeguards

Participants discussed few safeguards for this measure as they believed that it would be difficult to game. The main safeguard was that there should be a system in place for ensuring the system has up to date information about other related conditions, so that it takes all the patient's circumstances into account. They raised specific concerns about whether or not health data would be sufficiently joined up, as discussed further in the section on data quality below.

> **"This factor should also be fluid. Later on if someone is still waiting and they get diagnosed with something else that could be linked, the factors should be updated to reflect that."**

One group also made a link to understanding the impact of the wait itself on the condition and wanted assurance that conditions which could get worse would be prioritised over those that were stable.

3.4 Disability

Overview of measure

There were mixed views on the inclusion of disability as a factor. A couple of groups gave disability a high weighting, most gave it at least some weight and only one group did not think it should be included as a factor. Some considered it important because it was proven to lead to a shorter life expectancy and therefore these patients were already disadvantaged health-wise. Others felt that that having a disability alone should not lead to immediate prioritisation. If the disability was directly related to the condition the patient was on the waiting list for, then almost all participants felt it should be taken into consideration.

When evaluating 'disability' in Workshop 3, some participants mentioned thinking about disability differently due to the specialist's talk during that session in which it was explained that a patient with both a disability and a health condition may already have a lot to deal with. For this reason some participants thought the 'disability' factor deserved more weight. As a whole, however, participants' views on 'disability' in workshop 3 stayed consistent to workshop 2.

Benefits

Some participants felt that patients with a disability should be prioritised, as they are already experiencing an impediment in life, and not prioritising them would only exacerbate challenges to their quality of life, because it was one other thing they needed to worry about.

> **"Disability is important, because it impacts on the entire life cycle. If the condition you have is making life so difficult, that is another aspect that's very high for me."**

Most participants spoke about what having a disability may mean in relation to the procedure patients are awaiting. They felt that if the disability directly impacted the procedure, then it should be taken into consideration for prioritisation. If it did not, then it was a factor that could be weighted less.

"I wonder whether disability needs to be in the context of the procedure being suggested. I have partial hearing loss, but I don't think that should give me more priority for a new hip."

Many participants held the view that those with a disability have lower life expectancy and felt they should be prioritised based on this.

> **"We gave that [disability factor] a 10, I don't know if people view that differently knowing it's people with a physical disability and who have a possibly shorter lifespan."**

Drawbacks and concerns

Some participants wanted more information on the 'disability' factor to be able to weigh it up. They supported those with disabilities being prioritised more if other considerations were present that negatively affected the patient, such as a lack of mobility or mental health issues. Participants thought the context of the disability needed to be taken into consideration in order to understand what the implications of that disability are.

> **"Having a disability doesn't mean anything. You have to understand what it's going to mean."**

Others felt that that having a disability alone should not lead to immediate prioritisation on the waiting list and that the weight of the factor depended upon the nature of disability, as many people with disabilities can still function and do not necessarily have a lower quality of life.

> **"It shouldn't be just because you're disabled, you're automatically more at risk. If it has an impact yes, but just because someone with Down Syndrome needs a knee operation, does that mean they should get it before someone?"**

A few participant groups felt that the disability factor could fall into another factor, such as 'other health conditions that have impact or previous diagnosis of condition', and so it did not need to be listed on its own. However, others spoke about distinguishing between people with permanent disabilities and those who may be experiencing a temporary disability caused by their condition or illness. They suggested that those with temporary health conditions should not be prioritised the same as those who are disabled. One participant explained that these differences are already enshrined in disability legislation which requires a substantial and long-term negative impact on a person's ability to do normal activities in order for them to be classified as disabled. This may be a safeguarding issue as well.

> **"The legal definition of disability is something that affects them for more than a three-month period, so I do think there needs to be a distinction between [this and the other health conditions factor]. I get that they're similar, but someone in a wheelchair works full time, if changes are made in their job, they can get on fine, because they don't have chronic fatigue, some people don't want to consider themselves disabled."**

Participants also felt there should be a holistic view of patients with disabilitieswhen prioritising. For example, other factors that should be taken into consideration alongside the disability itself were if a young patient with a disability has siblings who are affected by their parents caring for the patient, if the patient is unable to work and how well they can cope with the disability.

Safeguards

Participants spoke about some disabilities being easier to gamify over others. A safeguard measure discussed by participants is requiring patients to have legally registered disabilities to be considered in prioritisation.

> **"You'll need a registered disability that is recognised."**

Participants also mentioned there already being safeguards in place to avoid classification biases of disabilities. Some patients may classify their disability as being more or less debilitating than it is, in actuality, prompting an unfair distribution of prioritisation.

> **"There are already systems in place in terms of when you want to apply for a blue badge or PIP payments that grade how your health is, and I feel like the more specific that could be, the less subjectivity would be involved. And the less subjective we are the more fair the system will be."**

3.5 Significant impact on mental health

Overview of measure

Over half of the groups gave a high weighting to mental health, and none gave it a zero rating. Participants thought some of the other factors were closely related to. and could impact on, mental health such as quality of life and ability to work. Many participants spoke about how being on the waiting list could result in or aggravate mental health issues and thought that the mental health scores assigned to a patient in a prioritisation system would need to change over time to reflect this.

> **"Mental health is huge for me, and how waiting would impact somebody's mental health."**

When considering the case studies, participants paid attention to the mental health of patients and thought it was an important consideration. Participants discussed whether or not patients were actually aware their mental health had been impacted, or whether they would have shared this with health professionals – they wanted to ensure these patients did not fall through the cracks. They noted that mental health could affect others, such as family members, as well.

> **"For me, he has been given a score of 0 [for mental health] but aren't we looking at the impact of the family's mental health as well, and whether that will have any bearing on that score."**
> **[Comment about Norman case study]**

Benefits

Overall, participants could see a number of benefits to prioritising people who are having difficulties with their mental health while on the waiting list. They were also concerned about how difficult it can be to treat mental health problems. Some participants spoke about the NHS being able to do more to prioritise mental healthcare and the need to ensure that there is an effective system in place to support patients.

> **"If your mental health is good, you're more likely to say there is light at the end of the tunnel... It is so much harder to repair than a physical issue I think, mental health can be ongoing for the rest of your life."**

Many participants discussed the potentially fatal impact of patients experiencing mental health problems and as a result they believed that the NHS should prioritise people at risk of deteriorating mental health as a result of their condition.

> **"If someone has [poor] mental health, and it pushes them into self-harm and taking their own life, the NHS is all about saving lives, so it's a big priority."**

Participants discussed how mental health can impact on a person's quality of life as a whole. If someone experiences poor mental health, other aspects of their life may begin to be impacted as well, as a result of not being able to cope. It was important to participants to provide support for patients before their mental health reaches such a point.

> **"[Mental health] has a significant impact on everything else. If your mental health is not good it changes everything. And how you are able to care for yourself and reach out for support. How isolated you may become. I'd say that's definitely important."**

Many participants also discussed how pain may impact on a patient's mental health, either directly or indirectly – for example by preventing patients from going outside, spending time with others or getting adequate levels of vitamin D.

Drawbacks and concerns

Many participants were concerned about the potential biases in identifying patients experiencing mental health problems, and whether all patients would recognise or share that they are struggling with their mental health. Participants reflected that attitudes towards mental health have changed over time but that stigma might still prevent some people from coming forward. In particular, they were concerned that some older patients may not describe their mental health in the same way as younger people, even when facing similar circumstances. One proposed mitigation was to ensure that the most potentially vulnerable patients have advocates to help them access and navigate the system.

> **"Mental health is hard because I feel that people's measurement of mental health is different. Older people measure it differently to younger people."**

There was also concern about how to capture the fact that people can experience mental health problems to differing extents. Some participants questioned whether or not everyone who experiences mental health problems has a substantive decrease in quality of life, and consequently needs prioritising.

> **"It's like pain thresholds, someone might be different, some people's tolerance to dealing with mental health issues can be different. I've suffered with mental health issues in my past, but I've got a lot of friends who are much more liable to suffer with mental health, and should they be above me just because they generally can't cope."**

Some participants were not confident that clinicians would be able to identify and gauge mental health fairly, and therefore were unsure how this would work as a factor in a prioritisation system. These participants preferred to put more weight on other factors, such as 'ability to work', which could possibly affect mental health.

There was some apprehension about people gaming the system and falsely claiming to have mental health problems. Participants considered the time required to diagnose mental health problems and were concerned that diagnosis would have to be done quickly which would make it easier to game as consultants would not be able to spend as much time diagnosing the condition and its impact as they would normally. However, the majority of participants did not want to see patients who genuinely suffer from poor mental health not being prioritised due to a minority of people who may try to game the system.

> **"You could really lie about mental health. It would be very easy."**

A few participants mentioned that prioritisation based on mental health could be dependent on the clinician's own personal lens and view of mental health. They wanted safeguards in place to ensure that the patient would not be negatively impacted by this.

> **"Everyone's mental health is important to me. I can only believe them. But it's subjective to the doctor's background as well, and how important it is to them."**

Safeguards

Most participants discussed the importance of the clinician's role in recognising if a patient is experiencing mental health problems and to ask the right questions to be able to identify this (and provide support if necessary). Some participants mentioned that questions relating to mental health may discourage some patients from disclosing any issues, due to fear or stigma, and thought clinicians should approach this with sensitivity. They also noted how mental health could change over time so it would be important to check in regularly in order to identify any potential decline.

> **"Also, someone might have no mental health issues at the beginning of their journey, but when they're struggling to practice due to pain, somewhere during that waiting process they may have problems with mental health."**

Some participants discussed the difficulty of measuring mental health, unless it leads to a significant event, such as self-harm. They suggested there is a need to define what is meant by 'significant' impact and proposed that the prioritisation system should consider additional information such as medications being taken, the risk to others, and the risk to the patients themselves.

> **"We need to be careful about judging mental health and prioritising, if you look at DWP, depression and anxiety, they don't judge it that much, if you haven't been self-harming or sectioned, they make it count lower. So, the way we'd measure mental health I think they would have to be careful."**

Participants discussed potential negative implications of clinicians talking to patients about their mental health, such as making them feel uncomfortable. Many participants mentioned the importance of a 'human' touch, when assessing mental health, so that the process is not mechanical and cold. However, they also wanted to ensure that the process was as objective as possible so that patients could be compared fairly. They wanted clinicians to understand and pick up on the more subtle and less quantifiable signs including nonverbal clues, or information about their home environment, and to record these when interacting with patients.

> **"With mental health and pain, even if you make it more objective, you're still relying on a person with 'On a scale of 1 to 10, how much does this hurt?' I'd like to understand how you could be objective. It's subjective to the person asking that question as well. How do you take the emotion out of that?"**

Participants in the last workshop discussed the fluidity of mental health and the difficulty in measuring it. Therefore, they posited that a reliable and valid tool to track mental health conditions is needed, for instance, the NHS scale of depression questionnaire. If a significant mental health event occurs or the impact on the patient (or others) is measured to be high, then it is crucial to ensure the waiting list prioritisation changes to reflect this.

> **"I would use the depression and anxiety questionnaire that the NHS normally does."**

3.6 Needing to attend A&E or GP because of condition

Overview of measure

There was variation across groups in responses to the measure of needing to attend A&E or the GP because of the patient's condition. Around half gave it a high weighting, while others weighted it lower or even gave it zero. Those who rated it highly saw it as an indicator of high clinical need and thought it was potentially correlated with pain. They also believed that treating these patients more quickly could reduce the overall burden on the NHS.

> **"For me it's partly down to resource because if he's going to A&E regularly. By dealing with him, you're taking pressure off elsewhere." [Comment about Reece's case study]**

In contrast, other groups felt that whether or not this was true, it would be too risky to have it as a stated criteria because at best it may encourage people to use A&E more, and at worse it would deprioritise those who were doing their best to manage their condition at home without putting more strain on the NHS.

Benefits

The benefits of this factor were seen by many to be self-evident. Not only would attending A&E or a GP on a matter directly related to the condition they were on the waiting list for indicate that they had a high level of clinical need, but also, by addressing the issue, pressure on A&E could be reduced.

> **"Does this not happen automatically? If you have to access A and E services, is that not an indication that your disease has progressed and naturally become higher priority?"**

Although some were concerned this would benefit those willing to shout loudest, others thought this might still be rational, given that those shouting loudest are using more NHS resources while waiting.

> **"If I look at my mum and myself. She has a high pain threshold, I don't. For the same issue, I'm more likely to go to A&E. Some people go quicker than others. Those who go quicker cost the NHS more money."**

Similarly, while there was significant concern about how this factor could be gamed (see below) others thought that attending A&E or even a GP would often require a long wait, and as such only those who were most desperate would be willing to attempt to play the system in this way.

Drawbacks and concerns

The main concern about this factor was that it could reward what people perceived to be 'bad' behaviour – attending A&E unnecessarily.

> **"Once people learn that if you shout loudest, you're likely to be noticed, that's going to create its own problem. They'll be turning up at A&E with headaches and whatever because they know it will go on their record and they'll get boosted up. Then A&E will get more overwhelmed."**

Participants thought that people who self-manage their condition should not be 'punished' for not using scarce A&E resources, and that not attending A&E did not necessarily mean a person was not suffering quietly at home. Some drew the analogy with the scene of an accident, where the paramedics might typically prioritise the quiet patients first.

> **"I'm concerned about the ones that don't go to A&E and suffer. One is screaming, one is silent, and the consultant says the silent one doesn't even have the energy to scream, they are feeling worse. Some people are sitting at home, physically they can't go to A&E."**

Fewer participants discussed drawbacks associated with patients having GP appointments related to their conditions. However, again GP appointments were seen as scarce resources that should not be abused. Also, as outlined below, people perceived there to be significant variability in people's experiences with GPs and therefore they were not convinced that the metric would be a fair one.

> **"You may get one GP that you feel you connect with and therefore you wouldn't feel bad about going to see them three times, but another one might be more officious and you might not want to go and see them."**

Some thought that this factor could be combined with admission, or that admission was a much more important indicator as it suggests the clinician had serious concerns about the person's condition.

Safeguards

This factor led to extensive debate about potential safeguards. However, even with these in place not all groups would be satisfied that the benefits of applying this factor to prioritise waiting lists would outweigh the risks.

Safeguards included:

- Not using a simple 'count' of A&E or GP visits, but instead using that visit as a chance to reassess the underlying condition and either put someone up or down the list based on their current condition / the speed at which they are or are not deteriorating.

> **"You'd have to be physically examined, and if your condition is no worse than before you can be sent home."**

- Only being prioritised if the A&E consultant believes it is appropriate (i.e. not automatic) and with detailed notes saved on the file so that the surgeon or other specialist consultant can make the final judgement about whether or not the A&E visit was clinically relevant.

> **"If someone goes into A&E and has something put on their notes, will that be highlighted with the consultant? Because they're not experts. Would they say these are my findings on the night, and they can make an assessment based on that. Maybe to you it didn't look bad, but to me as a specialist it is obvious it is."**

- Consider also taking into account a factor for overuse of A&E.

> **"They would also need to be recording what the outcome of that visit is, so if they say there was no need for them to attend, that should be in the notes."**

- Ensuring systems join up, so that wherever in the country someone attends A&E, or whichever NHS service they choose to use, this always makes it onto their hospital record so it can be taken into consideration when prioritising the waiting list.

One group suggested that a visit to a GP might have a higher weighting if the GP thought it should, based on their knowledge of the patient. However, as discussed in the section below about data collection, not everyone has this level of confidence in GPs.

3.7 Other significant impact on quality of life

Overview of measure

Just under half the groups weighted this factor highly, but a similar number gave it a low weighting and several groups excluded this factor altogether. The groups that weighted it highest often combined it with other factors including mental health and ability to work. Those that weighted it lower were concerned about the high level of subjectivity associated with the measure, and how difficult it would be to apply it fairly and without a very good understanding of every patient.

For example, when discussing the case studies one group noted that taken in isolation the description of the impact of a child's dislocated elbow seemed significant until another group member compared it with a child needing brain surgery. Another group noted in response to the case studies that quality of life should be weighted higher as otherwise people with no quality of life could be waiting a long time (in the case studies exercise, each factor was given a similar weighting to encourage discussion).

> **"Here you equalised the point system. But actually some should be weighted more than others. If you have no quality of life, you have nothing." [in response to case studies]**

Benefits

The ambiguity and broad definition adopted for this factor was perceived to be both a benefit and a drawback. For example, some thought that it would be helpful to have a factor that took into consideration people's activity levels before they joined the waiting list so that a more active person who was unable to get out would be prioritised over someone who would not be going out anyway. Most suggested the impact that is important to measure is the impact the condition is having on normal daily life.

> **"That could be even if you have someone that's really active and that was part of their life and then quality of life goes right down. That can mean lots of things, like if you can't do the sport, you normally do."**

Many groups discussed how a condition that impacts on a person's quality of life would have wider repercussions, as low quality of life could in turn lead to issues with mental health or reduced fitness, which could further exacerbate a condition. Additionally, as a problem worsened and impacted further on quality of life it could trigger A&E visits as the person becomes more desperate. They also thought that this factor could potentially capture the impact on dependants such as children or people that the patient cares for.

> **"It could be someone has one thing, they might be unhealthy, in a deprived area, but actually, having that treatment won't make a big impact, they have a sit-down job, they don't need to drive, and actually, in terms of their life it doesn't make much difference. Where someone else it could be an active young person, and all the things deprioritised them, it might have a massive impact on their life."**

Others also reflected that impact on quality of life would be a way to adjust for some people coming to the doctor earlier than others. They suggested that somebody who sought help earlier would be likely to describe a lower initial impact on quality of life and as such they would be deprioritised against someone who left it longer before seeking help.

> **"All of us want to be treated the same and fairly. However, if all of us wanted a knee replacement, if mine was I was beginning to get an ache but Kevin wasn't able to get across his room, I would expect you to go ahead of me."**

Drawbacks and concerns

The main concern about this factor was how it could be measured fairly and whether it could create perverse incentives. Specifically, people were concerned that it would encourage people to reduce their normal activities and discourage people taking proactive measures to support themselves while waiting such as receiving counselling or attending a physiotherapist.

> **"My worry is not that people will gamify the system, but that people will be penalised for proactively managing their pain. For instance, say… I see a counsellor so my mental health is better and try to be more social… and suddenly you're penalised. It doesn't mean the pain is any less or I need the surgery any less. It's just I'm proactively trying to maintain a quality of life or hold onto that."**

Other groups debated how the baseline should be set for this measure. Specifically, whether the factor should mainly focus on core activities everyone would be expected to be able to do, such as being able to feed yourself, or whether it should be tailored to reflect what the individual patient was able to do before they joined the waiting list.

> **"It shouldn't be just about quality of life, but basic functions of life. 'Can you feed yourself, can you get to the toilet?'. 'I feel really sad' versus 'I can't get to the toilet'."**

Safeguards

Participants suggested using a validated self-complete questionnaire (for example, created by World Health Organisation) to measure quality of life. They wanted it to be validated so that they could be confident it will be fair and proven to take into account cultural differences. While participants expressed some concerns about self-completion, on balance they thought it was the only practical way to collect it and that validated surveys would include checks and balances within them.

Questions should relate to different aspects of people's lives and should focus on which activities they normally do but cannot do as a result of their condition. Participants thought this would be less subjective than asking people to score themselves for the impact on their quality of life. They made comparisons with the questions that are asked to establish if somebody should be given a blue badge for parking.

> **"I think it's more like, what can't you do, while you're waiting, what are the impacts on your life? Are you still able to work, can you still take part in social activities, how is your life impacted? Is it that you can't go and see your mum once a month, or friends every day? How frequently does that impact occur?"**

Some expressed concerns that such a questionnaire would be very intrusive and were not sure that they, or other people, would want to provide that information. They were also concerned that different people would complete the survey in different ways, with some seeking to give socially acceptable answers to avoid stigma, which could lead to them being scored lower than they should be, while others would ‘play up’ their limitations in order to boost their score. To overcome this concern they suggested that a consultant who knows the patients could moderate the final score.

3.8 Length of wait (been waiting the longest)

Overview of measure

As outlined above, participants did not want to accept that patients would need to join long waiting lists and thought it is important that everyone waiting is seen as soon as possible. Most assumed that conditions will naturally worsen over time without treatment and that therefore length of wait will correlate, at least to some extent, with clinical priority.

For some, once clinical priority is taken into consideration, a queue based on first come first served was seen to be the fairest approach, and in line with people’s expectations. In some of the case studies, participants noticed information about time on waiting list was not provided and thought that this made it hard to judge who should take priority.

> **“We’re British. We queue. That’s part of the cultural heritage of the Brits.”**

Benefits

The main benefit of including a factor related to length of wait when prioritising waiting lists is that it ensures that everyone gets treated in a relatively timely manner. Participants thought it was important that the system has a built-in failsafe to ensure that even lower priority patients get seen, and do not have to wait too long. Participants thought that without such a failsafe, the NHS could not ensure people’s rights under the NHS Constitution, and that people would start to game the system if they felt it was unfair or there was a risk they would not be seen.

> **“I think length of wait is important. Maybe that's because I'm old school. You get in a queue and you wait until you get to the front and you get seen. I think that still holds. I've been on a waiting list and gone down the longer I've been on it, which is frustrating.”**

Several groups suggested approaches to capping how long people waited, for example, only prioritising between a cohort of people who joined a waiting list at the same time or putting an absolute limit on how long people can wait.

> **“You might have people waiting forever until they get treatment. There should be a limit on the amount of time people can wait.”**

One group also questioned what would happen to people who had been allocated a date which was then postponed by the hospital. They thought there should be a mechanism for prioritising these patients.

Drawbacks and concerns

If the main emphasis of the prioritisation system was on waiting time on the list, some participants noted that those who go to their GP sooner with a problem will be seen much sooner and will experience less detriment as a result. They thought that the time a patient joins the list is therefore quite arbitrary and not necessarily closely related to clinical need. As such, they down-weighted time waiting as they wanted priority given to those whose case was deemed more clinically urgent.

> **“It’s interesting that time on the waiting list is one of the lowest for us, when that's been one of the main determinants in the NHS so far. It’s just so arbitrary. It’s when you turned up and got your referral.”**

Others suggested having too much weight on waiting time would result in double-counting as many people’s conditions would deteriorate if they waited too long, and this would be picked up by the other factors.

> **"The length of the wait, at some point it would be overwritten by the very first one. If something's left for quite a while, it will get worse. From the other factors, the longer you wait, the worse it gets, the higher you get pushed up the list."**

Safeguards

Participants did not feel that it would be possible to 'game' this factor and therefore did not propose any safeguards. However, as seen elsewhere in this report, they did suggest that more active outreach should be undertaken to ensure people from all communities are encouraged to come forward early.

3.9 Unable to attend school/education while waiting

Overview of measure

Just under half of the groups gave this factor a relatively high weighting, while some ranked it middling and others allocated a zero weight. The groups that rated it highest were concerned about the long-term impact on children of missing school, while those who applied lower weightings thought that the school had a duty to provide access to learning and that COVID-19 demonstrated home learning was a possibility.

Benefits

The main benefits of this factor were threefold:

- Not being able to attend school is considered a good indicator of a 'serious' condition which is likely to be significantly impacting on all aspects of a child's life.

> **"If you can't go to school or uni, it's got to be a certain level of seriousness."**

- Additionally, the specific fact that a child cannot attend school is concerning for some, especially as children have already lost opportunities to learn as a result of the pandemic. Some thought that even a short period off school could be damaging, which in turn could have longer term impacts on the child's future career and even their ability to relate to others. They were not convinced remote learning could address these concerns.

> **"If it's keeping them out of education, that's got to go high up on the list, especially post-pandemic when their education is already suffering."**

- Some were also concerned about the impact on working parents if children could not go to school as somebody would have to stay at home to look after the child.

Some also considered the impact on students and compared studying with going to work and suggested both should be equally weighted.

Drawbacks and concerns

Others were less convinced by the importance of this factor. Some thought that children could be successfully home-schooled, especially for shorter periods, and that it is the responsibility of the school to ensure they continue educating the child, rather than the NHS.

> **"There's a system called ECOS – Education for Children Outside of School, where they can educate kids in a bubble for any reason, at home, online."**

They also suggested that the impact of a child being off school would be much lower than the impact of an adult on a zero-hour contract not being able to go to work.

Some participants also raised concerns about whether adults who were taking evening classes, or even students with part-time jobs, might end up getting 'double points' as a result of this factor.

> **"That could be an adult in education…. Where you could be missing education and work and getting double points for it."**

Safeguards

The main safeguard that participants proposed was for the NHS to speak with the school who would know the individual child and their family circumstances. They thought this would be a good way to collect wider contextual information which might be helpful.

> **"You have to have that conversation with the school, you have to know if it's already impacted on their attendance already, is that getting worse, is it bringing in other issues. Schools are a wealth of information."**

3.10 Unable to work while waiting

Overview of measure

Being unable to work while waiting was one of the most debated factors, with just under half of the groups weighting it relatively highly, while the remainder gave it little or no weight. For some groups this was because they merged this factor with the patient's ability to attend school or volunteer, or because they wanted to tie it more explicitly with the impact on household income.

The case studies led to further discussion about how this factor could work in practice. For example, for the child with a dislocated elbow some thought that the impact on his mother's ability to work was perhaps the most pertinent consideration. Others noted that unpaid care did not appear to be valued by this factor (or by society at large) but should still be considered work.

Benefits

Those who thought this factor was important identified the following considerations:

- For many participants, being able to work (or not) has a direct link to quality of life. This is particularly true if the person's income is reduced to statutory sick pay or lower if they do not work. It could also be exacerbated if the person is the primary breadwinner for a household.

- Some expressed concerns about whether or not a job would be kept open for someone who could not go to work while on a waiting list, particularly for those on zero-hour contracts or who were in probation for a new role.

> **"It's the long-term impact we're not thinking about. Particularly on the work side of things, if they can't work until they have a procedure, they might lose their job, their house. You've got that direction that could spiral into a worse situation which will put pressure on the NHS in other ways like mental health, or the local council with housing."**

- Being able to work was seen to link to self-esteem and good mental health.

- Some mentioned particular concerns about the self-employed, or small businesses where the business owner was the one waiting for treatment. In both cases, they thought there was less of a safety net if the person could not work.

> **"My husband is waiting for an operation on his knees. He has his own business and has 20 people working for him. If he's not there, they won't work either. He's delayed it because if he took time off, then they don't work."**

- Sometimes ability to work might not be directly related to clinical considerations. People may not be able to work while waiting, even if clinically their condition might not be considered very severe. Equally, they may not be able to work despite not being in pain. For example, if someone needed the toilet regularly or could not stand up for long periods. For those who thought ensuring time out of work was minimised, having 'not able to work' as a separate factor was therefore valued.

> **"There are lots of symptoms that could stop you working that are not painful."**

Drawbacks and concerns

Participants' main concern about this factor was that the financial support available for people who cannot work can be variable. Specifically, some people might be able to take time off work for many months on full pay, while others might receive nothing or the statutory minimum. Both would qualify for being 'unable to work' but one would have a much more difficult wait.

> **"Depends on what effect that has on your quality of life. If you have an employer who's supporting you then that's not a factor. It only becomes a factor if you need to come back to work because you're a breadwinner or whatever."**

For some people, the idea of taking type of work into consideration raised concerns about fairness and potential discrimination. These participants preferred to revert to clinical factors only to prioritise.

> **"There should be no discrimination. We should look at their condition. Let's say they suffer from a severe disease, that person should have a shorter waiting time. You don't want people that are healthier to also be waiting. There should be limits. And no discrimination. I don't think work should be considered here."**

A particular concern about this factor was the impact it would have on certain groups – effectively deprioritising pensioners for the fact they were able to retire, or disabled people or full-time mums (or carers) for the fact they may not be able to work. Participants thought that pensioners had paid their taxes and should be entitled to the same level of service as those still working. Equally, just because a person happens to be unemployed or not employed when joining the waiting list, this should not necessarily count against them.

> **"What if you have an elderly patient that is in severe pain? You are prioritising the person who can't work over someone in absolute agony that is older and doesn't work."**

These concerns about potential discrimination also related to job types. Some noted that those with manual jobs might be more likely to be impacted and commented that this could become an alternative route to adopting means testing as manual workers might typically be paid less and would be likely to get priority. Generally, people did not support means testing (see section on income below).

> **"I am just thinking we could end up sailing close to means testing on this and I would say the NHS needs to be careful because that would get a lot of negative press."**

Some were also concerned that it might be difficult to assess whether someone was fit for work. They noted that some people will drag themselves to work, even if they probably should not, while others will seize the opportunity to avoid work if they can. Equally, some suggested there is nothing in the system to verify that what someone tells the GP about their job is accurate.

> **"If you wanted to game the system, you could just say you do manual work. If you had a bad knee or hip, it would put you up the priority list."**

Safeguards

Many of the safeguards around using inability to work as a factor for prioritising waiting lists related to how supportive the employer is and ensuring that information is updated as the person continues to wait. Some suggested changing the question to whether or not the person's ability to earn an income is impacted by the wait.

> **"What if you have an understanding employer at the outlet, then your sick leave runs out? Then they make you redundant. How do you notify the NHS of that change in circumstance?"**

Participants suggested a GP might be better placed to judge whether a person should continue working, rather than asking the patient. They thought this would help overcome the challenge identified above of some people over-estimating and others under-estimating their ability to continue to work.

> **"Could the GP be asked to provide a view on whether the patient cannot work at all with the condition and therefore this would necessitate a higher priority. So, it might mitigate against a person reluctant to give up work for whatever reason… Whether the person chooses to work or not it doesn't matter, it's the GP saying in his clinical opinion they think it would be detrimental to that person's health if they chose to work."**

Some suggested it was important to understand if the person was the primary breadwinner, while others thought that people make different contributions to households so the knock-on impact of the secondary income might be larger than it might look on paper.

One group suggested merging this category with whether the person works for the NHS and using a scale to measure it rather than a binary yes/no measure.

3.11 Carer for a relative, friend or neighbour

Overview of measure

Nearly all the groups included this measure in their final design, although in all but two groups it had a relatively low weighting compared with the other factors. Few disagreed with including it as a factor, but there was some concern about how to define 'being a carer' fairly, and whether it should include formal care, or care for any dependants including children.

> **"…If they can't care for the person they're caring for, you've then got two people on the waiting list. The person they're caring for may then need medical intervention."**

When discussing the case studies in the final workshop, several groups noticed that in the example provided, being a carer no longer gave people increased priority, and felt that was an omission.

Benefits

Participants reflected that both formal and informal carers are important because of the knock-on impact that their inability to care has on those around them. Some reflected it was similar to the need to prioritise NHS workers, as if they cannot work then it puts more strain on other parts of the system.

> **"If my mum were not there to care for my dad, my dad would be in a home. He depends 24 hours on my mum. I could say I give him lifts to the hospital when he needs it. It might deserve a higher weighting depending on the level."**

Some suggested a more nuanced approach would be helpful, prioritising carers for people who are bedridden or who cannot function without their carer, and circumstances where the person on the waiting list is the sole carer. Others wanted to widen out the definition to include anyone who has someone dependent on them, potentially including parents, although others disagreed. They noted that while it could be appealing to use data about Carer's Allowance to verify whether someone was a carer, in many cases the role would be more informal so this would miss out people who are still playing an important role.

> **"When my mum was dying, I was a carer for my mum. That was only a short-term thing because she was very ill with a very aggressive cancer that went from nought to 70 within a month, so I was never registered as a carer."**

Drawbacks and concerns

As discussed above, participants were unwilling to use metrics that excluded informal carers, but they were also concerned that, without robust measures in place, the system could easily be gamed.

> **"If we're talking about the gamification side of things, saying you care for a friend is very easy to say. It is important, but easily gamified."**

One group thought that a high proportion of people (up to seven in ten) are carers and as such were concerned about the impact that could have on the priority list, as many people would be able to claim they had some caring responsibilities. Another suggested there are agencies who can provide care if the primary care giver is not able to and noted alternative care would be required when the person went for their operation anyway.

> **"In terms of carer, I think we'd have to have quite a tight definition on what that is. It's very different if you're a sole carer or sometimes getting some shopping in for the neighbour next door."**

Safeguards

The difficulty identifying carers was a tension that participants were unable to resolve, with some groups concluding the only efficient but fair approach would be to prioritise registered carers.

> **"It's difficult because if you're not getting Carer's Allowance, then it's your word against anybody else's."**

However, others suggested that for cultural reasons some families might not register as carers, thus leading to an unintentional bias entering the system.

> **"We [Indian families] don't let our parents, grandparents, go live in a home. We care for them. For example, my sister has my father living with her. She doesn't claim money to care for him. She sees that as her duty. She wouldn't be on the register."**

3.12 NHS worker who is unable to work while waiting

Overview of measure

A couple of groups weighted this factor relatively highly, while most attributed it a little weight and a few attributed none. Those who allocated more weight were mainly considering the resource constraints within the NHS and saw this as an effective way to get NHS workers back to work. In contrast, others thought that NHS workers are not the only key workers and thought such a decision would reflect badly on the NHS.

> **"It just feels wrong that if you're working for an organisation that is an organisation for the people, about equality. Then just because you work for them, you get bumped up. It feels wrong."**

Benefits

Participants generally thought that one of the reasons that waiting lists are long is due to lack of staff. Therefore, for some participants anything that could be done to get people back to work would be worthwhile, including bumping them up the waiting list. This was particularly true for roles seen as 'crucial' to delivery, including surgeons.

> **"NHS workers should be prioritised, the less of them we have, it makes a huge problem for the whole system."**

Drawbacks and concerns

However, while for some the benefit of prioritising NHS workers was self-evident, many felt uncomfortable with the idea that it would mean that they could 'jump' the queue, just because of their role, and thought this could be perceived to be favouritism. This was particularly true because some believed the NHS sick pay package is generous compared with many employers.

> **"Some people are more important than others they said, like if you work in the NHS should you go up the list because you need to get up the list, but supermarkets are front line workers too, everyone is as important as everyone else. We live in a democracy."**

Participants were keen to emphasise the difference between a surgeon and a porter or cafeteria worker. All do important jobs, but some are much more easily replaced, and therefore less important to prioritise. Some also suggested that care workers are not employed by the NHS but also have a significant impact on the health and care system overall.

> **"With carers and people who often get ignored, they don't work for the NHS but their jobs are just as important. It says caring for a relative friend or neighbour, but it doesn't say 'caring as a job'. That front line worker, regardless of whether they work for the NHS or not, should be in that for me."**

Safeguards

As noted above, if this factor was adopted, people would require assurance that only vital NHS workers who cannot easily be replaced would be prioritised.

> **"I get why it's there, but also what do you class as an NHS worker – someone who sweeps the floors, or someone who's on frontline services. The NHS is a huge organisation."**

3.13 Age

Overview of measure

While most groups attributed a low weight to age, none attributed a high weighting and only a few attributed zero weight. However, groups spent time debating how to use age in prioritising waiting lists, with some suggesting that it should only be used to separate adults and children, while others thought it could also be used to prioritise people within the adult list.

> **"We obviously judge our humanity and our progress on how we look after our old people as well as our young people. I find it hard to put the others in order."**

The case studies helped to bring these decisions to life, with participants noting that the working age adults would get 'points' for not being able to work, while retirees would be disadvantaged unless their age was considered. Some thought that the child case study helped clarify that a condition in a child should be given priority over the same condition in an adult due to the potential long-term impact on the child. However, others thought children were more resilient and could heal quicker so may not require priority on a list.

Benefits

Some thought that older people might find a condition more debilitating than someone younger in a similar situation and as such they thought the older person should be prioritised. They suggested that without priority an older person might become isolated and lonely due to their condition which in turn could impact on their mental health.

> **"If it's going to be really debilitating because of their age, then it should be a factor but if not, it should be the same as everything else."**

Equally, they were concerned that older people might have fewer healthy years left to enjoy so time is of the essence.

> **"If you're enjoying the last years of your life and your enjoyment is taken away by issues caused by a condition, it's unfair that you're on a waiting list for two years and can't enjoy the last years of your life… they've paid into the NHS their whole life. "**

However, others thought that while it was important to prioritise children over adults, prioritising by age of adult was not necessary. There are economic reasons for prioritising younger adults, but fairness led many to suggest that older people should not be deprioritised due to their age.

> **"I understand that the economic burden of Covid will be carried by younger generations, but you can't discard how much the older generation has paid in."**

Reasons for prioritising children included that the time spent on a waiting list would feel longer and could result in them missing more than an adult waiting the same amount of time. Also, as children are still growing and developing there was some concern that a long wait could be detrimental to their physical and mental development which could be long-lasting.

> **"For me, if there is a child on the list, that should be given priority. Just because from a few years from now, that will have a massive impact on the rest of his life. If it's not caught now and he ends up with a health condition for the rest of his life he's going to cost the NHS a lot more in the long term that getting him in and fixing him now."**

Drawbacks and concerns

The main drawback was that, as outlined above, groups could not agree which age group should receive priority and were worried about 'discriminating' based on age.

> **"You look at an elderly person compared to a child, as you were saying earlier, a child's got his whole life ahead of him. But why should the elderly person suffer in their later years? When life is already closing down. They deserve to be looked after and helped."**

Even the idea of prioritising children over adults was not consistently supported.

> **"I don't completely agree that it's always going to be children over adults. I don't think that every child should take precedent over an adult in all scenarios. It's a subjective thing. It'll be different. With certain conditions, you might still be able to go to school. But an adult might not be able to go to work and lose their job."**

A few tentatively questioned whether the oldest patients would need treatment or would benefit from it, although they recognised this would be contentious and were not proposing that older people should be taken off the waiting list.

> **"You could say why does a 96-year-old need a knee replacement if he's not going up Snowdon."**

Safeguards

Participants did not suggest many safeguards as they could not agree which age groups would be prioritised and did not think that people could 'game' their age. A few expressed concerns about children becoming adults while on the waiting list and the importance of ensuring they did not lose their place in the queue when this happened.

3.14 Ethnic group (from a minority ethnic background)

Overview of measure

One group thought that ethnicity was important while most attributed it a few ‘points’ and a few gave it zero. People did not necessarily understand spontaneously why a system might want to prioritise different ethnic groups, and even when possible reasons were given, not everyone thought that the NHS waiting list was the right place to seek to address racial inequalities. As such, for some people there was a tension between what they thought should happen in an ideal world, and what must happen given the world we live in.

> **“It’s hard because for this to even not be a factor, which I think should be in an ideal world, we need to understand why it’s made this way in the first place. Why is ethnicity a thing, a factor?”**

Benefits

The main benefit was perceived to be addressing health inequalities and supporting people from different ethnic groups to achieve better health outcomes. Those who offered their support reflected that people from different ethnic groups could be starting at a disadvantage and that by prioritising them on the waiting list this could potentially be mitigated.

> **“Half of my family is black. I’m really hyper aware of how badly they are affected by struggling through the healthcare system. I feel like if you are a person of colour then you have probably struggled at some point, they should be prioritised to make sure their needs are being met.”**

However, people were concerned that access might not be the only reason that outcomes are worse and were keen for the NHS to spend time in communities to understand what is driving the discrepancies and ideally address them earlier on.

> **“I think it can be important, but you need to speak to the ethnic groups and find out what they need, not just assume that they have greater needs.”**

For some, the priority for these communities should be time limited, while the NHS addresses the more fundamental issues around access and experience which are impacting on outcomes.

> **“If the problem is about them accessing care in the first place, if we can use the waiting list to balance some of the challenges people are facing, that would help. If we prioritise them, we are making a more level playing field. While the system is broken, we should consider those from minority ethnic backgrounds and deprived backgrounds. They should be bumped up the list.”**

Drawbacks and concerns

Although some people could see the benefits, many felt uncomfortable with this factor and thought it would be hard to ‘sell’ to the wider public.

> **“I’m not sure why the ethnic group would be there. It’s almost like we’re discriminating, I don’t know if it’s negative or positive.”**

Some thought there were better proxies for identifying people who need to progress quicker on the list, which they thought were already captured elsewhere in the approach. For example, they thought that factors including clinical priority and having related conditions might lead to people who visited the health service later receiving the priority they needed.

> **"If we're talking about giving points for a priority list, it should be more about how other factors that are already being considered like how advanced is a disease, I feel like all that is already considered."**

Ultimately, most participants did not believe that prioritising people from ethnic minorities would improve the system. They were uncomfortable endorsing positive discrimination in this way and thought it could lead to division or tension in communities if people thought that particular ethnic groups were being prioritised as a result of their ethnicity.

Safeguards

As with other demographic factors, this was not perceived to be at risk of being gamed and no safeguards were discussed.

3.15 Lifestyle factors (e.g. diet, smoking, drinking)

Overview of measure

This factor caused confusion as some groups interpreted it as meaning people with unhealthy lifestyles would be prioritised as their prognosis might not be as good or their need for treatment might be more urgent, while others assumed it would be those living 'healthy' lifestyles who would be prioritised.

> **"I don't know if they mean if you smoke you should go down the list or up the list. Is it if you're more unhealthy you'd go through quicker? Is it to do with health inequalities, because in deprived areas you're more likely to have issues? Would it go up or down?"**

Fewer than half of the groups gave lifestyle factors any weighting. The only group to give it a significant weight grouped it with mental health and other impact on quality of life as they thought lifestyle factors could be exacerbated by being on a waiting list a long time. On balance, most concluded lifestyle factors should not be included, unless the patient's current behaviour would be very detrimental to the outcome of their surgery.

> **"Personally I don't think it's a reason to not go ahead, unless of course their lifestyle is going to severely impact the result of that procedure and it's not a good thing for them to go through it anyway."**

Benefits

Some participants argued that the benefit of considering lifestyle factors would be that people who were working actively to look after their health would get priority and this would encourage people to live healthily.

> **"Not to say they're not deserving of healthcare, because everyone is. But just to say if there are two people on the list with exactly the same condition, and one's condition is worsened by lifestyle factors which they 'choose' – 'choose' I put in quotes because, if they use them as coping mechanisms, it might not really be a choice… I wouldn't see why they should get higher priority than the person who's doing everything right."**

In other groups, people reflected that these factors could be a symptom of someone suffering, and that the behaviours would lead to worse outcomes in the long term. Consequently, they considered whether people who smoke, drink or who are obese should receive higher priority, although often included this would be unfair on those who make an effort to be more healthy.

> **"That seems grossly unfair. That if you're a non-smoker, you'll get deprioritised opposed to someone who smokes."**

Some suggested lifestyle factors should only apply where they are directly relevant to the reason someone is on a waiting list. For example, people awaiting knee or hip surgery might need to lose weight, while someone awaiting a liver transplant should stop drinking.

> **"If you're waiting for a joint replacement and you are obese or excessively overweight, you are actively encouraged to get rid of some weight before the surgery. But that's more of a common sense that they want the surgery to be successful."**

Drawbacks and concerns

The main concerns about this factor relate to whether or not participants believe drinking, smoking and being obese are a choice. Most believed there could be things outside someone's control which influence their weight, and suggested drinking and smoking could potentially be a coping mechanism for people in pain.

> **"I think it's too complicated. There are so many cultural economic factors into how someone eats… I was a nurse… We had people dying of cancer next to alcoholics because they had 'done it to themselves.' They were equally ill. It's always more complicated. It's self-medicating. I think it's a dangerous place to be going."**

Others thought that excessive drinking or smoking could be driven by local culture, and that a consequence could be that using lifestyle factors could unfairly discriminate against people from certain backgrounds.

> **"It's always important to take into account the social and culture aspect of it. In Britain drinking is a big part of the culture. For example, someone who has grown up in an area with a pub, it's very much deeply engrained into you, where you have other places where you have grown up with a small glass of wine with dinner, it's very different."**

People felt that attributing scores relating to lifestyle would be 'judging' the patient and did not feel comfortable with it. They also commented that it would be easy to game, and that many people regularly lie to their GP about their weekly alcohol intake.

> **"Maybe I'm biased because my mother is a smoker, but I'd hate for that to be an influence on her suffering longer. Addictions are not something people have chosen. It's something they physically cannot help… If they have some sort of joint issue or back pain due to an injury, how is that relevant?"**

Safeguards

Ultimately, most groups concluded it was not obvious whether to prioritise people with or without the specified lifestyle factors and therefore they thought that neither should be included. However, they did propose that the NHS should be providing support to enable people on waiting lists to become or remain healthy.

> **"I think the lifestyle factors should be included but only to the extent of, is that going to impact the success of the operation."**

3.16 Live in a more deprived area

Overview of measure

The suggestion that patients could be prioritised by taking into account the level of deprivation associated with their postcode generated a high level of consternation within the groups. The reason this might be included as a factor was not immediately obvious, and even after the benefits were set out by experts, people felt uncomfortable with the mechanism.

One group allocated this metric a relatively high weighting as they valued the argument that it would lead to fairer outcomes. However, fewer than half the groups allocated any weight at all. Some noted that even labelling an area 'deprived' was potentially unhelpful.

> **"The problem I have is it's a generalisation. It's probably mostly true, but not all the time, so it makes me feel uneasy. People will get missed out and some will get prioritised more than they should be."**

Benefits

Spontaneously most participants did not see any benefits to this factor. However, after listening to the experts and discussing the issues in depth, some came to the view that it could be a mechanism for achieving more equal outcomes.

> **"But we are not equal. People in deprived areas should be given a higher priority because they have already been neglected and so they have a lower chance."**

Participants did not necessarily think that the waiting list was the right place to be addressing inequalities but suggested that it might be necessary in the short term and in the absence of other levers.

> **"I think we need to be putting quite a bit of weight on the deprivation element. I know in the chat it has been something that has been contentious, but I have read around it and think I have my head around it now. It is not just about length of life and stuff like that, it is about how well you will recover and what support you will have… What you're trying to stop is someone being ill for a longer length of time, just because they've sat on the waiting list for the same length of time."**

Drawbacks and concerns

Discussion about this factor mainly focussed on concerns. Key issues were:

- The perceived unfairness of a 'postcode lottery' where the accident of where you happen to live could impact significantly on how quickly you are helped. At its worst they thought this could lead to a 'two-tier' system and discontent between those people living in affluent areas and those from deprived areas.

> **"If they start to base it on postcodes, that's unfair, because that is not what they're about. That's not what the NHS is supposed to be about. Everybody, everybody in a fair manner."**

- Concerns that using postcode would result in over-generalisations where more affluent people living in more deprived areas could be given an unnecessary boost, or people scraping by but living in an affluent area might be down-weighted despite having a low disposable income. They were particularly concerned about new estates where affordable housing and high value properties could be next door to each other, or people who had lived in the same area for a long time, while property became more gentrified around them. Fundamentally, participants suggested data such as household income would provide a more accurate picture of family circumstances.

> **"I think when you're looking at where you're living and say they are going to have less life expectancy, I suppose you can't generalise that much. You can live in quite a nice area but live in a very difficult living situation. I think that should be taken into consideration, but it should be more down to individual circumstances, not just about whether they live in East Green."**

- Some participants explored whether aspects of life in deprived areas could exacerbate problems for people on a waiting list, and as such might justify them being given a higher priority. However, while they could think of some examples where this might be relevant, in most instances they did not see why deprivation would be relevant.

> **"If two people who need a knee operation. I'm trying to work out how deprivation would have a factor there. I see how pollution has a bigger impact for a lung disease. But certain operations, like tonsilitis, orthopaedic surgery, the deprivation doesn't work for everything."**

There were also some more general concerns about the idea of using deprivation as a measure. Most were not familiar with the index of multiple deprivation and, even when it was explained to them, thought it was not a particularly relevant measure on which to make healthcare decisions. Some questioned whether people living in deprived areas were necessarily as disadvantaged as the statistics suggest:

- Some suggested that inner city areas might be classed as more deprived, but patients might have better access to health services than those in rural areas where public transport might be limited.
- They also noted that people do not necessarily work where they live so if deprivation led to health issues as a result of air pollution, this might not apply to everyone living in the area.
- One group questioned whether lower life expectancy in more deprived areas was due to high rates of teenage deaths (e.g. due to knife crime) which would significantly impact the average, even though most people continue to live into old age in the same way they do in affluent areas.

Where groups accepted that there might be a correlation between deprivation and health outcomes, they still expressed concerns about using deprivation in any weighting.

- Some feared that deprivation could lead to similar issues as school catchment areas – rewarding richer families who can afford to rent a property with the right postcode for just long enough to achieve priority on the waiting list. However, others thought this was unlikely.

> **"If you can afford £10k to move house to get a lower waiting time, you can afford to go private. It just isn't a life choice people will make."**

- Others suggested that the issues in deprived areas would not be solved by prioritising people on a waiting list and instead these were bigger issues that should be addressed by government rather than the NHS. They suggested the NHS might work to promote access but would prefer information campaigns over a process that would prioritise some people over others because on average they were less likely to present early.

Safeguards

Overall, participants thought that other factors would ensure that someone who arrived at the GP later and in more need would be seen more quickly, and as such they suggested deprivation might duplicate these other factors which were perceived to be fairer at an individual level.

> **"…[will] the impacts of, for example, living in a deprived area, push them up on other ratings? For example, if they're in a manual job and can't attend appointments, will they hit more things on other weightings because of the effects of that?**

As most groups did not propose that deprivation carried any weighting, they did not suggest further safeguards for this factor.

3.17 Unable to volunteer or work in local community while waiting

Overview of measure

Although some groups reflected that they would 'like to' attribute some weighting to this factor, in reality no groups decided to do so. The factor had limited perceived benefits.

> **“I understand that's really important for the organisation they volunteer for, and the person themselves, for their life, but I’m not sure that should really take a huge weighting.”**

Some groups thought that this measure would be subsumed into others, such as ability to work or having a role as an informal carer. They also suggested not being able to volunteer could impact on quality of life and mental health scores.

> **“We said that work in the local community, if it’s delivering a food shop to an elderly person, that counts as a carer for a neighbour.”**

4 Additional suggestions

Over the course of the workshops, participants discussed a number of additional factors that could be considered. Some were included and given weights in the prioritisation exercise, while others were considered and then rejected. Both sets of factors are outlined briefly below.

Suggested and included	Suggested but not included
Measures that aggregate multiple factors together of those already discussed	Income
People who have no support network	Failure to engage / missed appointments
Prognosis / recovery time	If waiting for a procedure or operation which can be performed by the NHS quickly and/or with minimal resource
Impact of waiting on condition	Children in household
Pain level	
Access to transport, support, interpretation	
No salary / negative financial impact	

4.1 Suggested and included

The following measures were proposed and were included in the final output of at least one of the groups.

Aggregate measures

Due to concerns about double-counting outlined above, some groups decided to merge some of the factors and attribute an overall weighting. Commonly this included grouping the use of NHS services metrics (admission/readmission, use of A&E, use of GP), or the quality-of-life measures (quality of life, mental health, ability to work/be educated/volunteer).

People who have no support network

In the context of discussions about prioritising people with dependents, some groups considered the needs of people who have no support network around them. They thought that these patients would be more isolated and consequently more at risk than others on the waiting list. Therefore, a couple of groups gave this factor a small weighting in their final model.

> **"Whether they have someone to support them or not, because isolation is a huge killer as well."**

Prognosis / recovery time

Some groups discussed including consideration of the patient prognosis and likely recovery time within the prioritisation tool and allocated this factor some weight. The topic often arose during discussions of the case studies. However, others discussed and then dismissed the idea. Even among those who wanted to give it some weight, it was unclear whether quick wins or preventing high usage of services was the priority.

> **"But then there is an ethical dilemma. If someone has months to live and they are terminal, should they be prioritised over somebody who has a good chance of being cured? It's like rescue workers. It's a brutal decision, but it has to be done."**

Some groups wanted to prioritise the operations that had the greatest chance of success. However, they realised this could be controversial as they did not want to see the NHS refusing to treat any patient for whom there was a potential treatment, even if it was not likely to work.

> **"If someone has a very high likelihood of surviving the procedure and making a good outcome, then it makes sense to prioritise them over someone who in all likelihood is going to pass away during the procedure. I know that's quite contentious, but it's probably something that all healthcare systems worldwide have to think about."**

A few went further and also wanted to take into consideration details about the patient such as their likely compliance with the necessary rehabilitation and post-operation medications. Again, they explained they wanted to prioritise the operations that were most likely to succeed.

On balance, if two patients were similar and joined the list at the same time but one would take longer to recover, some suggested that the person with the longer recovery time should go first so that they could start their recovery and the time at which both patients were 'back to normal' would be similar.

> **"The person taking longer to heal should be seen quicker…they recover around the same time, which seems fair."**

Others pushed back against the idea that prognosis or recovery time should be considered. This was particularly common amongst those familiar with conditions which could benefit somewhat from treatment, but for which there is no cure. They were resigned to the fact that surgery would not make them 'better' but thought that it was still important they kept their place on the list.

> **"It would be horrible if someone didn't tick the right boxes because all aspects of their health weren't considered. Someone could actually lose the opportunity to be treated because they are not fit to be treated because of the length of time they wait."**

Equally, some expressed concern that because older people are perceived to heal less well, they might be deprioritised if prognosis was taken into consideration – an outcome that they were not necessarily comfortable with.

> **"Why, just because you are perhaps older or your operation is more complex, why should you be treated differently from someone else?"**

Impact of waiting on condition

Often people discussed the impact of waiting on the condition alongside the prognosis.

> **"I work in maintenance. When we prioritise maintenance tasks, one of the things we look at is it getting worse quickly. Then we deal with that quickly."**

This was less contentious and where it was raised most groups agreed that if a person's situation would decline while waiting, they should take priority over those whose problem was stable. Equally, if waiting longer could also result in a longer recovery time (e.g. due to muscle wastage) they wanted to ensure these patients were seen more promptly.

> **“Is there somewhere on there that mentions how likely the deterioration in your condition is? If someone waits for six months for one thing, it will be a bit worse, but six months for another thing will be really bad. The deterioration and the timeframe.”**

Prioritising those whose conditions would otherwise decline was seen as a pragmatic approach as it would minimise the demand on the NHS in the medium to longer term. Therefore, participants thought it would be important to monitor patients on the waiting list to identify quickly if somebody’s condition was deteriorating.

> **“You also should look at the prognosis as well. Certain operations, if they take place sooner, mean there won’t be further intervention.”**

Pain Level

A few groups discussed the importance of considering pain levels, although many decided to reject this as a metric as they were unsure how the measurement could be objective.

> **“It’s also about pain threshold. If you are asked about your pain on a scale 1-10, you might class it as a six and to somebody else it might be a nine.”**

There was disagreement between participants about whether this mattered – some thought that people likely to be experiencing similar pain levels should be treated equally, while others thought that the patient self-reporting higher levels of pain should be prioritised due to the likely impact on mental health and quality of life for people who are in great pain. Some suggested the GP should have a role in allocating points based on this metric so that it was fair.

> **“How do you measure pain? If you said me and my mum, she can handle a lot of pain and I can’t. That's something that could be gamified.”**

Some were concerned that people from different backgrounds could report pain differently. Some communities, or older people in particular might be less willing to ‘complain’ or to rate their pain appropriately, while others might exaggerate their pain or might be able to describe it more eloquently in order to be given priority. Others expressed concerns that patients working hard to minimise their pain could be deprioritised, creating a perverse incentive not to help themselves too much.

> **“What I found was when I went to these pain clinics, how different people’s approaches are to manage their pain. I do anything to manage my own pain. There are people in the room who don’t do anything to try and help themselves.”**

Some noted that prioritising pain is important because it is the humane thing to do. Additionally, they reflected that chronic pain can have other impacts including reduced mental health, so if untreated it could lead to increased burden on the NHS.

> **“You can become totally isolated because you can’t go outside because you are in too much pain that it could affect your mental health, and there is a developing pyramid of other aspects.”**

Access to transport, support, interpretation service etc

In the workshops, the experts explained how access issues (whether physical barriers or issues with support) could impact on outcomes. Therefore, one group proposed that people with more limited access to transport and support could potentially have a higher weighting, to overcome the potential detriment resulting from their circumstances.

No salary/ negative financial impact

This factor was related to ability to work but some participants thought it would be more robust and useful. Specifically, it would ensure the NHS focussed its efforts on those who would suffer genuine financial detriment while waiting, rather than those who could not work but were at home on full pay.

> **"You might still be getting a full wage. That needs to be captured. Unable to earn, rather than work."**

Some groups also thought greater weight should be given for a 'primary breadwinner' who could potentially be seen as more important. However, others thought this was a false distinction as the second income might not be significantly lower, or the individual might be looking after their children so that their partner could work.

Having no salary was seen to be detrimental on both the individual but also their health outcomes. The most obvious impact would be struggling to pay bills etc., but equally participants noted that this would then have an impact on quality of life and mental health which in turn could impact on the success of the surgery.

> **"The recovery time will also be affected by the mental worry of money. If they're stressed, the body isn't getting the rest it needs."**

However, for some the concerns raised about being able to work applied equally to a factor relating to not having a salary. Specifically, they did not see it as the role of the NHS to plug issues created by a perceived inadequate benefits safety net.

> **"I have some doubts about having a waiting list which is affected by people's income and expenditure and lifestyle. I think the whole ethos of the national health service is that everybody would be treated equally and get equal service, which is what I'd like to see."**

4.2 Suggested but not included

The following factors were suggested in discussion but not included in the final prioritisation systems.

Income

In the first workshop, the case studies led to a lot of discussion about what should happen to patients who could afford to receive care privately. While everyone was in agreement that the NHS should be available to everyone, some thought that people with more money could potentially be encouraged to go private (for example, by making it clear how long they are likely to wait, or potentially even by deprioritising them).

> **"Everybody is entitled but it's that, when the pile of food is a certain size, who gets the food? The people who need the food the most. If you're not hungry you don't need to be in the queue. In the simplest terms. It shouldn't be that way. Everybody should have a right to it all. But it is that way. We don't live in an ideal world do we? The pandemic has ensured that medically the NHS is at breaking point."**

However, on reflection, many were concerned that if higher income families felt forced to take the private route they might object to paying for the NHS. If this happened, some feared the NHS could quickly deteriorate and become more like the American insurance-based model.

> **"I'm kind of uncomfortable with it [considering income] to be honest… if we have a national health service, then it should be for everybody. I really worry once we start… where does that stop and how do we not end up like America if we go down that route?"**

For some participants this came back to fairness and ensuring everyone has access to healthcare when they need it.

> **“If we're trying to make things fair, the same way we wouldn't want lack of money to disadvantage somebody, we wouldn't want having money to do it either.”**

Failure to engage / missed appointments

Some participants thought that if people appear not to prioritise their own health the NHS should not do it for them. Specifically, they thought that if people fail to engage with support while they are on the waiting list such as physio or pre-habilitation, or if they missed appointments, that the patient should be deprioritised.

> **“Anything that can get down the list or reduce the waiting list, the better. I think if they say there are people on the waiting list missing appointments or are rearranging all the time, then they don’t see their own issue as a priority. It would be good for the NHS to recognise that and not give them operation dates they keep cancelling.”**

However, others raised concerns that people might have good reasons for missing appointments, including not being able to take time off work, or not understanding the purpose of screening, and suggested it would be wrong for the NHS to penalise them further due to factors outside their control.

> **“You don’t know why people aren’t engaging and I think you have to be really careful there, otherwise you’re just wiping out a group of people who aren’t engaging for a number of reasons. It might be they can’t read the letters, or they could be moving about.”**

Some noted a difference between a missed appointment where the patient has been in contact to explain or cancel in advance compared with a ‘no show’. However, some gave personal examples that demonstrated how missed appointments could be a reason to prioritise rather than deprioritise a patient.

> **“If you don’t attend, you’re taken off the list. It’s happened to me many times… I struggle to attend because I’m too tired, or I got confused about the days… You get, you didn’t attend, you’re off, go. The opposite should happen. People should be concerned rather than telling you off.”**

Others thought it would depend on the reason for the cancellation but that if someone was desperate to have surgery, they would cancel a holiday if it meant they could have the procedure.

If waiting for a procedure or operation which can be performed by the NHS quickly and/or with minimal resource

Some groups initially suggested the NHS might choose to prioritise procedures or operations which were ‘quick wins’ so that it could see it was making progress. Also, by doing this they thought it could potentially prevent some people declining further and thus save resources later.

> **“If you do time management training, they always say deal with the quick wins first and get them out of your way.”**

Others suggested that the easier, quicker surgeries which require less inpatient care should be completed in winter where resources are more stretched.

However, for some people, perhaps due to the examples given in the case studies, a ‘quick win’ was associated with treating otherwise healthy patients who were not experiencing much difficulty while on the list, and who therefore might not be the priority.

Children

Finally, some groups proposed considering whether a family has children in the prioritisation factors. This was because a parent being out of action would ‘impact on multiple lives’. One group noted that whereas there is government support if a disabled person’s carer is unavailable, there is no support for a parent in a similar situation. However, on balance groups concluded that having dependants (whether children or adults) should probably not be weighted in the final model as it would be unfair on those who were alone, who might also struggle.

5 Views on data collection

How to collect the data on which patients on an elective care waiting list would be prioritised was a recurring theme throughout participants' discussions. This section explores the key questions, concerns and reflections of participants on the topic.

5.1 How data should be collected

In the course of the discussions, the following elements were considered to be important:

- The system must be simple and cost-effective to implement. It should not divert resources (time or money) from the teams addressing the waiting lists.
- Detailed data should be collected by the hospital when the patient is referred (potentially using a self-completion questionnaire initially, although the data provided must be validated). Participants would prefer this work was done by somebody with clinical training, although it would not have to be a GP or consultant necessarily.
- It was seen to be important to minimise subjectivity in the data collection by considering carefully which metrics to use and how they can be implemented. Some also suggested that at least some of the data is manually validated and others suggested that patients should be able to see their own data and provide evidence for amendments where necessary.
- The approach should build a rounded picture of the patient and the impact the surgery would have.
- The data collected should be reviewed regularly:
  - To ensure the data being considered is up to date
  - To check for any unintended consequences and refine if necessary
- The data collection should also be used to signpost people to other services which might be useful to them while waiting.

As outlined above, people had different views about whether a computer or a human should make the final decision about the priority order. This question was not resolved during the workshops, although there was a strong preference for a hybrid approach as outlined in Section 2.6 above.

Quality in data use, linkage, access, and management in the NHS throughout the research, a considerable concern was whether the NHS systems are equipped to handle this level of sophisticated prioritisation, given that important decisions will be made based on the data.

> **"You won't interrogate each person's circumstances as we are doing now [in the case studies]. Even with the limited information, it is still difficult, and we are saying we need extra information and nuances. This is going to go into a machine and a machine will churn out a number which won't give you a holistic picture of that person's circumstances. I think this has to be the biggest consideration if this is implementable or not, because the quality of the data is critical. If you don't have all the information, then what you are going to churn out isn't going to be of high quality."**

The main concerns were:

- **The potentially high cost of collecting data**: participants were unsure if this investment would be worthwhile, especially if resources are limited and could be spent on working through the waiting list more quickly. They struggled to identify the best person to collect the data and thought that some important factors, such as mental health, would not necessarily be captured in existing notes.

"If we're going to use all this extra resource to try and sort it out and it's not going to reduce this waiting list, it's just going to rearrange it, is it worth it?"

- **The additional cost of verifying the data:** where participants were concerned about patients playing the system, they expected some checks to be put in place to ensure the information being used is accurate. However, they realised this might not be straightforward to implement. Consequently, some prioritised factors where the data would already be verified (e.g. from NHS systems, from other government departments including benefits claims, disabled blue badges or tax returns etc). Others thought that this concern came from exaggerated media stories, and that in reality it would not be a widespread issue.

"It is a human condition to see how we can trick the system, but I don't think it happens as much as we think. If you look at benefit fraud, it's as if everyone is doing it, but the figures are 0.1% of claims are fraudulent. It's so tiny I think it is unlikely."

- **The importance of ensuring the system is dynamic:** participants wanted assurance that the system would update if somebody's condition changes, or if they are diagnosed with a different condition which could compound the issue they are waiting for treatment for. Similarly, if someone manages to quit smoking or loses/gains weight, this should be updated and taken into account. They struggled to see how this would be achieved.

"I think [it needs] a three-month check-in. My father-in-law is 79 and waiting for a hip replacement. In the last three months he's gone from walking normally to walking with a stick. Now he's out and about in a wheelchair, he's lost weight and is waiting for an operation. He's losing weight quite quickly because he's in so much pain. In those three months his condition has worsened so much."

- **Ensuring fairness in the assessments:** participants suggested that the patient rating scales should be explained in detail and scores pre-defined to ensure that they are applied consistently by the people inputting the data. They also wanted checks and balances in place to ensure that people do not under report or exaggerate their needs as they thought this could distort the system.

"I worry that a lot of this depends on what you say to your doctor. My grandma won't say things to a doctor that she should. That makes me worry."

- **Minimising the invasiveness of the assessment:** some were concerned that questions such as the impact of their condition on their quality of life might feel overly invasive for some patients. They suggested some people might be unwilling to share this information because of concerns about who it could be shared with or how it could be used.

"I think a lot of people are very afraid. As soon as they start opening up, they're afraid they'll say something wrong or get deprioritised."

- **Improving NHS data flows:** participants were concerned to learn that not all interactions with the NHS are held in one place and therefore available to support prioritisation. They were frustrated that using a walk-in centre or a hospital across a boundary line could mean that their experience was not visible to support prioritisation.

> **"What about if you go to a different trust, since I go to a hospital in Stourbridge, they have no records from Coventry. But one of the consultants works in Stourbridge, so they wouldn't capture that data at all."**

> **"I think data sharing with the NHS should be a first priority. You can live in Coventry but you can travel to Cornwall, what if something happens to me in Cornwall? If you want to take care of the health of the people you have to know everything about them no matter where they are."**

- **Ensuring data is accurate:** participants were concerned that errors in the data could have serious ramifications for the individuals involved. They thought there was a risk data could be entered quickly and that checks would be vital to ensure errors are minimised. Some participants wanted the opportunity to check their own data to ensure it was accurate.

> **"Without sounding rude, seeing the quality of the NHS' data, I would not be happy with them prioritising me based on it."**

5.2 The role of GPs

Most people thought that GPs would play a role in the prioritisation process. Some people had a good relationship with their GP and thought their involvement would be helpful, but others described having no relationship and issues with access which led to concerns if the GP could influence how quickly they would be seen. Some noted that accessing GPs had become particularly difficult during the pandemic.

> **"Lucky people like me, who is on a name-by-name basis with her doctor can get an appointment in three days. My sister sometimes waits months. How is that fair?"**

Some wanted GPs to be involved as they thought they would be well placed to evaluate whether people were describing their circumstances accurately. However, others had previously found their GP to be dismissive and consequently were concerned that their assessment might not be accurate.

> **"If the GP is the key point of referral, you could be in extreme pain and have a GP that is dismissive."**

One of the speakers noted that the level of detail in GP referrals could be highly variable. Participants were not surprised by this as it reflected their personal experiences but were concerned if it could impact where somebody would be placed on a waiting list.

> **"I believe there was an article in the news not that long ago… where people who are registered at the same GP surgery, have the same GP for a year generally end up with better healthcare outcomes because the GP knows a lot more about their background. Whereas someone who has just moved into the area or moves round quite frequently doesn't get that kind of benefit because they change GP so often."**

Participants also talked about the potential for GPs to introduce bias into the process if they did not have clear guidance on how to score the criteria. Specifically, they suggested a GP might have a better rapport with some patients than with others, and that this could impact on the scoring. However, others thought that GPs are professionals and trusted them to do their job.

> **"It'll sound negative but GPs have different personalities. Some are more receptive to the social determinants, and some are just not willing to listen. If it's GPs inputting the data, there will be a real disparate quality to the data."**

Finally, participants expressed concerns that GPs could be manipulated to move particular patients up the list. For example, participants suggested that if someone on the waiting list continually calls their GP for an update or to request priority the GP might agree to push them up the list in order to stop the patient calling. They were concerned that this would be very unfair and would effectively be rewarding ‘bad’ behaviour.

> **“My guess was what a lot of people probably do, which is phoning and phoning until the doctors get so fed up with them and want to get them out of the way. I know a lot of people who do that.”**

The perceived high level of variability led some to suggest that patients of GPs which are difficult to access should potentially be given priority over those who have GP practices that are easier to access, although this idea was quickly dismissed. Another group discussed whether the patient themselves could send supporting evidence if they did not believe their referral accurately reflected their situation.

> **“I wondered if it could be possible to send supporting evidence that all these concerns aren’t considered because I'm concerned, if they go to the doctor and they're busy, and they don’t take in everything, and there’s not much of a rapport, they put you on you can wait at least a year but actually there’s a lot of things going on.”**

6 Wider context

While out of scope for the deliberation, there were other important considerations participants raised for the NHS:

- Measures to reduce the length of the waiting list more quickly
- Information about the length of wait
- Providing support to people on the waiting list
- Improving access to the waiting list and other NHS services

These are outlined below.

6.1 Measures to reduce the length of the waiting list more quickly

In the early workshops, some participants were resistant to the idea of prioritising the waiting list as they did not feel that this was the priority. Rather, they wanted to talk about ways in which the NHS could reduce the waiting list more quickly, including by hiring more staff and by making better use of existing resources.

> **"I realise that this is short-term, but I don't understand why the NHS is not working on a long-term solution. To find more people to work for the NHS to make it better."**

While it was not the focus of discussions, a range of solutions were proposed including:

- Using private care providers or Nightingale hospitals to expand capacity in order to work through the backlog.
- Improving staff retention and discouraging or preventing NHS staff from also taking on private work or going overseas.
- Extending hours so that operating theatres do not lie empty at evenings and weekends.

> **"Theatres are sat not being used most nights. You have a lot of expensive equipment and theatre that could be used better. You can have surgical teams working throughout the night, maybe on less serious cases."**

- Improving efficiency and reducing time wasted. Several participants offered examples of visits to hospital that had not gone smoothly (for example, because appointments happened in the wrong order or test results were not available) and which consequently wasted the time of the patient and the consultant.

> **"Could resources be used smarter? Normally you go and see the consultant, who says you need an MRI. Then you go back to the consultant who says yes you need a hip replacement, and then you go back again. Is there any way to free time up?"**

- Encouraging staff to move between hospitals, so that resource is 'shared around'.

Some also suggested that doctors should be more open to recommending alternatives to surgery including physiotherapy, social prescribing and investing more in preventative care. This would reduce the number of people waiting and so would ensure that cases where surgery was essential would be seen quicker.

> **“Social prescribing, is that what they call it? That’s what they’re trying to get you to do now anyway. Operations should be a last resort, which really it is.”**

Most people did not appear to blame the NHS for the current situation, but nonetheless wanted to see it addressed as quickly as possible. Fundamentally, they did not believe that changing the order of people on the waiting list would have much impact, not least because by moving someone up the list somebody else would move down.

> **“You’ll still have the same problems. I don’t think this will resolve much.”**

6.2 Information about length of wait

Recognising that waiting lists would not be improved overnight, many also reflected on how people’s experience of being on a waiting list could be improved. Most thought that it would be helpful to have updates and know (approximately) where you were on the waiting list.

> **“I think for me, personally, if I were in one of the shoes of these people, what would help me would be more transparency of where I am in the waiting list. That's one thing from my experience. You see your GP. You're triaged by them. There's a clinical triage. Then it sort of goes into a black hole, and that's where I struggle.”**

They noted that any waiting list will be somewhat fluid, depending on who else needs help and how urgently, but thought that it should be possible to give some indication of how long a person could expect to be waiting – even if that is a date range rather than a specific month. They suggested patients can use this information to help them prepare, including getting childcare arrangements in place or discussing leave options with employers. They also discussed the mental health impact of not knowing, and the stress it can cause.

> **“If you’re told how long you're going to wait, you can manage that. It may be depressing, but at least you have an end date. If you don't know how long you’re going to wait, that’s worse.”**

However, as patients get towards their expected operation date, participants were concerned that their position could jump around and they might drop down the list which could be very frustrating, so they noted this would have to be carefully managed.

> **“It’s a benefit to know where you are, but it could be detrimental if you find out you’ve gone backwards in the list. It’s a double-edged sword.”**

6.3 Support while on waiting list

Finally, participants wanted to see more support for people on waiting lists.

They suggested more could be done to make people aware of services which could improve their quality of life while they wait such as physiotherapy, symptom management workshops or support with eating a better diet. Some thought this could be a good opportunity to address other lifestyle factors which otherwise would go unaddressed.

> **“I think there are a range of issues in those scenarios. They’re not limited to prioritisation. A lot is about community awareness, knowledge, other support like physiotherapy, nutrition. There are other support mechanisms to address.”**

They also wanted people to receive help to access financial support, such as advice on claiming benefits, to mitigate some of the impact on people who cannot work while waiting. One group suggested there was precedent for this because of the support given to people who had to isolate due to COVID-19. Doing this would take the burden off the NHS to prioritise those who might experience financial hardship.

> **“Perhaps it needs to be stepping back from that prioritisation and looking at the support given to the people who need the operations. There was a lot of support for people who had to isolate from COVID. There needs to be something where sick packages are looked at, and they are supported to take part in the waiting list.”**

6.4 Improving access

Throughout the workshops, participants were encouraged to consider the social determinants of health and whether they were important considerations in waiting list prioritisation. While most disagreed with this approach, they nonetheless expressed concerns that different communities have different health outcomes. Consequently, they emphasised the importance of ensuring NHS services are available to all, including providing translation services, flexible appointment times and potentially outreach services to support people to seek help.

> **“With some people, especially with Asians and the black community, for most of the old people, it’s difficult for them to express themselves when they come to the GP and the hospital. Sometimes, they call the GP or the NHS and they’re being asked, ‘Go to the website. You can book the appointment from there.’ These people find it so difficult. So if they don't get the help, they feel like, ‘Let me leave it.’ They feel like they’re being ignored because of the communication barrier. What do we do for them?”**

7 Conclusions and recommendations

In conclusion, participants' views about waiting list prioritisation are very mixed. Fundamentally, participants would prefer that prioritisation was not necessary and ideally everyone would be seen quickly - even if this means allocating more resources to the NHS to allow this to happen, noting that the feasibility of this or the source of additional resources were not discussed. In the absence of this, the factors on which patients on an elective care waiting list could be prioritised with most support related to clinical considerations. Most wanted to see the people in most clinical need treated quickly. They expect that clinicians will be well placed to make these judgements and were broadly comfortable with the proposals suggested, as long as work is done to ensure that they do not have unintended consequences.

Participants were introduced to the concept of prioritisation and introduced to different evidence from experts to support discussion and deliberation, as well as being given the time and space to consider the overarching question of whether prioritisation should be undertaken on the basis of variables other than length of wait. A range of specific possible criteria for elective waiting list prioritisation were presented for discussion, but were iterated by participants, who added some of their own criteria and refined the interpretations of those provided.

The majority of participants feltthat if the collection of data about patients on the factors involved in the prioritisation could be done efficiently, and if the metrics could be made fair (avoiding discrimination and/or bias, for instance), that an enhanced system of waiting list prioritisation would be preferable to the existing system. However, they did not underestimate the difficulties in doing this and encouraged sufficient monitoring and oversight to minimise the risk of any unintended consequences.

Moving beyond clinical and resource considerations, some were more comfortable than others with including additional factors in an attempt to improve the current system. However, they were very alert to potential limitations or risks associated with incomplete data or unanticipated bias which could be introduced by the selected factors. For example, while for some prioritising the primary breadwinner if their income would be reduced felt like it could be important, others were concerned this could result in working age men being prioritised over women or retirees which did not feel fair. Broader categories such as 'quality of life' or 'mental health' felt more comfortable than demographic or social factors, but participants wanted to see careful thought given to how this could be standardised and collected fairly.

With regards to the factors discussed and deliberated, previous admission/readmission and related health conditions were seen as the most important prioritisation measures. Disability, mental health impact, healthcare attendance, quality of life impact and length of wait were also favoured. Participants were less comfortable attributing weight to a range of factors including ethnic group, lifestyle factors, deprivation and impact on volunteering or community working. It was particularly evident that factors relating to a specific individual on the waiting list (such as number of readmissions that individual had), were preferred to population-wide or group-level factors (such as ethnicity or deprivation).

Whichever approach the Trust adopts, it is vital that it is carefully monitored for unintended impacts. This would include checking how radically people's position on the waiting list moves as a result of the scoring, and whether this feels intuitively right when reading their notes. Equally, it will be important to check for systematic biases impacting people with different protected characteristics. Ultimately, people put their trust in the NHS to treat everyone fairly and to prioritise getting people better, and as such the system will come under a lot of scrutiny if people feel that it is biased towards particular groups of people, whoever they might be and no matter whether the intentions were good.

There was some debate in the workshops about whether the NHS should be transparent about how it prioritises waiting lists. Some thought it would be vital to be transparent that additional factors are taken into consideration, so that people realise the importance of keeping their data up to date and understand why they are being asked for additional information. Also, not sharing the information could be interpreted as 'hiding' it. For some, this included giving people an opportunity to review their own prioritisation and the data sitting behind it. However, others expressed their concerns that too much transparency could make it easier for people to game the system.

Ultimately, more work is necessary to develop a standardised scoring criteria for the chosen factors to ensure the approach is fair, regardless of who a patient's GP is or how forthcoming the patient is with information. Once up and running the system should be simple and straightforward to run, as while the input data might be complex and messy, resources are precious and so a compromise will be necessary. Over time, it will be important to be open to developing and adapting the approach as the consequences are observed. It might also be possible to make it more sophisticated – for example, using different factors depending on the type of surgery required.

8 Next steps

As highlighted throughout the report, participants shared a range of suggestions to improve the waiting list prioritisation tool's considerations going forward. Potential next steps based upon the views of participants cited throughout the report can include:

- **Increasing awareness within GP practices of the practicality of targeted communication** with patients, asking them questions that address various barriers they may face, such as with income, education or mental health that may provide a more comprehensive idea of how patients could be ranked on a waiting list.
- **Taking initiatives to connect patient data via IT** between GP practices, hospitals and other medical providers so that practitioners have a complete view of patients when deciding where they could fare on a waiting list.
- **Allowing for flexibility on the waiting list, where circumstantial factors could be taken into consideration** towards prioritisation.
- Piloting waiting list changes, based upon existing research and then **the NHS Trust commissioning an evaluation of the new changes made,** to see what is working and not working and what additional changes may need to be made.

Appendices

Appendix A: Recruitment Sample

The recruitment agency was requested to recruit participants to the below quota specification.

<table>
<tr><th>Demographic</th><th>Quotas (minimum)</th><th>Rationale</th></tr>
<tr><td>Gender</td><td>Male: 20
Female: 20
We also recognised that not everyone self-defined in a binary way and adjusted accordingly.</td><td>Reflective of the broad gender split across the UK and in Coventry and Warwickshire, we recruited for a broadly even 50/50 gender split</td></tr>
<tr><td>Age</td><td>18 to 39: 17
40 to 59: 17
60+: 16</td><td>Recognising the importance of the difference in age groups across Warwickshire (predominantly older age groups) and Coventry (predominantly younger age groups) we have sought to strike a balance in ensuring that a range of ages are reflected in sampling.</td></tr>
<tr><td>Ethnicity</td><td>Asian/British: 7
Black/British: 6
Mixed/other: 5
White British: 32</td><td>Coventry is an ethnically diverse city, with around one-third (33%) of the population from minority ethnic groups compared to 20% for England as a whole. The largest minority ethnic group are Asian/Asian British communities, making up 16.3% of the city's population, including 8.8% with an Indian background. In contrast Warwickshire’s White British population is approx. 88.6% (2011). We sought to reflect the need for a diverse sample by sampling for approx. 33% minority ethnic participants</td></tr>
<tr><td>Experience with waiting lists for health services</td><td>Currently or have prior experience of being on a waiting list: 10</td><td>Recognising that approximately 10% of the population are currently on a waiting list, we have sought to ensure there is adequate representation of those who are either currently or have prior experience of being on an NHS waiting list</td></tr>
<tr><td colspan="3">Urban: 17
Rural: 16
Market town: 17
Approximately 20% of the population of Coventry and Warwickshire live in rural areas. However, recognising the importance of adequate diversity, we recruited from across a range of areas including agricultural locations, towns such as Leamington Spa, and cities such as Coventry.</td></tr>
</table>

Socio-economic demographics (ONS social grade classification), based on education, income and occupation:

AB (Higher and intermediate managerial, administrative, professional occupations): 8
C1 (Supervisory, clerical & junior managerial occupations): 12

C2 (Skilled manual occupations): 8
DE (Semi-skilled and unskilled manual occupations, unemployed and lowest grade occupations): 12

Reflective of the broad range and distribution of social grades across the West Midlands region, aiming to ensure diverse representation by employment status.

Appendix B: Workshop stimulus materials and design

Workshop 1

Prioritising Coventry and Warwickshire's NHS Waiting List

Workshop 1 - Tuesday 29th March (18.00 – 21.00)

Introduction to the team

Note takers

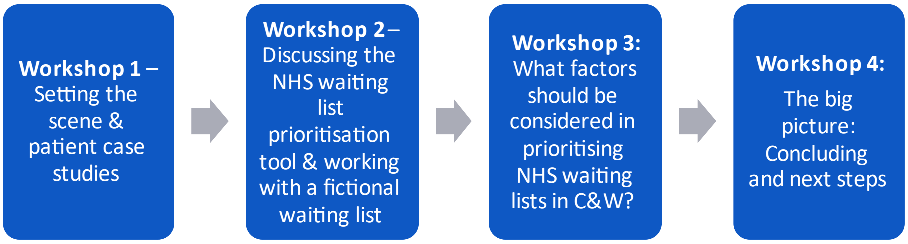
You! 50+
Coventry and Warwickshire residents

NHS Coventry & Warwickshire staff

Specialists

Ipsos moderators

Observers



Workshop 1 – Setting the scene & patient case studies

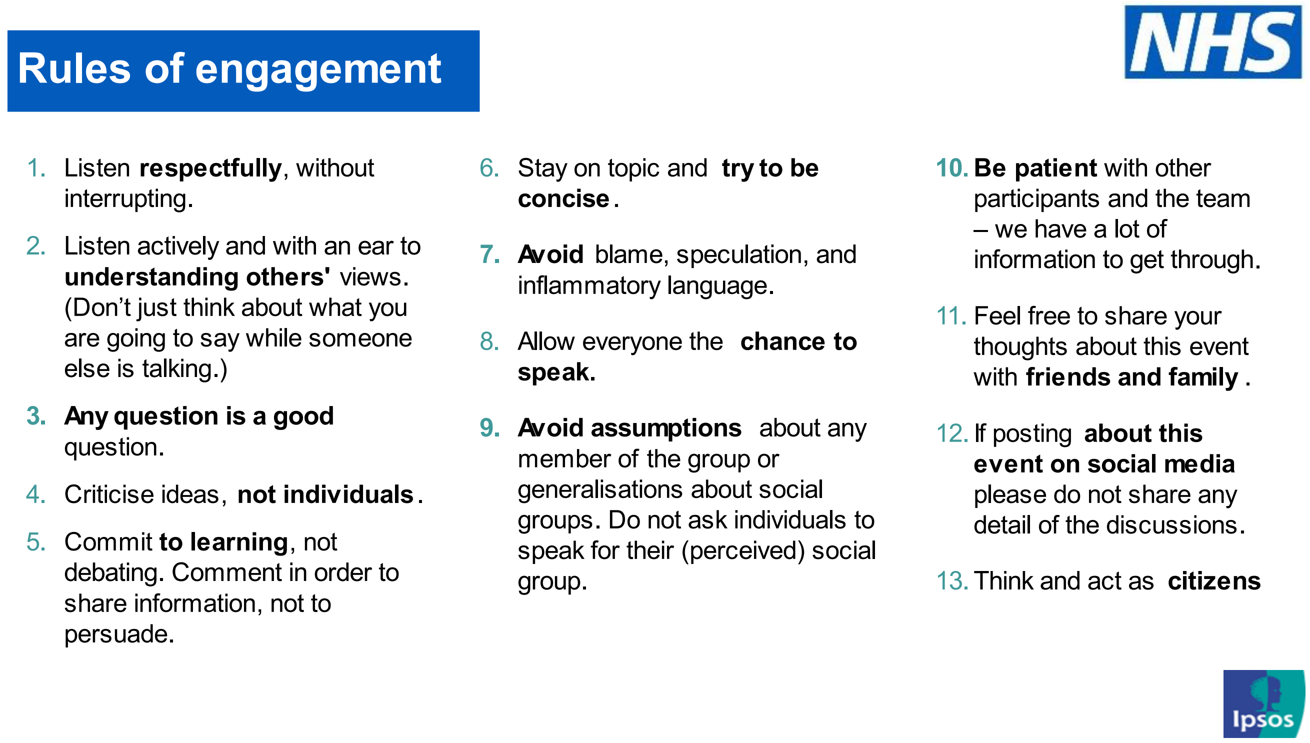
Workshop 2 – Discussing the NHS waiting list prioritisation tool & working with a fictional waiting list

Workshop 3: What factors should be considered in prioritising NHS waiting lists in C&W?

Workshop 4: The big picture: Concluding and next steps

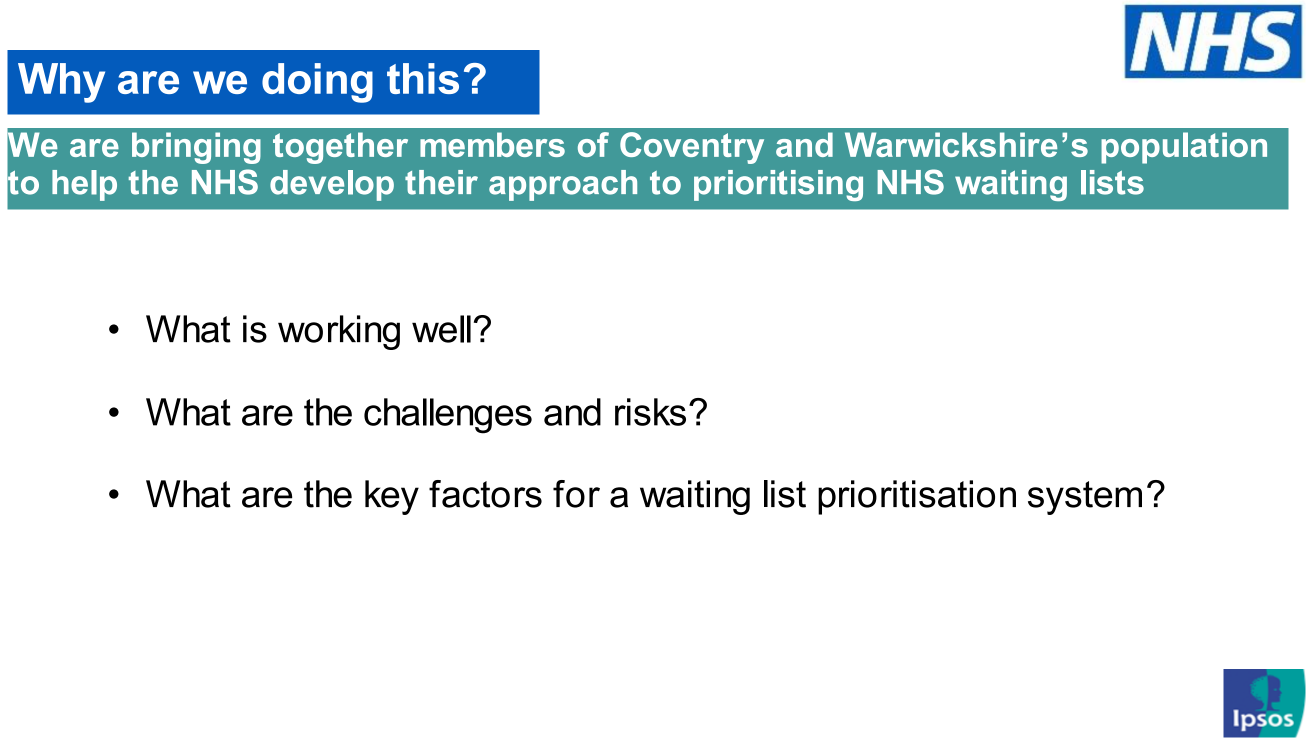
House keeping

- Recording and note-taking
- Confidentiality
- This is online – we get there'll be some distractions, it's ok!
- Quotes in final report, no attribution
- Respect each others' views and be polite
- Do try to stay focused (multitasking discouraged)
- Where possible, turn your video on (although of course there may be some technical issues, in which case we understand!)



Rules of engagement

1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. **Be patient** with other participants and the team – we have a lot of information to get through.
11. Feel free to share your thoughts about this event with **friends and family**.
12. If posting **about this event on social media** please do not share any detail of the discussions.
13. Think and act as **citizens**



Why are we doing this?

We are bringing together members of Coventry and Warwickshire's population to help the NHS develop their approach to prioritising NHS waiting lists

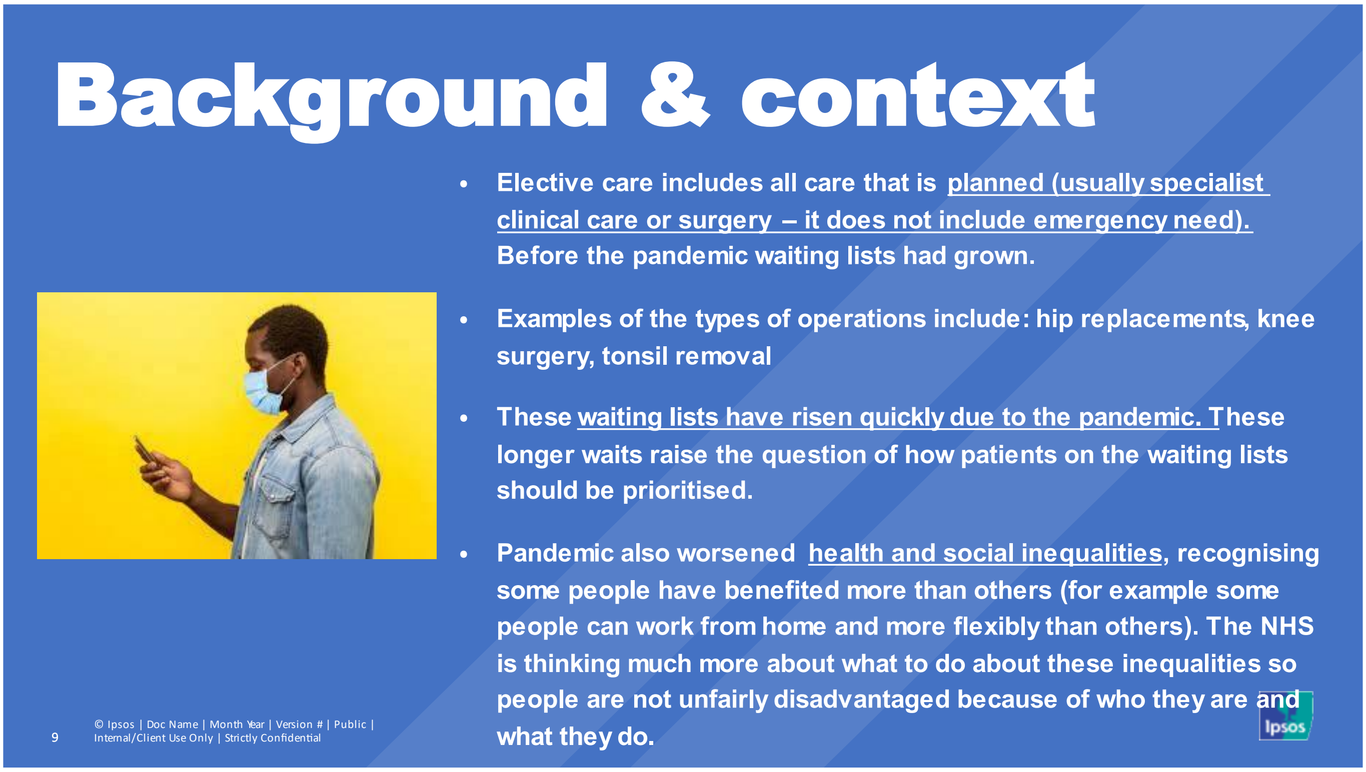
- What is working well?
- What are the challenges and risks?
- What are the key factors for a waiting list prioritisation system?

This evening's agenda

Time	Objectives
6.00pm - 6.10pm	Welcome and introductions
6.10pm - 6.20pm	**Presentation – NHS Waiting Lists and Inequalities – Rachel Chapman, Consultant in Public Health**, NHS University Hospitals Coventry and Warwickshire Trust
6.20pm - 6.40pm	Group discussions – Your initial reactions
6.40pm - 6.50pm	**NHS Waiting Lists Prioritisation -** Presentation – Dr Dawn Adamson Clinical Lead for ACHD and Obstetric Cardiology Services and Consultant Interventional Cardiologist , NHS University Hospitals Coventry and Warwickshire Trust
6.50pm - 7.05pm	**Q&A with Dr Dawn Adamson & Rachel Chapman**
7.05pm - 7.15pm	Break
7.15pm - 7.25pm	**Patient Experiences -** Presentation – **Dr Dawn Adamson,** NHS University Hospitals Coventry and Warwickshire Trust
7.25pm - 8.00pm	**Group Discussions about the Patient Case Studies**
8.00pm - 8.10pm	Break
8.10pm - 8.55pm	Plenary and Q&A
8.55pm - 9.00pm	Thank you and close

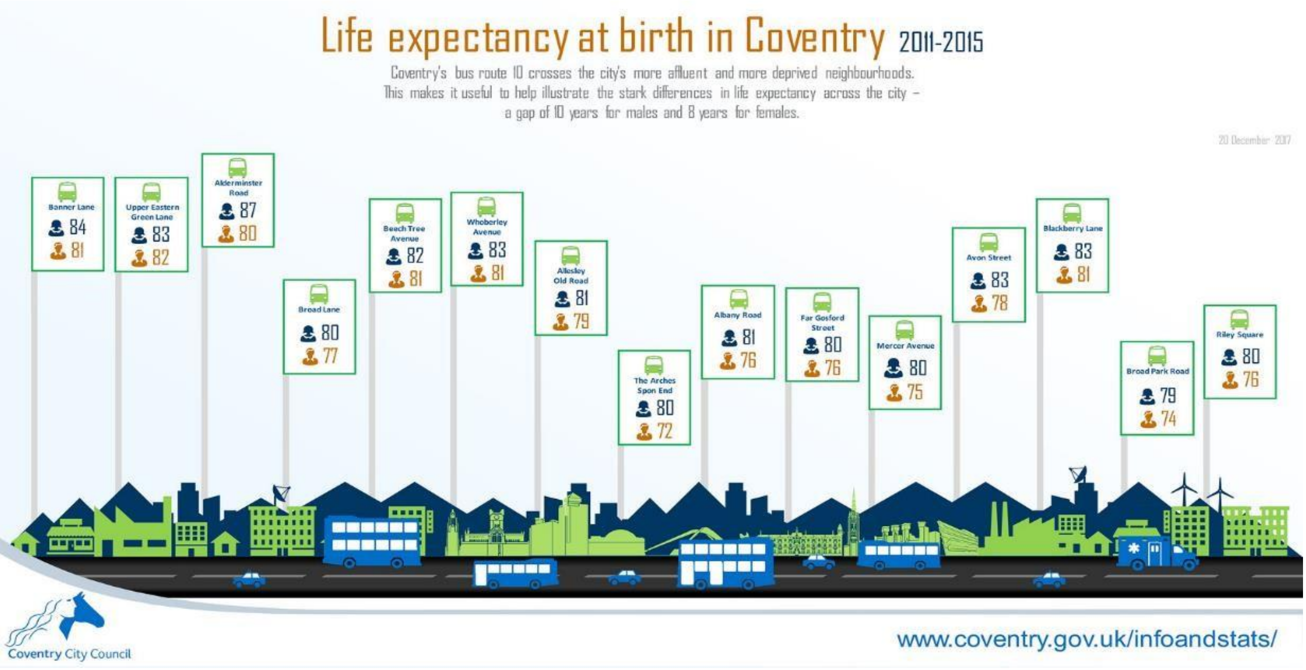
Presentation: NHS Waiting Lists and Inequalities

Rachel Chapman, Consultant in Public Health, University Hospitals Coventry and Warwickshire NHS Trust and Coventry City Council



Background & context

- Elective care includes all care that is planned (usually specialist clinical care or surgery – it does not include emergency need). Before the pandemic waiting lists had grown.
- Examples of the types of operations include: hip replacements, knee surgery, tonsil removal
- These waiting lists have risen quickly due to the pandemic. These longer waits raise the question of how patients on the waiting lists should be prioritised.
- Pandemic also worsened health and social inequalities, recognising some people have benefited more than others (for example some people can work from home and more flexibly than others). The NHS is thinking much more about what to do about these inequalities so people are not unfairly disadvantaged because of who they are and what they do.



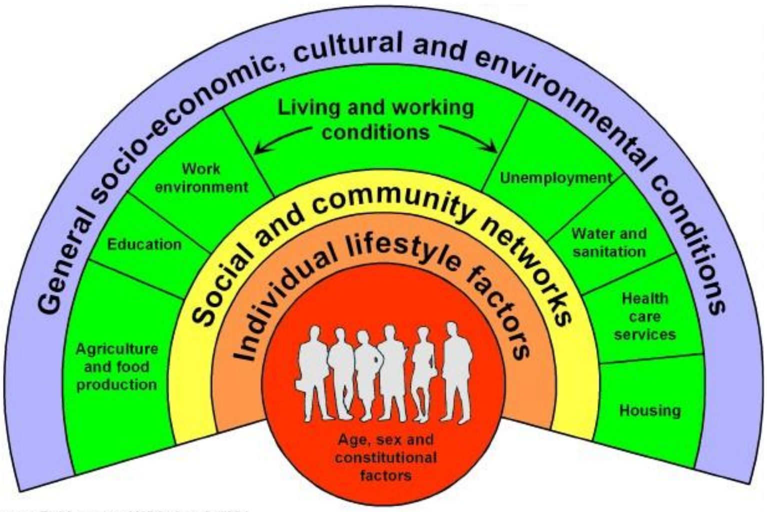
Life expectancy at birth in Coventry 2011-2015

Coventry's bus route 10 crosses the city's more affluent and more deprived neighbourhoods. This makes it useful to help illustrate the stark differences in life expectancy across the city – a gap of 10 years for males and 8 years for females.

20 December 2017

www.coventry.gov.uk/infoandstats/

What affects our health?



Source: Dahlgren and Whitehead, 1991

2 buses and a 20min walk to hospital appt

Limited English language, frustrating interactions with Drs

Multiple medications for different conditions

You only had to ask

What people with multiple conditions say about health equity

A report from the Taskforce on Multiple Conditions, July 2021

Unclear advice, missed appointments

Visual impairment, sent letters

Mixed sex physio sessions

THE TIMES

The trouser takeover

What the style set are wearing

Would you pass the couples' test?

Johnson pins hopes on summer reshuffle to cement position

Tories push PM to act faster on waiting lists

Numbers must fall before next election, MPs warn

Yoo-arr very welcome: tips for farmers to be less rude

DAILY EXPRESS

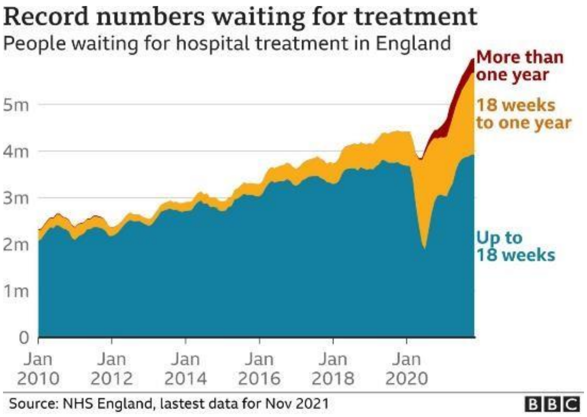
BRITONS LEAD THE PACK FOR OSCAR GLORY

Fury as BP fuels flames with £5.6bn profits

RESCUE PLAN TO 'BUST COVID BACKLOG' AS WAITING LISTS GROW

SHOCKING: 10M MISSING OUT ON NHS CARE

Adele, a smash hit at the Brits



Record numbers waiting for treatment

People waiting for hospital treatment in England

Source: NHS England, lastest data for Nov 2021

The Problem: Waiting lists fuel inequality

William from Warwick

GP at first symptoms
No comorbidities
Physio

Waiting List Time 18 weeks

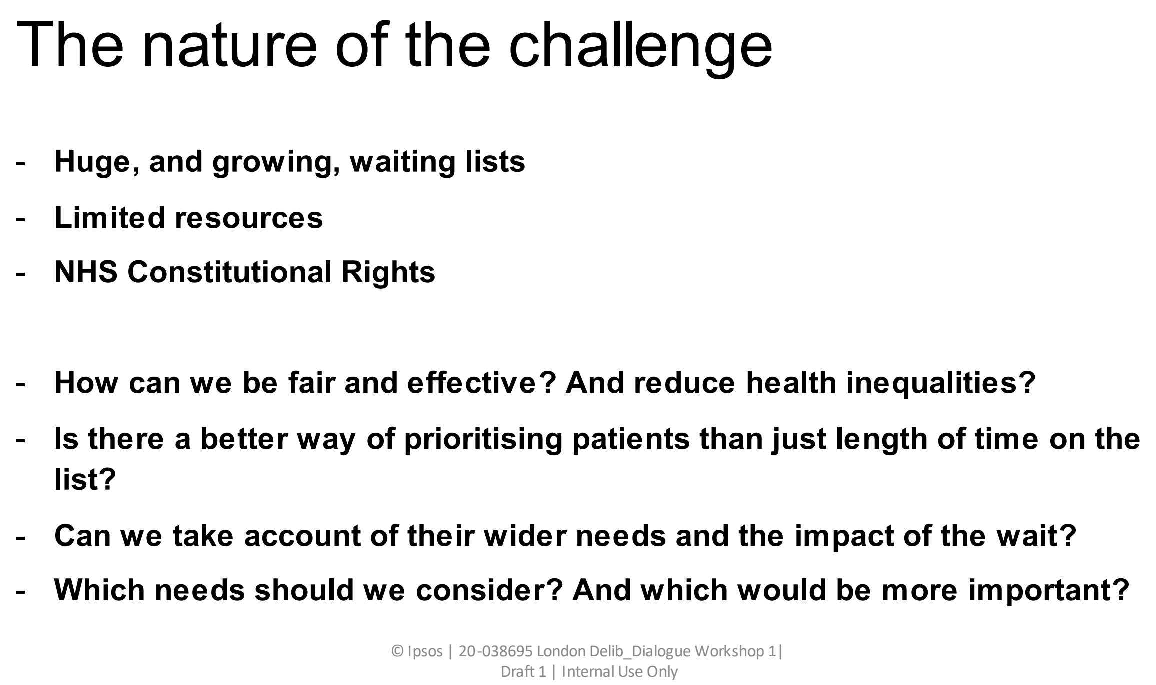
WFH + supported return
Full recovery
No impact on family

Norman from Nuneaton

GP when can't work
Smoker, diabetes, HTN
No physio

Waiting List Time 18 weeks

Late stage surgery
Poor recovery
Loses job
Depression
Increased healthcare cost

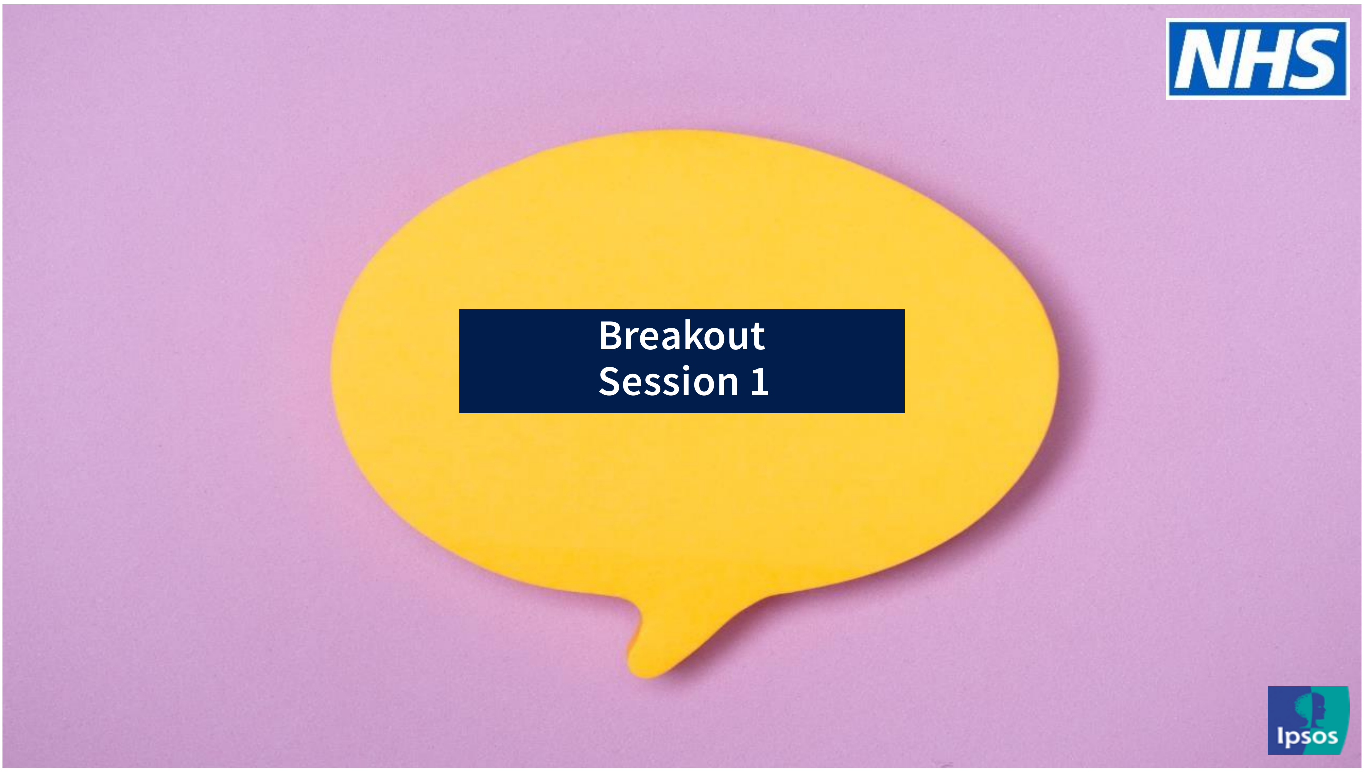


The nature of the challenge

- **Huge, and growing, waiting lists**
- **Limited resources**
- **NHS Constitutional Rights**

- **How can we be fair and effective? And reduce health inequalities?**
- **Is there a better way of prioritising patients than just length of time on the list?**
- **Can we take account of their wider needs and the impact of the wait?**
- **Which needs should we consider? And which would be more important?**

© Ipsos | 20-038695 London Delib_Dialogue Workshop 1|
Draft 1 | Internal Use Only



Breakout
Session 1

How are waiting lists managed?

Dr Dawn Adamson, Associate Medical Director (AMD), Clinical Lead for Adult Congenital Heart Disease and Obstetric Cardiology Services and Consultant Interventional Cardiologist

How are waiting lists managed?

- Before Covid19: urgent or routine then length of time
- During Covid19: loss of elective care activity and reduced capacity
- Need to ensure that treatments are prioritised for the most urgent patients to effectively manage clinical risk on the waiting list.
- 6 categories introduced based on clinically how long a patient can wait:
  - P1 – urgent
  - P2 – less than 1 month
  - P3 – less than 3 months
  - P4 – more than 3 months
  - P5 and P6 – patient wishes to postpone

Current Prioritisation Process

The process is currently :

Patients are referred by the GP who gives them an initial priority (Routine, Urgent or Two Week Wait)

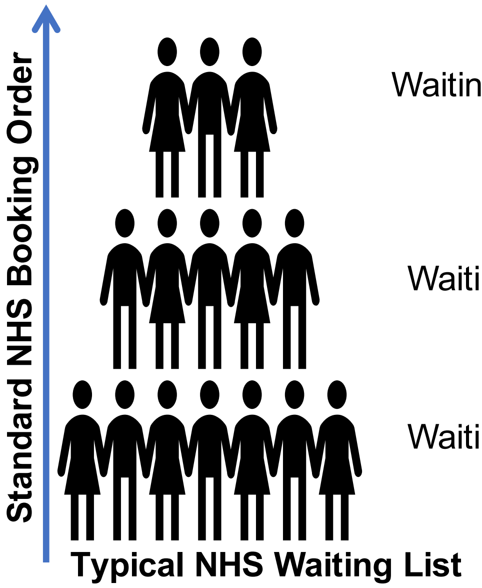
They are seen as an outpatient by the Service the GP referred them for, in the order of the GP priority and referral date

If treatment is needed, they are given a Clinical Priority by the Service (P1-P6)

They are booked for treatment within the Service- once they move to the top of the Waiting List (either due to Clinical Priority, or due to Wait Time)

Patients Waiting for a Hip Replacement

Clinical Priority 3



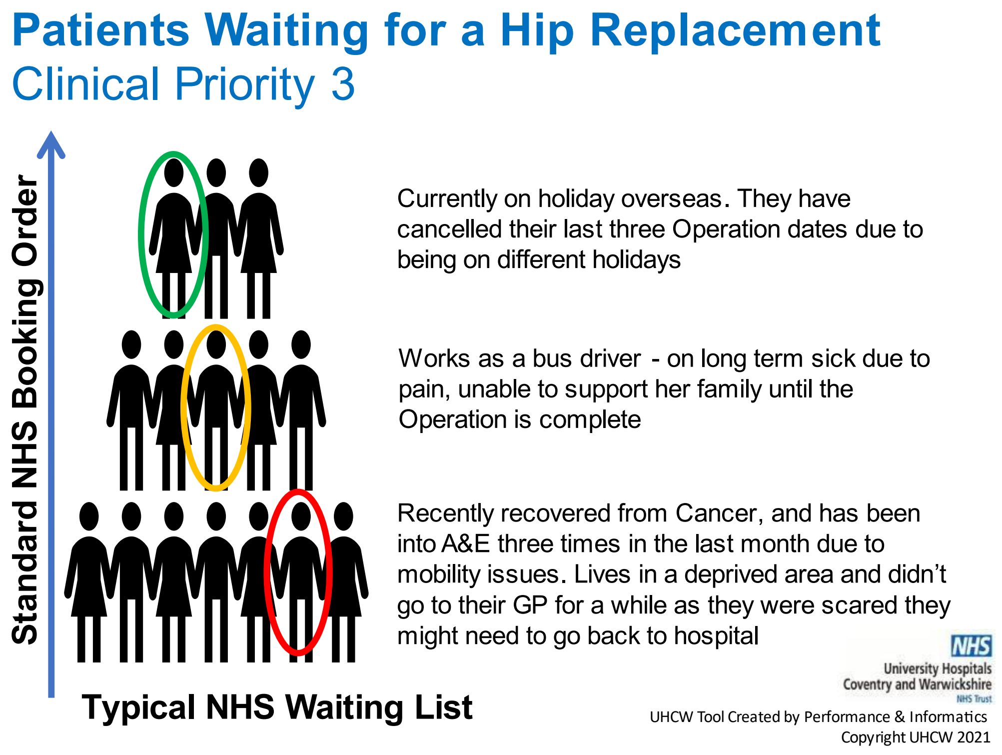
Waiting 3 months for Treatment

(Next to be booked)

Waiting 2 months for Treatment

Waiting 1 month for Treatment

UHCW Tool Created by Performance & Informatics



Patients Waiting for a Hip Replacement
Clinical Priority 3

Currently on holiday overseas. They have cancelled their last three Operation dates due to being on different holidays

Works as a bus driver - on long term sick due to pain, unable to support her family until the Operation is complete

Recently recovered from Cancer, and has been into A&E three times in the last month due to mobility issues. Lives in a deprived area and didn't go to their GP for a while as they were scared they might need to go back to hospital

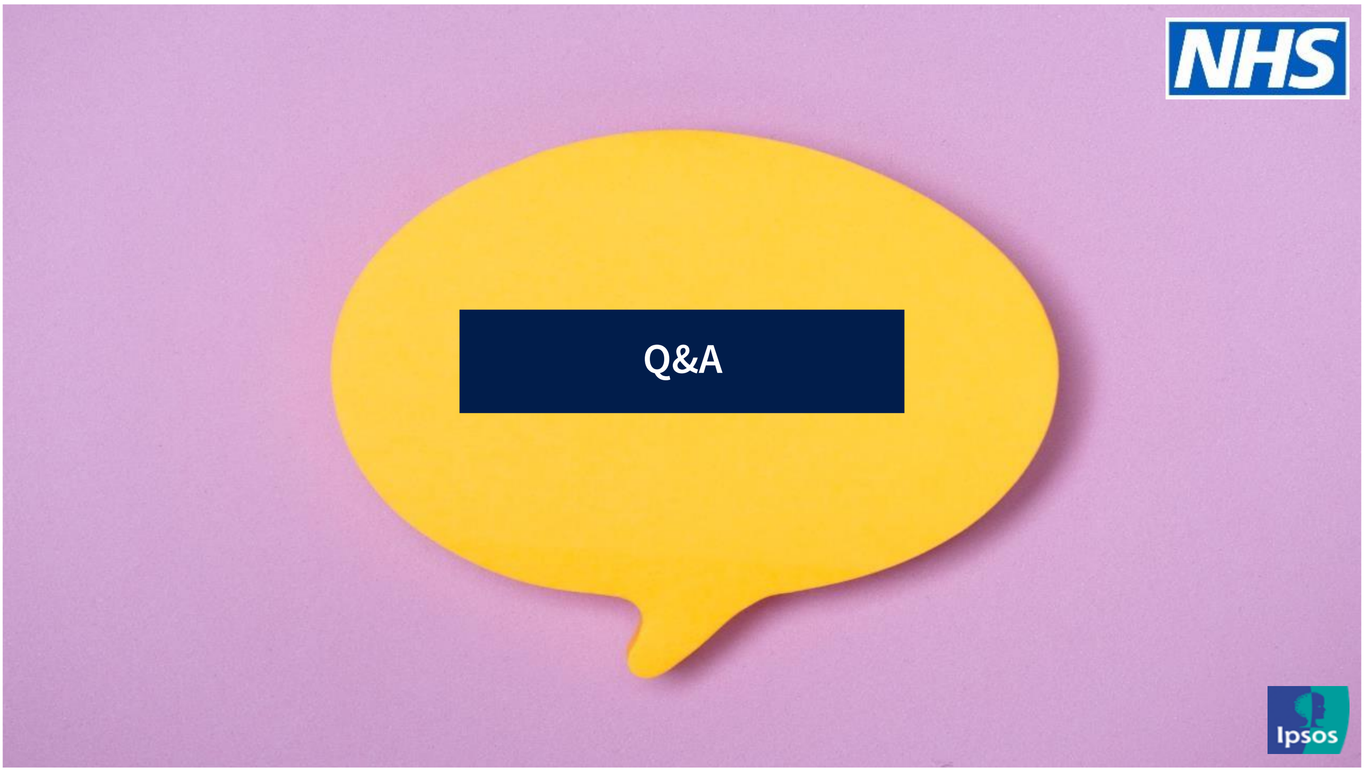
NHS University Hospitals Coventry and Warwickshire NHS Trust

UHCW Tool Created by Performance & Informatics
Copyright UHCW 2021

Future possibilities for the prioritisation process

- Include other health factors eg
  - Attend A&E due to condition
  - Suffer from multiple health conditions or previously had cancer
  - Affecting mental health
- Include other social factors eg
  - Can't work while waiting
  - Can't care for a close relative while waiting
  - Impact on education
  - Live in a more deprived area, lower life expectancy

© Ipsos | 20-038695 London Delib_Dialogue Workshop 1|
Draft 1 | Internal Use Only



Q&A

Comfort break: 10 minutes

Please be back for 7.15!

Norman from Nuneaton – Urgent and persistent hip pai

Norman is a 40-year-old builder living in Hill Top in Nuneaton, hailing from a deprived area. He is a smoker and has raised blood pressure. He has sharp and pressing hip pain all of a sudden after shifting some bricks at work but is reluctant to stop working as he relies heavily on his daily income and does not have much in the way of savings. His family and children also rely on him as he is the primary breadwinner.

Finally, the pain gets so bad that he goes to the GP. He is referred immediately to orthopaedics who book him in for an appointment and he joins the waiting list. However, because his construction company is working to a tight deadline on a major project he cannot attend prehabilitation to help him prepare for surgery.

Chandra from Coventry: Diabetes, anxiety and chest pain

Chandra is a 52-year-old Asian British woman from a deprived area who suffers with diabetes, high blood pressure and anxiety. She lives in Foleshill with her husband and children, one of whom has a learning disability. During the pandemic she noticed she was sometimes a bit short of breath but found it difficult to get an appointment with the GP.

She has recently developed chest pain. However, because her English is limited and she is not confident with technology, she struggled to get in through the door to see her GP so didn't see them straight away. Her GP has now referred her to see a heart specialist and she has joined the waiting list.

The pains come and go and she is increasingly worried about her condition but also who will help look after her mum who lives nearby.

Lucy from Longford – Elderly patient with arthritis

Lucy is a 78-year-old woman living in Longford in Coventry. She has arthritis in her knee which causes pain and has resulted in her knee giving way, putting her at high risk of falling. She lives on her own and has been independent but has recently become a lot less mobile.

She was due to have surgery next month at her local hospital under the consultant that had previously replaced her other knee. Whilst she has a lot of confidence in her consultant, she was worried about going into hospital because of Covid -19, and she missed her last appointment.

Reece from Rugby – Spinal operation delayed

Reece is a 40-year-old Black male living in Rugby with his wife and 9 year old son who is disabled. He suffers from a condition called spondylolisthesis which is where one of the bones in his spine has slipped out of position.

The condition causes significant pain and discomfort, and is extremely debilitating. He has been to A&E 5 times in the last year when the pain has become too severe to manage at home. As a result Reece is currently taking sick-leave, on reduced pay, from his job as a delivery driver. He is the sole earner in the family as his wife cares for their son. He is very worried about his lost income and how the family are going to cope.

Reece's condition is so severe that it requires surgery, he has now been on the neurosurgery waiting list for 6 months.

Sakesh from Stratford - Child with long term elbow dislocation

Sakesh is a 7-year-old Asian British boy from Stratford who has dislocated his elbow after visiting the local playground. His mother, Prisha, is very worried and takes him to A&E. After an over 12 hour wait he is seen and attended to.

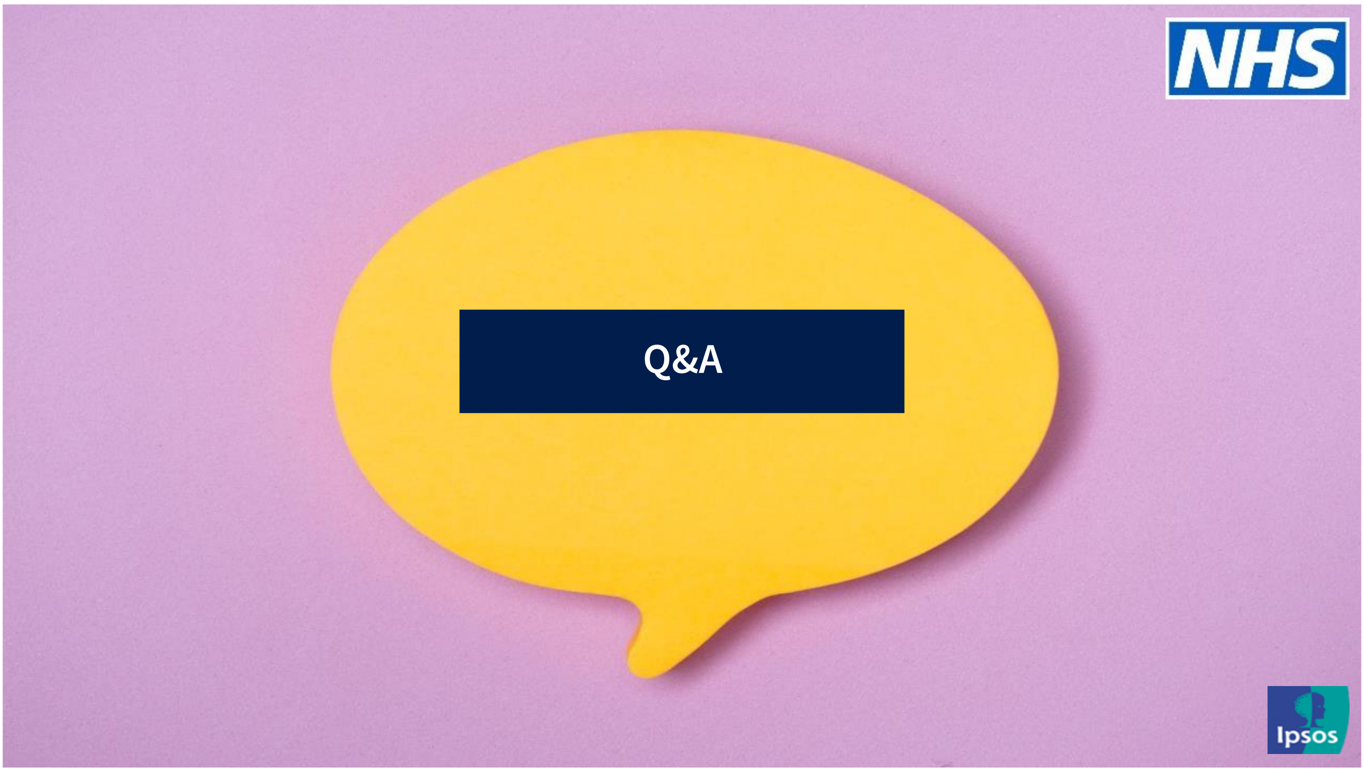
However, a few weeks later, he experiences the same situation again. This time Prisha books him in to the GP for advice. After answering a series of questions she is advised by the GP that Sakesh needs to be referred to an elbow specialist. He can't do any sports while he is waiting and is starting to put on weight. He has had quite a bit of time off school and his mum is worried the other kids are starting to bully him.

Prisha works as a nurse, she has had to take extra time off work to look after him.

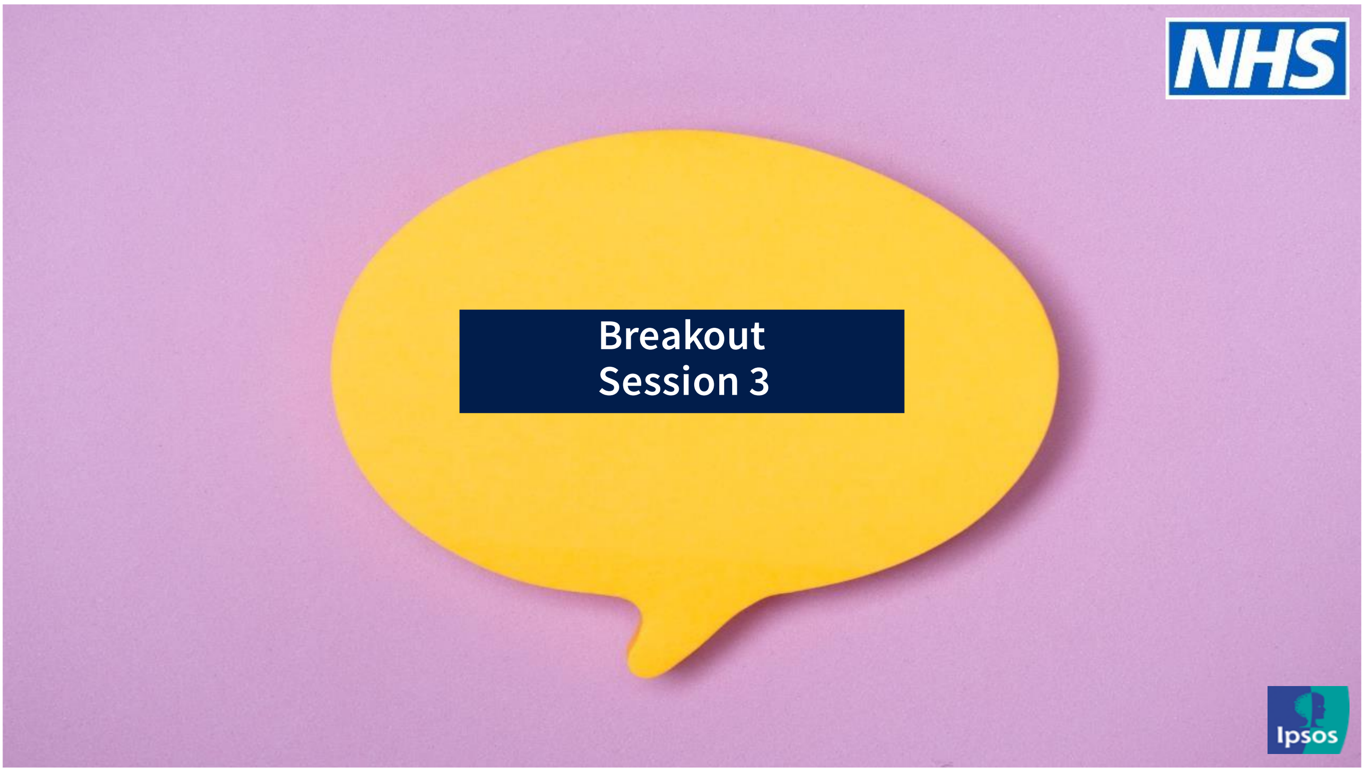
Wayne from Willenhall- suffering from jaundice

Wayne is a 50-year-old man who has struggled with alcoholism since he lost his wife to cancer several years ago He has recently stopped smoking but has gained a lot of weight and is now obese. He went to see his GP recently because he noticed he was "going a bit yellow".

His GP has diagnosed jaundice and has referred him to see a gastroenterologist. As well as his jaundice and weight gain his GP is very worried about Wayne's mental health. Wayne provides a lot of care for his elderly mum who lives nearby



Q&A



Breakout
Session 3

Comfort break: 10 minutes

Please be back for 8.10!

Plenary

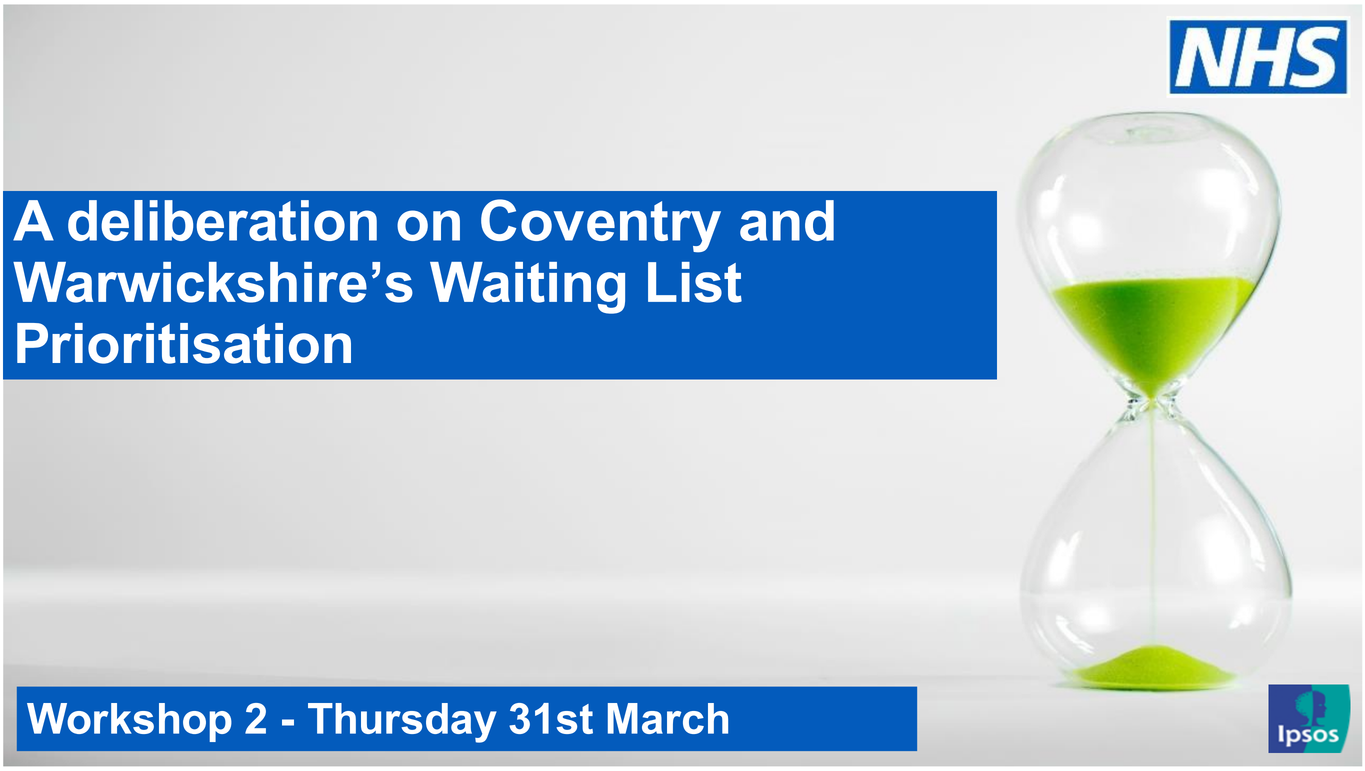
Next steps

- - This is the first project of its kind, as there is very limited research into what the public think about waiting list prioritisation development, so we're in a unique position to feed public views, hopes and concerns directly into the development of these sorts of tools
- - Strategy Unit at the NHS is also really interested in this, in terms of shaping wider NHS practice.
- - This is what the participants will focus on over the next couple of weeks with the opportunity for plenty of discussion and deliberation.
- Issues? Contact devina.sanichar@ipsos.com

- **See you on Thursday – same time and same place!**

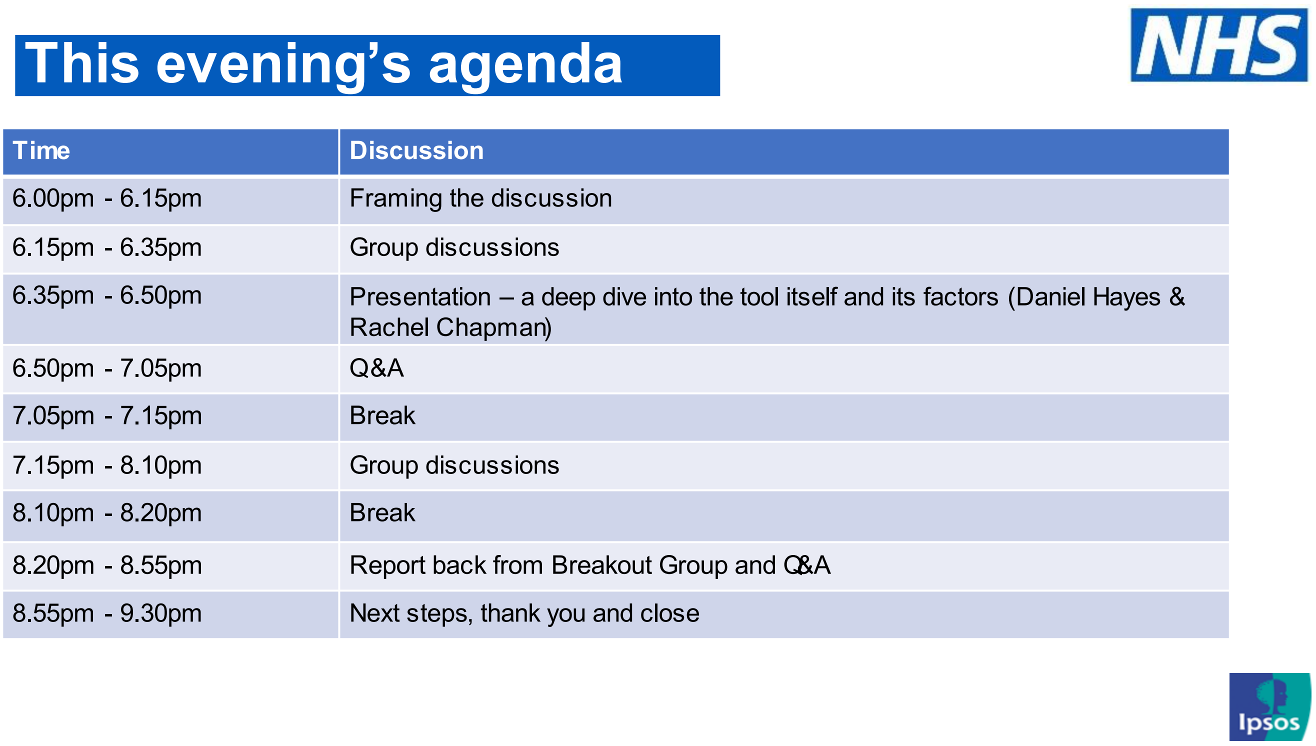
THANK YOU

Workshop 2



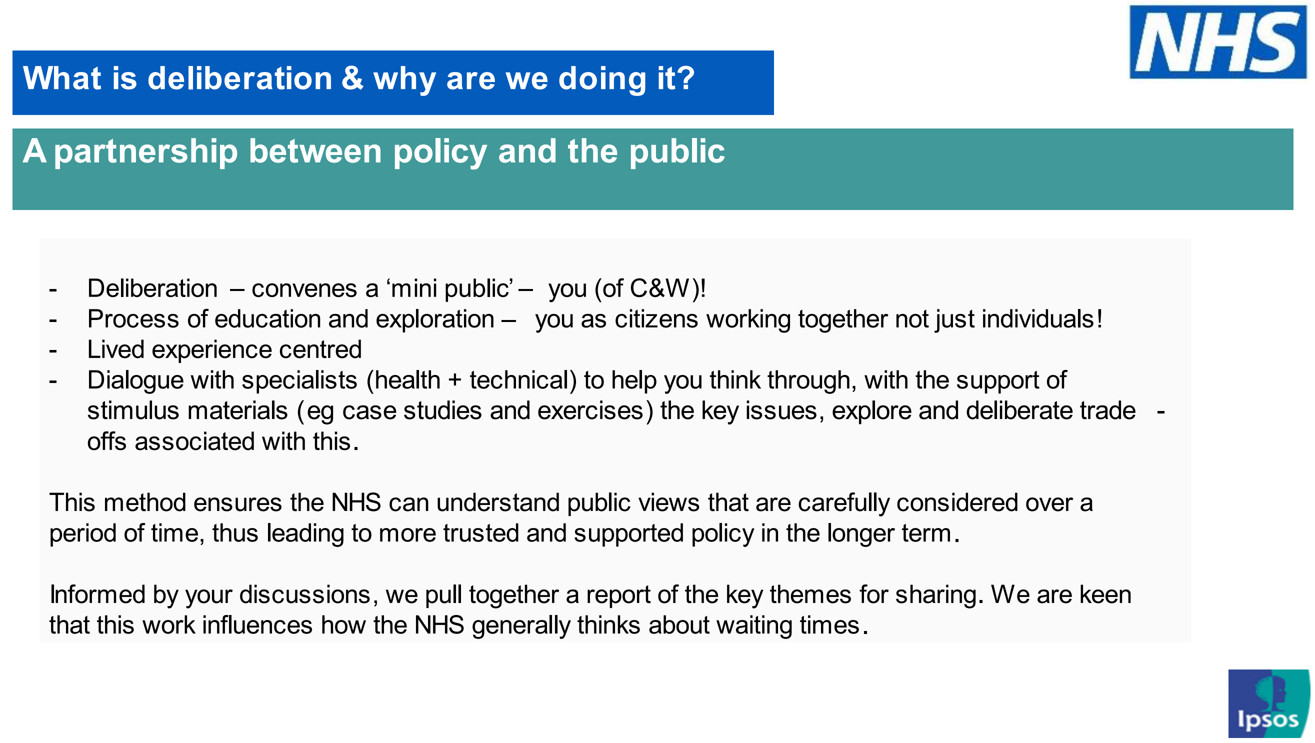
A deliberation on Coventry and Warwickshire’s Waiting List Prioritisation

Workshop 2 - Thursday 31st March



This evening’s agenda

Time	Discussion
6.00pm - 6.15pm	Framing the discussion
6.15pm - 6.35pm	Group discussions
6.35pm - 6.50pm	Presentation – a deep dive into the tool itself and its factors (Daniel Hayes & Rachel Chapman)
6.50pm - 7.05pm	Q&A
7.05pm - 7.15pm	Break
7.15pm - 8.10pm	Group discussions
8.10pm - 8.20pm	Break
8.20pm - 8.55pm	Report back from Breakout Group and Q&A
8.55pm - 9.30pm	Next steps, thank you and close



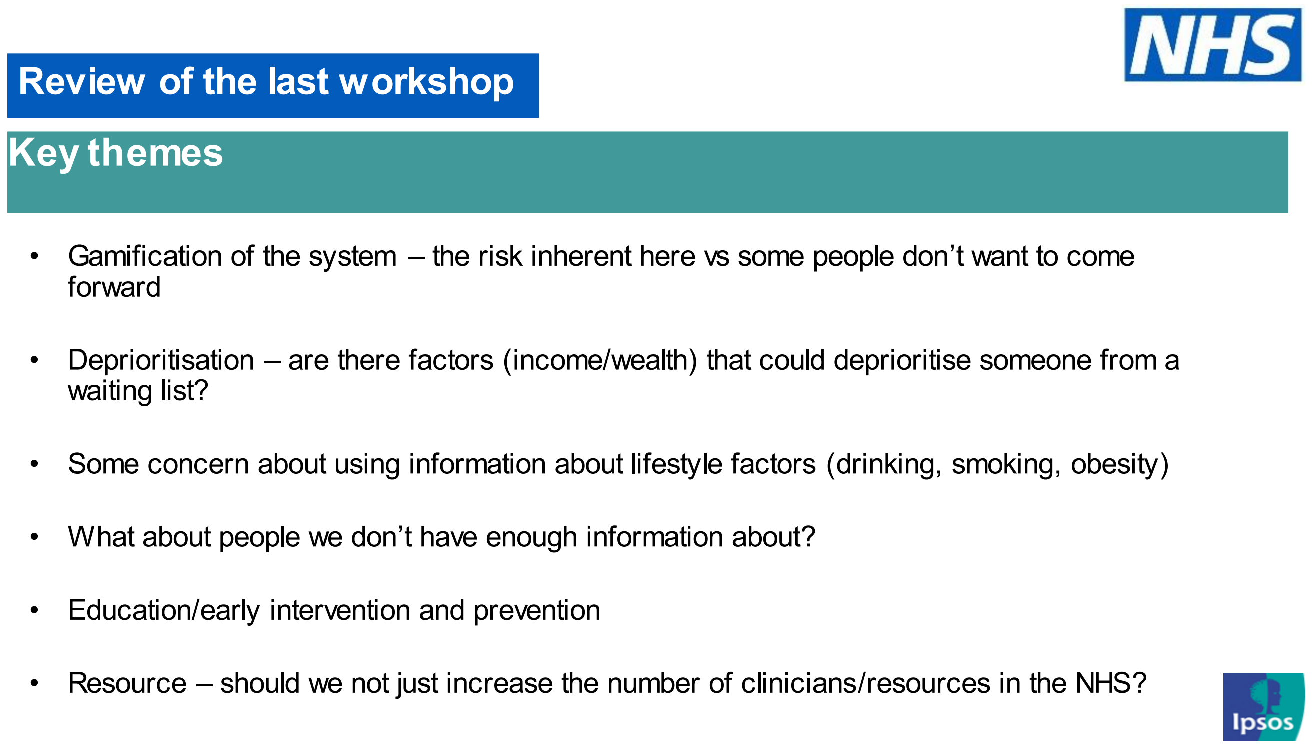
What is deliberation & why are we doing it?

A partnership between policy and the public

- Deliberation – convenes a ‘mini public’ – you (of C&W)!
- Process of education and exploration – you as citizens working together not just individuals!
- Lived experience centred
- Dialogue with specialists (health + technical) to help you think through, with the support of stimulus materials (eg case studies and exercises) the key issues, explore and deliberate trade-offs associated with this.

This method ensures the NHS can understand public views that are carefully considered over a period of time, thus leading to more trusted and supported policy in the longer term.

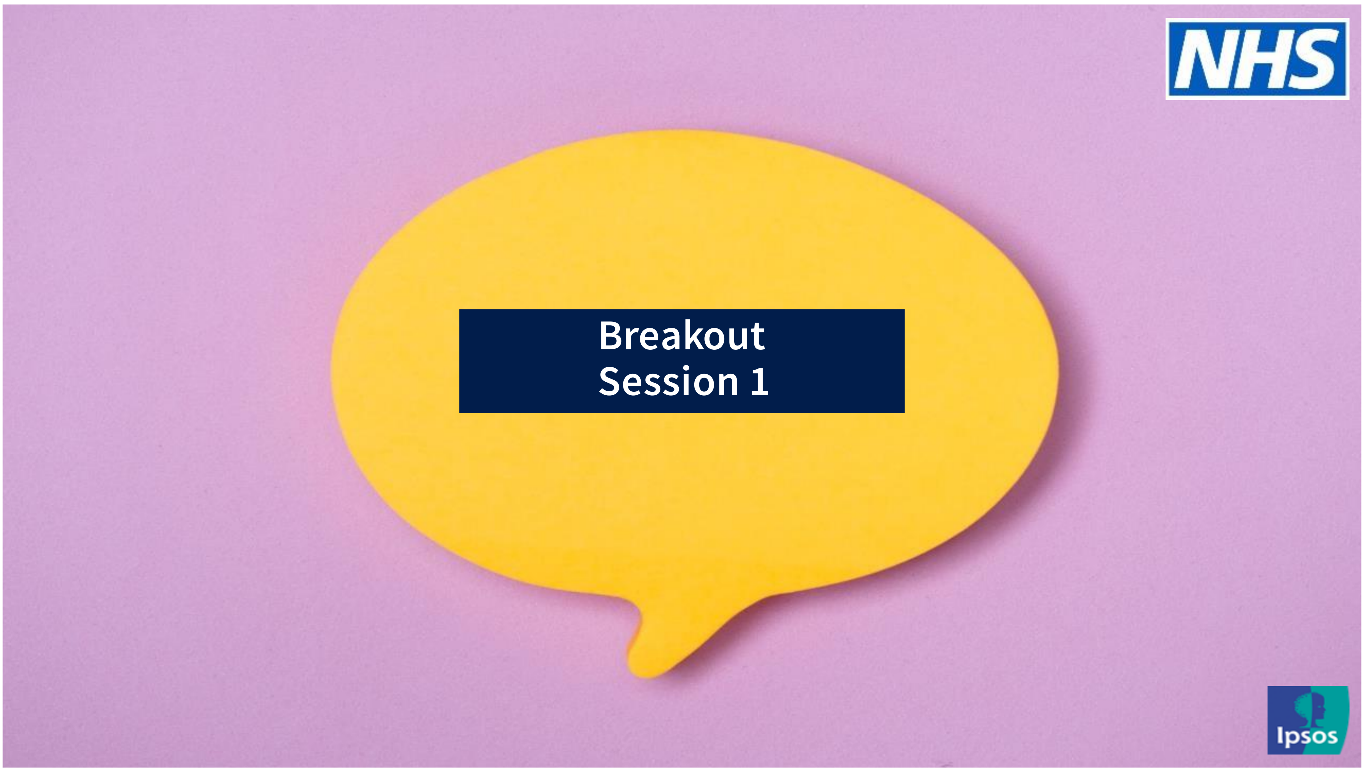
Informed by your discussions, we pull together a report of the key themes for sharing. We are keen that this work influences how the NHS generally thinks about waiting times.



Review of the last workshop

Key themes

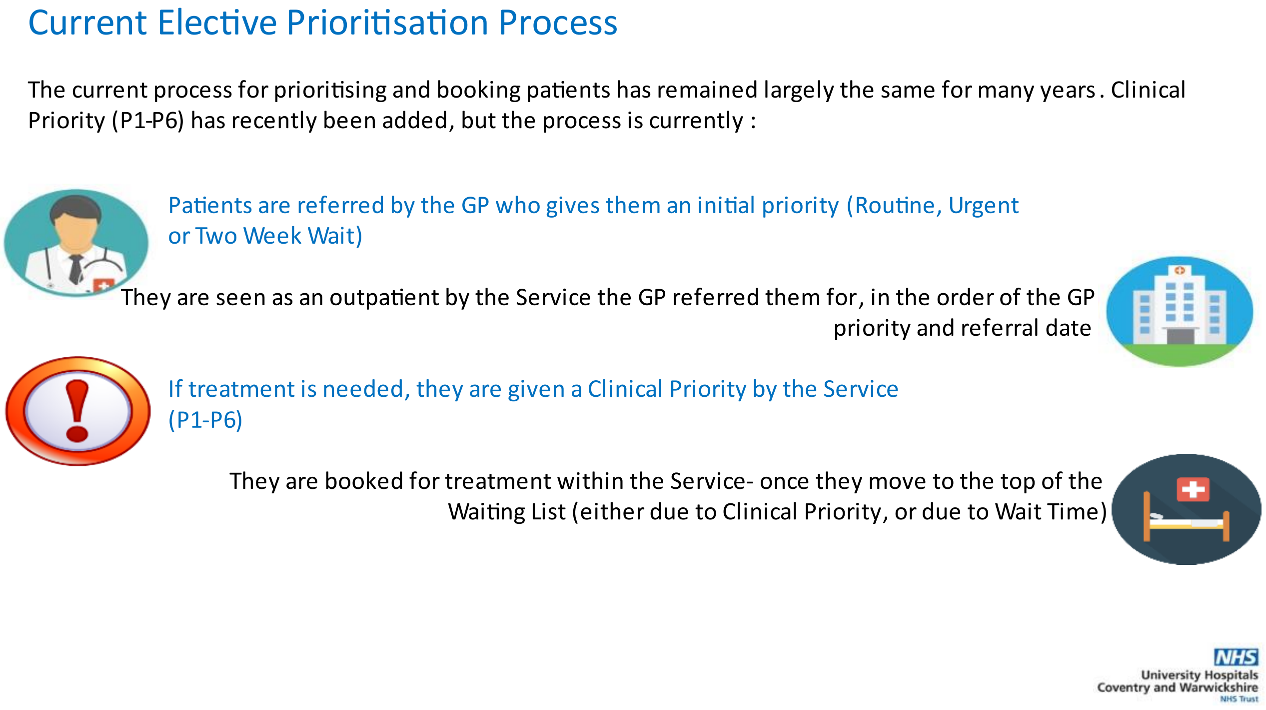
- Gamification of the system – the risk inherent here vs some people don't want to come forward
- Deprioritisation – are there factors (income/wealth) that could deprioritise someone from a waiting list?
- Some concern about using information about lifestyle factors (drinking, smoking, obesity)
- What about people we don't have enough information about?
- Education/early intervention and prevention
- Resource – should we not just increase the number of clinicians/resources in the NHS?



Breakout Session 1

An introduction to the waiting list prioritisation tool

Daniel Hayes, UHCW NHS Trust



Current Elective Prioritisation Process

The current process for prioritising and booking patients has remained largely the same for many years. Clinical Priority (P1-P6) has recently been added, but the process is currently :

Patients are referred by the GP who gives them an initial priority (Routine, Urgent or Two Week Wait)

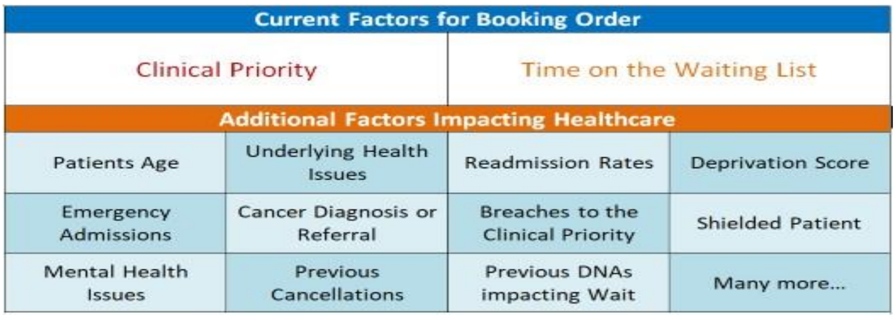
They are seen as an outpatient by the Service the GP referred them for, in the order of the GP priority and referral date

If treatment is needed, they are given a Clinical Priority by the Service (P1-P6)

They are booked for treatment within the Service- once they move to the top of the Waiting List (either due to Clinical Priority, or due to Wait Time)

Additional Factors Impacting Healthcare Outcomes

Within the existing categories are numerous patients, with many conflicting underlying health issues, and a range of factors which impact on their outcomes



<table>
<tr><th colspan="4">Current Factors for Booking Order</th></tr>
<tr><td colspan="2">Clinical Priority</td><td colspan="2">Time on the Waiting List</td></tr>
<tr><th colspan="4">Additional Factors Impacting Healthcare</th></tr>
<tr><td>Patients Age</td><td>Underlying Health Issues</td><td>Readmission Rates</td><td>Deprivation Score</td></tr>
<tr><td>Emergency Admissions</td><td>Cancer Diagnosis or Referral</td><td>Breaches to the Clinical Priority</td><td>Shielded Patient</td></tr>
<tr><td>Mental Health Issues</td><td>Previous Cancellations</td><td>Previous DNAs impacting Wait</td><td>Many more...</td></tr>
</table>

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

Waiting List Booking Process

Currently the teams on the ground book large numbers of patients with short time scales, and are unaware of many of these underlying factors

They will normally book based on only the two key principles of Clinical Priority and Wait time – with everything else coming down to who responds first

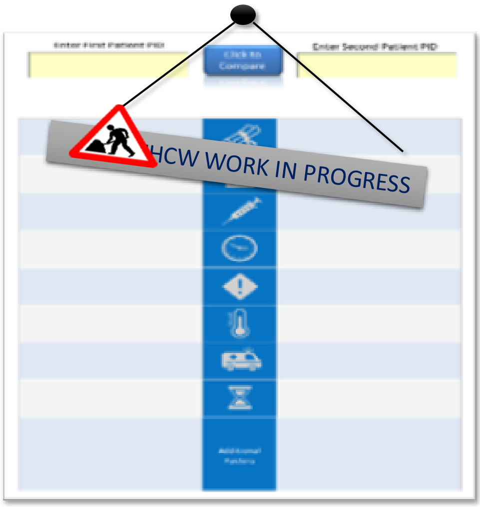
NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

UHCW Clinical Priority Tool

The Clinical Priority Tool developed by UHCW and Performance & Informatics team takes all of these factors into account, allowing a detailed comparison of patient need and making recommendations on booking when comparing patients on the same priority and procedure

This is not considered a clinical review, and is only used to help guide the booking teams when comparing similar patients

Everybody gets the NHS Constitutional Standards



NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

A bite-sized overview of the prioritisation tool

Patient A	Patient B
Consultant A	Consultant A
Direct Current Cardioversion	Direct Current Cardioversion
18 weeks	42 Weeks
P5	P4
3	16
0	6
59 Years	84 Years

The tool recommends Patient B

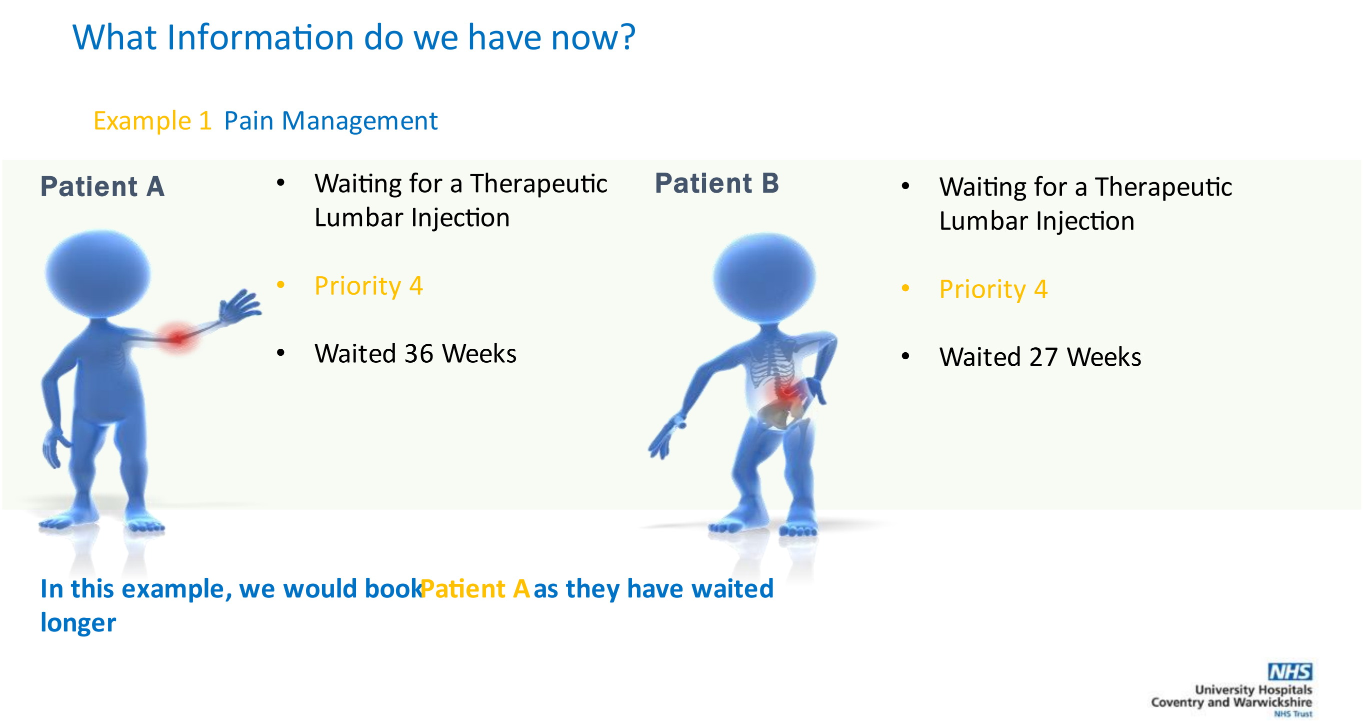
During the pandemic UCHW have developed a tool that helps us consider lots of different factors in prioritising the waiting list (other than wait time)

- The tool reviews patient records and history, applies a weight, and shows the outcome side by side
- It will highlight when one patient is potentially more urgent than another
- Weighting can be adjusted or reviewed by Clinical staff at any time. The tool will even suggest a clinician should review the outcome.

We would like your views on what we should consider and how best to develop this tool further.

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

UHCW Tool Created by Performance & Informatics



What Information do we have now?

Example 1 Pain Management

Patient A

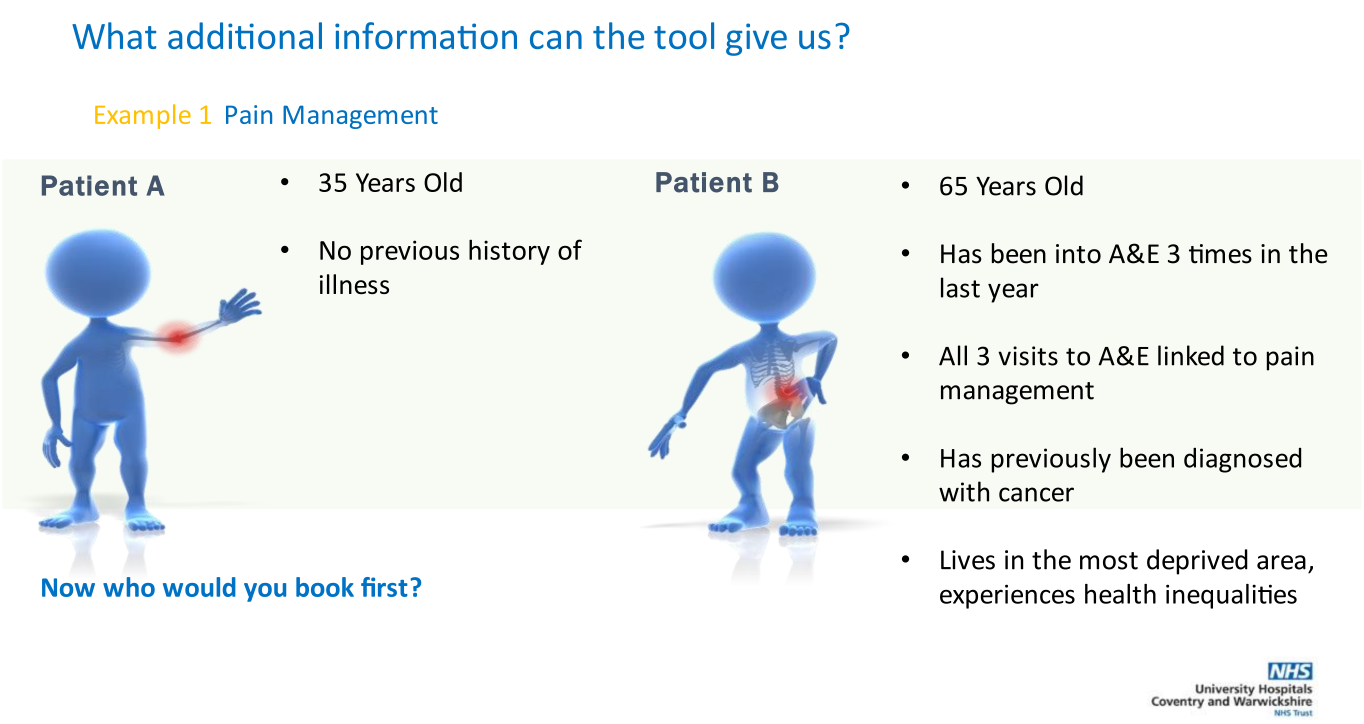
- Waiting for a Therapeutic Lumbar Injection
- Priority 4
- Waited 36 Weeks

Patient B

- Waiting for a Therapeutic Lumbar Injection
- Priority 4
- Waited 27 Weeks

In this example, we would book Patient A as they have waited longer

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust



What additional information can the tool give us?

Example 1 Pain Management

Patient A

- 35 Years Old
- No previous history of illness

Patient B

- 65 Years Old
- Has been into A&E 3 times in the last year
- All 3 visits to A&E linked to pain management
- Has previously been diagnosed with cancer
- Lives in the most deprived area, experiences health inequalities

Now who would you book first?

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

In this example, the Tool recommends we book Patient B

What should we do?

Example 1 – Pain M

Patient A

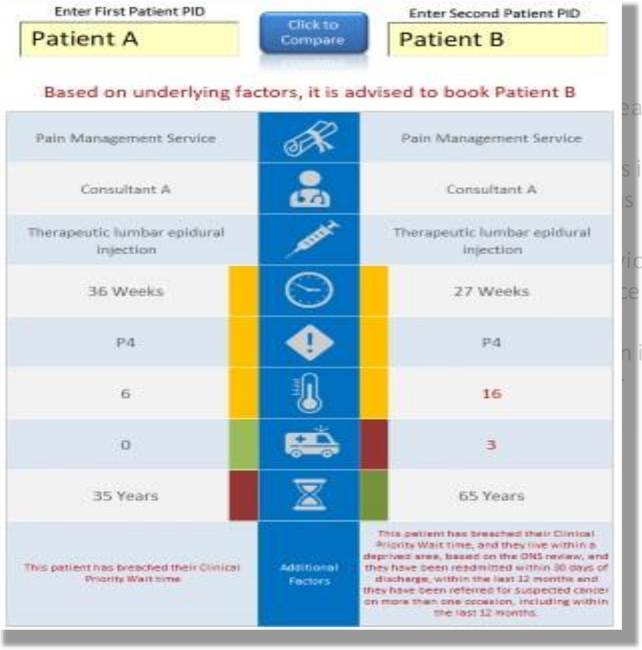
- 35 Ye
- No p

ears Old

s in one of the most deprived
s

iously been diagnosed with
cer

n into A&E 3 times in the last



Enter First Patient PID
Patient A

Click to Compare

Enter Second Patient PID
Patient B

Based on underlying factors, it is advised to book Patient B

Pain Management Service				Pain Management Service
Consultant A				Consultant A
Therapeutic lumbar epidural injection				Therapeutic lumbar epidural injection
36 Weeks	🟨		🟨	27 Weeks
P4	🟨		🟨	P4
6	🟨		🟨	16
0	🟩		🟥	3
35 Years	🟥		🟩	65 Years
This patient has breached their Clinical Priority Wait time.		Additional Factors		This patient has breached their Clinical Priority Wait time, and they live within a deprived area, based on the ONS review, and they have been readmitted within 30 days of discharge, within the last 12 months and they have been referred for suspected cancer on more than one occasion, including within the last 12 months.

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

What information do we have now?

Example 2 – Trauma & Orthopaedics

Patient A

- Waiting for Total Prosthetic Replacement of Knee Joint
- Priority 3
- Waited 15 Weeks

Patient B

- Waiting for Total Prosthetic Replacement of Knee Joint
- Priority 3
- Waited 47 Weeks

In this example, we would book Patient B, as they have waited longer

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

What additional information can the tool give us?

Example 2– Trauma & Orthopaedics

Patient A

- 75 Years Old
- 7 other conditions
- Has been referred separately to another service for suspected cancer
- Recently came into A&E after a fall
- Lives in a deprived area, experiences health inequalities

Patient B

- 54 Years Old
- Smoker

Now who ?

What should we do?

In this example, the Tool recommends we book Patient A

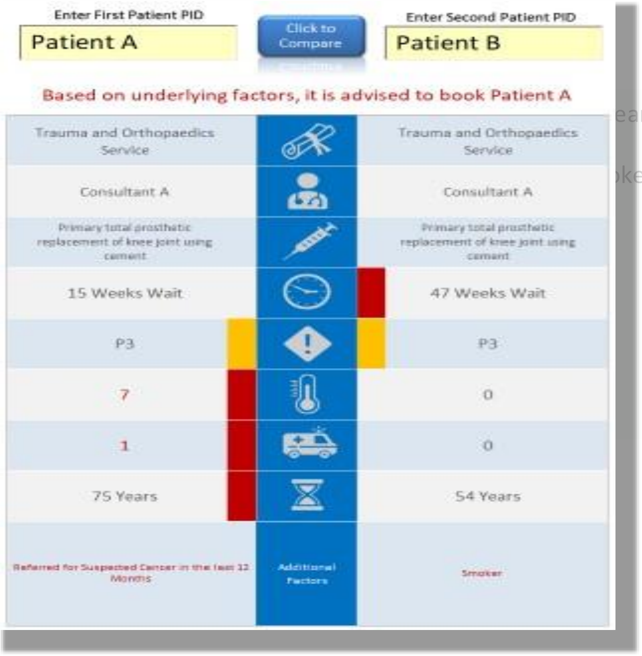
Example 1– Pain M

Patient A

- 75 Ye
- 7 Cor
- Has b to an susp
- Rece a fall

ears Old

oker



Enter First Patient PID: Patient A

Click to Compare

Enter Second Patient PID: Patient B

Based on underlying factors, it is advised to book Patient A

Trauma and Orthopaedics Service		Trauma and Orthopaedics Service
Consultant A		Consultant A
Primary total prosthetic replacement of knee joint using cement		Primary total prosthetic replacement of knee joint using cement
15 Weeks Wait		47 Weeks Wait
P3		P3
7		0
1		0
75 Years		54 Years
Referred for Suspected Cancer in the last 12 Months	Additional Factors	Smoker

What additional information can the tool give us?

Example 2 – Trauma & Orthopaedics

Patient A

- 75 Years Old
- 7 other conditions
- Has been referred separately to another service for suspected cancer
- Recently came into A&E after a fall
- Lives in a deprived area

Patient B

- 54 Years Old
- Smoker

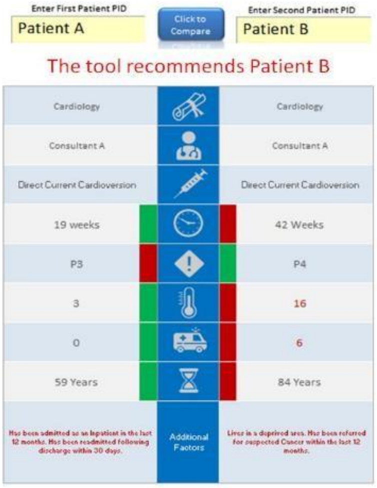
If we found out patient B was unable to work while on the waiting list would that change your view?

Now who ?

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

How the UHCW Waiting List Priority Tool works

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust



Enter First Patient PID: Patient A

Enter Second Patient PID: Patient B

The tool recommends Patient B

Cardiology				Cardiology
Consultant A				Consultant A
Direct Current Cardioversion				Direct Current Cardioversion
19 weeks	🟩		🟥	42 Weeks
P3	🟥		🟩	P4
3	🟩		🟥	16
0	🟩		🟥	6
59 Years	🟩		🟥	84 Years
Has been admitted as an Inpatient in the last 12 months. Has been readmitted following discharge within 30 days.		Additional Factors		Lives in a deprived area. Has been referred for suspected Cancer within the last 12 months.

Where patients have the same priority the Tool gives the booking staff the facility to enter both Patient ID's and compare directly.

The tool reviews the patient records and history, applies a weight, and shows the outcome side by side

It will highlight those where the weighting is indicating one patient is potentially more urgent than another

The top of the page will show which patient is recommended overall

Weighting can be adjusted or reviewed by Clinical staff at any time. In some cases the tool will even suggest a clinician should review the outcome.

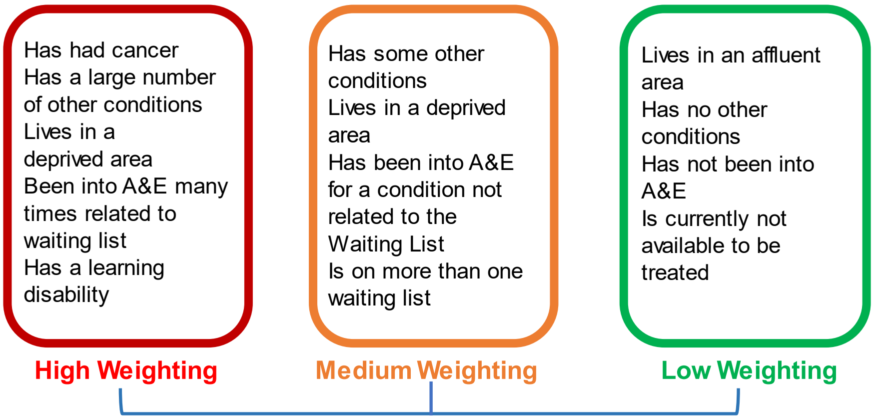
Weighting can also be applied directly to the whole waiting list, even at individual procedure level – and a new waiting list generated

UHCW Tool Created by Performance & Informatics

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

How the UHCW Waiting List Priority Tool works

The UHCW tool pulls the Background Conditions or Patient History from the various Hospital systems and assigns each factor a weight



Has had cancer
Has a large number of other conditions
Lives in a deprived area
Been into A&E many times related to waiting list
Has a learning disability

High Weighting

Has some other conditions
Lives in a deprived area
Has been into A&E for a condition not related to the Waiting List
Is on more than one waiting list

Medium Weighting

Lives in an affluent area
Has no other conditions
Has not been into A&E
Is currently not available to be treated

Low Weighting

Combined weighting creates the new patient waiting list position

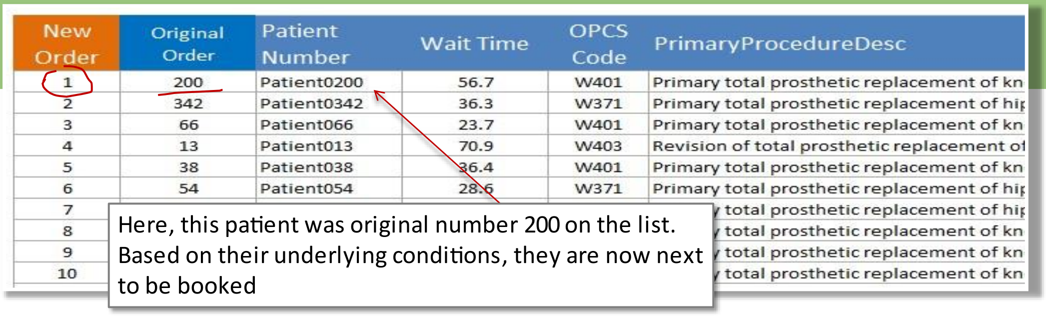
Those with greatest need or likely benefit can be prioritised, hence potentially reducing health inequality

UHCW Tool Created by Performance & Informa

Waiting List Generator

Using the weighting system within the Priority Tool we can apply the same process for comparing two patients to the entire Waiting List.

This is done on a Specialty, or even Procedure basis, to ensure a like for like comparison



New Order	Original Order	Patient Number	Wait Time	OPCS Code	PrimaryProcedureDesc
1	200	Patient0200	56.7	W401	Primary total prosthetic replacement of kn
2	342	Patient0342	36.3	W371	Primary total prosthetic replacement of hip
3	66	Patient066	23.7	W401	Primary total prosthetic replacement of kn
4	13	Patient013	70.9	W403	Revision of total prosthetic replacement of
5	38	Patient038	36.4	W401	Primary total prosthetic replacement of kn
6	54	Patient054	28.6	W371	Primary total prosthetic replacement of hip
7					total prosthetic replacement of hip
8					total prosthetic replacement of kn
9					total prosthetic replacement of kn
10					total prosthetic replacement of kn

Here, this patient was original number 200 on the list. Based on their underlying conditions, they are now next to be booked

Additional Features of the Priority Tool

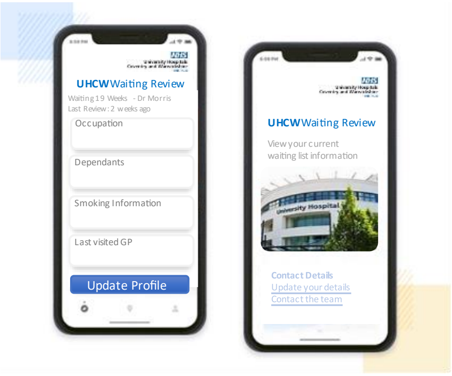
The Tool can generate a complete timeline of the most recent waiting list history, which can be viewed in one click – pulling data from numerous internal systems – saving staff large amounts of time in searching through internal data.

Machine Learning allows the system to remember other scenarios entered and look for corresponding factors, and adjust the weighting in future versions to make them more useful (all under the watch of Clinicians)

Additional supporting Apps in development by UHCW Performance & Informatics will allow the collection and comparison of further data from the GP or direct from the Patient, allowing for a constantly improving system

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

Further development



Waiting 19 Weeks - Dr Morris
Last Review: 2 weeks ago

The UHCW Equality and Waiting List Review process uses data from multiple patient systems to build up a full picture of each patient's medical history and potential risks.

To develop it further we will need to gather additional information from patients or GPs.

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

Factors we can currently include:

- Needing to attend A&E because of their condition
- Previous admission or readmission
- Other health conditions that have an impact (comorbidities)
- Previous diagnosis of cancer
- Length of wait
- Age
- Disability
- Health inequalities (live in a more deprived area)

Additional factors we could include:

- Need to attend GP because of condition
- Significant impact on mental health
- Ethnic group
- Lifestyle factorseg diet, smoking, drinking
- Carer for relative, friend or neighbour
- Unable to work while waiting
- Unable to attend school / education while waiting
- Unable to volunteer or work in local community while waiting
- NHS worker who is unable to work while waiting
- Other significant impact on quality of life

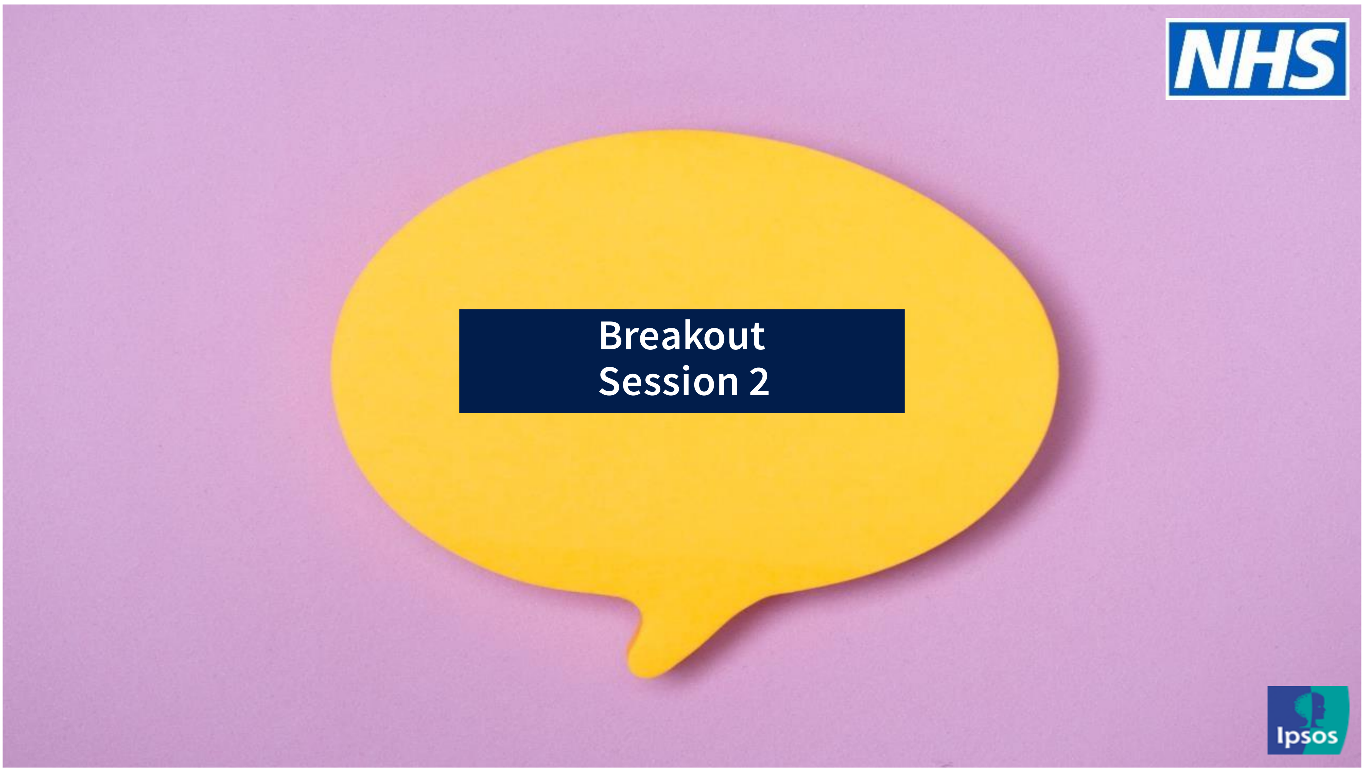
What factors could go into prioritising waiting lists and why?

- Impact of waiting on the individual’s physical health
- Impact of waiting on the individual’s mental health
- Wider health risks including other conditions
- Disabilities
- Health inequalities (poorer access, less opportunity for health)
- Need to use emergency health services
- Impact on individual’s wider situation – work, caring, education etc
- Length of wait
- Age, ethnicity

Q&A

Comfort break: 10 minutes

Please be back for 7.15!



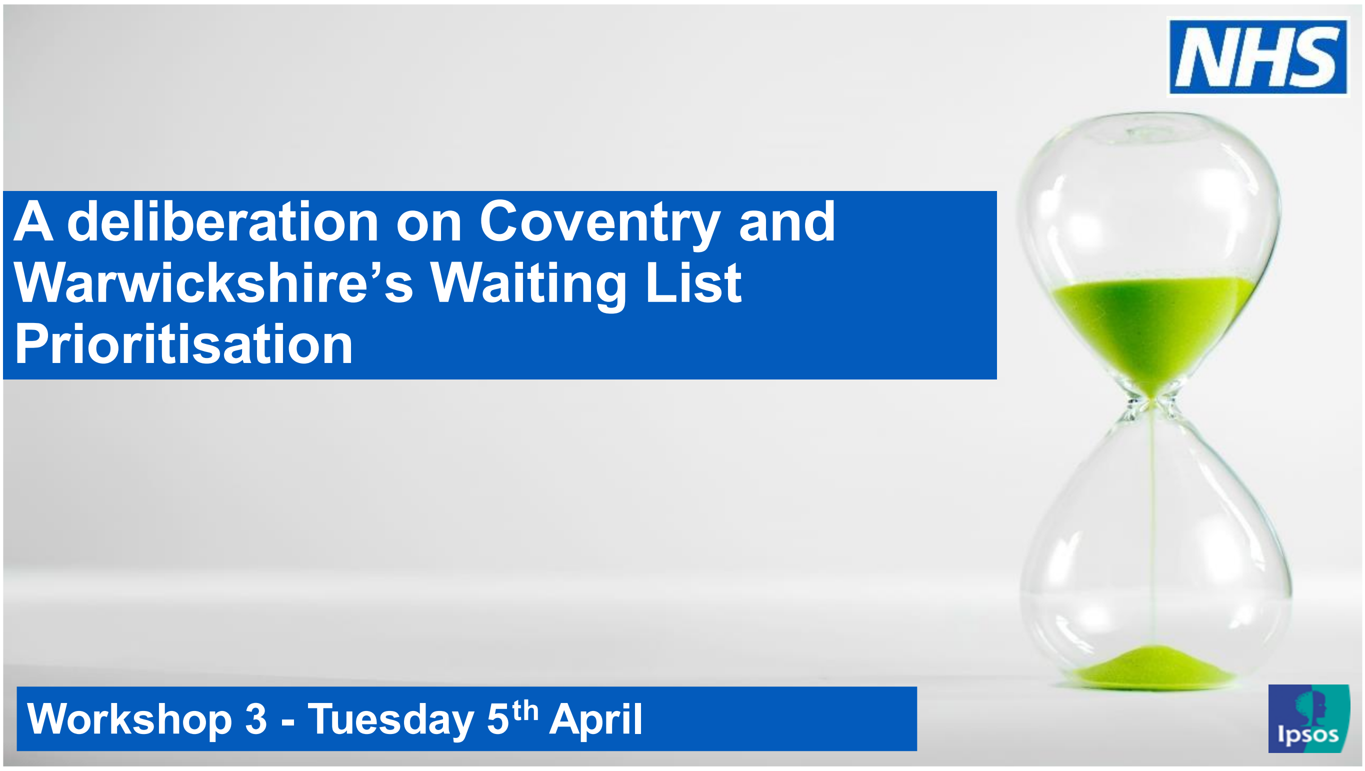
Breakout Session 2

Comfort break: 10 minutes

Please be back for 8.20!

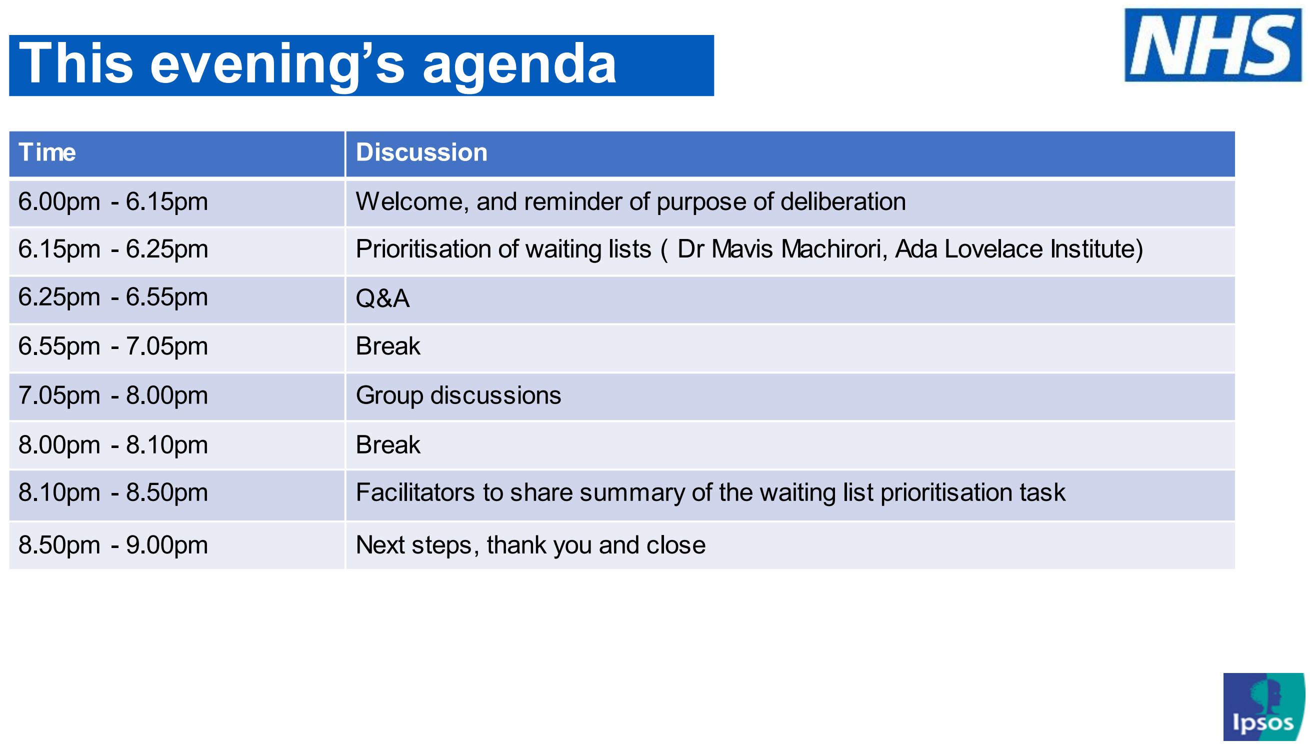
Q&A

Workshop 3



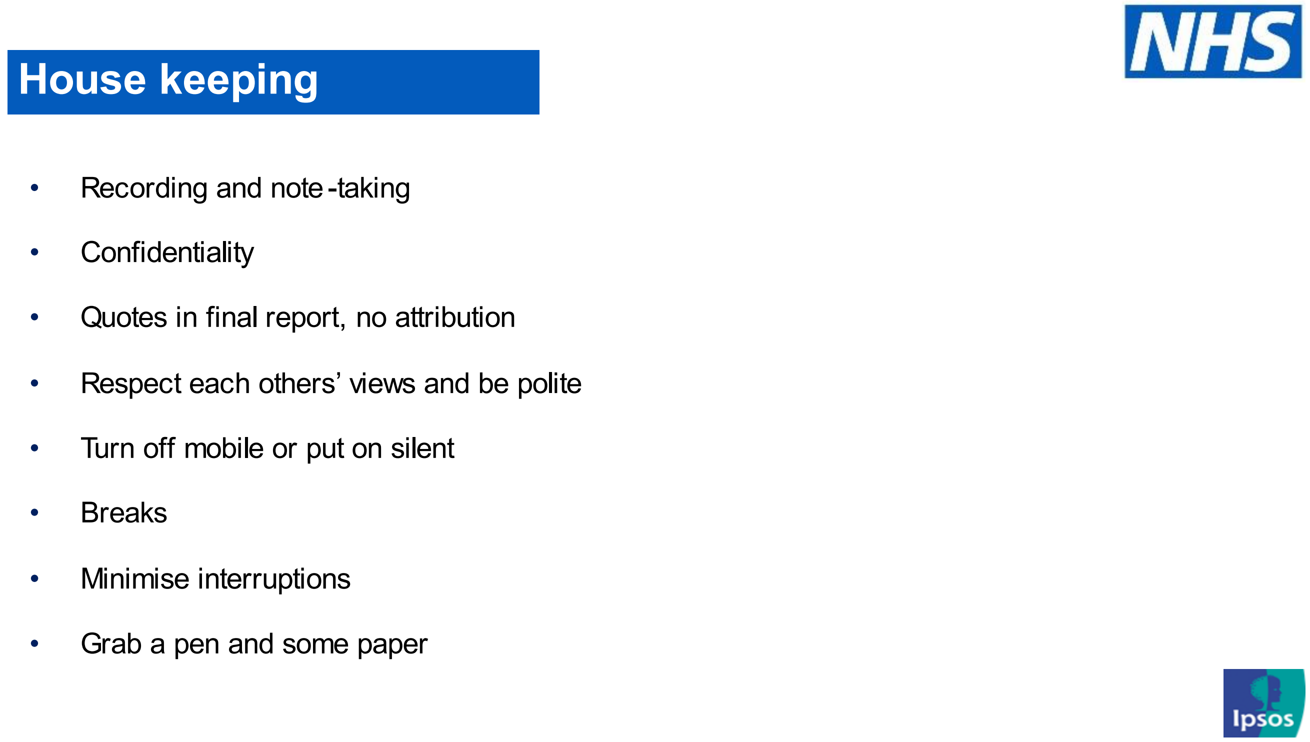
A deliberation on Coventry and Warwickshire's Waiting List Prioritisation

Workshop 3 - Tuesday 5th April



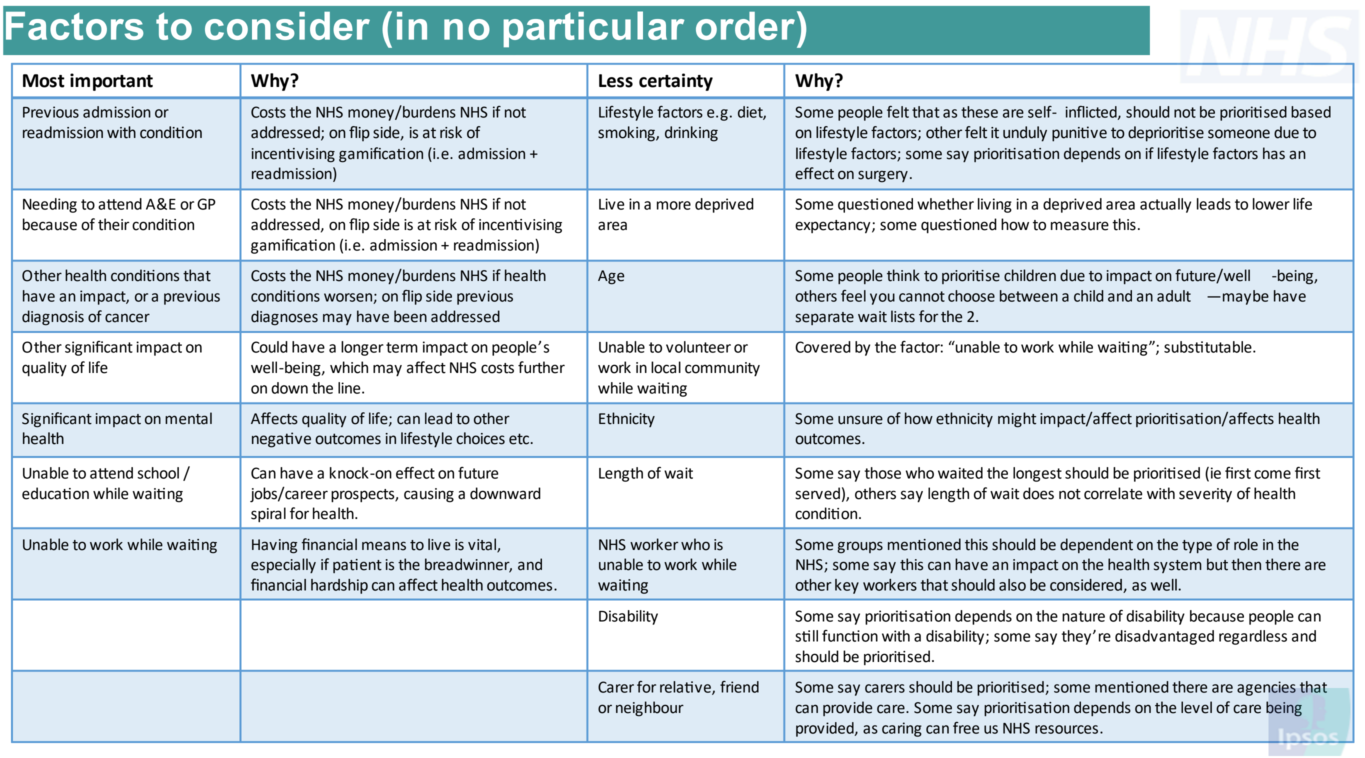
This evening’s agenda

Time	Discussion
6.00pm - 6.15pm	Welcome, and reminder of purpose of deliberation
6.15pm - 6.25pm	Prioritisation of waiting lists (Dr Mavis Machirori, Ada Lovelace Institute)
6.25pm - 6.55pm	Q&A
6.55pm - 7.05pm	Break
7.05pm - 8.00pm	Group discussions
8.00pm - 8.10pm	Break
8.10pm - 8.50pm	Facilitators to share summary of the waiting list prioritisation task
8.50pm - 9.00pm	Next steps, thank you and close



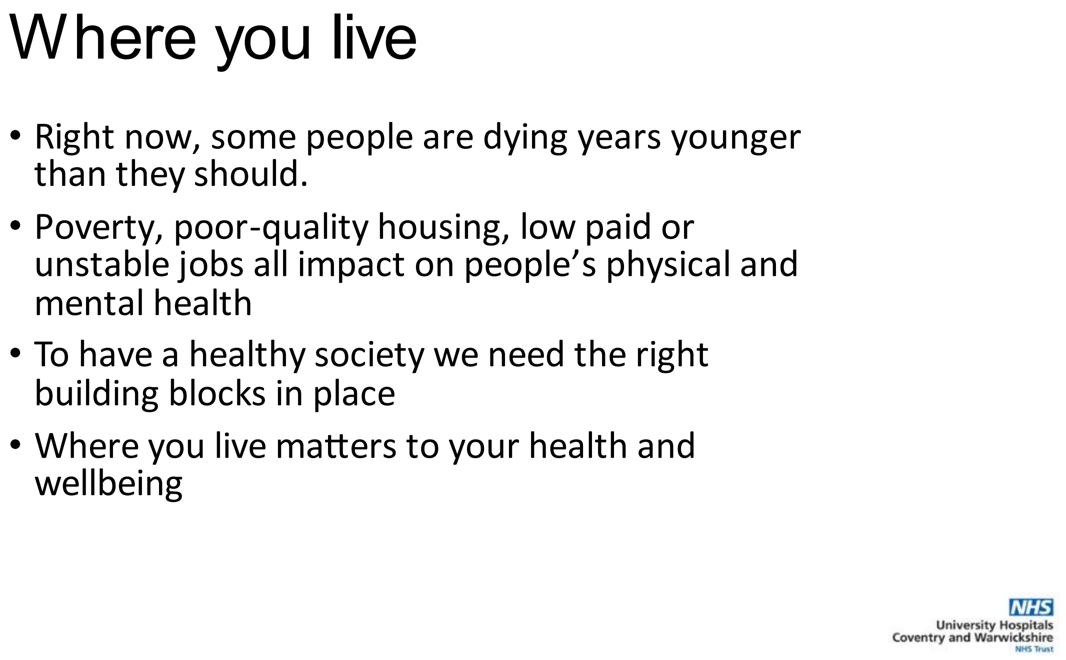
House keeping

- Recording and note-taking
- Confidentiality
- Quotes in final report, no attribution
- Respect each others’ views and be polite
- Turn off mobile or put on silent
- Breaks
- Minimise interruptions
- Grab a pen and some paper



Factors to consider (in no particular order)

Most important	Why?	Less certainty	Why?
Previous admission or readmission with condition	Costs the NHS money/burdens NHS if not addressed; on flip side, is at risk of incentivising gamification (i.e. admission + readmission)	Lifestyle factors e.g. diet, smoking, drinking	Some people felt that as these are self- inflicted, should not be prioritised based on lifestyle factors; other felt it unduly punitive to deprioritise someone due to lifestyle factors; some say prioritisation depends on if lifestyle factors has an effect on surgery.
Needing to attend A&E or GP because of their condition	Costs the NHS money/burdens NHS if not addressed, on flip side is at risk of incentivising gamification (i.e. admission + readmission)	Live in a more deprived area	Some questioned whether living in a deprived area actually leads to lower life expectancy; some questioned how to measure this.
Other health conditions that have an impact, or a previous diagnosis of cancer	Costs the NHS money/burdens NHS if health conditions worsen; on flip side previous diagnoses may have been addressed	Age	Some people think to prioritise children due to impact on future/well -being, others feel you cannot choose between a child and an adult —maybe have separate wait lists for the 2.
Other significant impact on quality of life	Could have a longer term impact on people's well-being, which may affect NHS costs further on down the line.	Unable to volunteer or work in local community while waiting	Covered by the factor: "unable to work while waiting"; substitutable.
Significant impact on mental health	Affects quality of life; can lead to other negative outcomes in lifestyle choices etc.	Ethnicity	Some unsure of how ethnicity might impact/affect prioritisation/affects health outcomes.
Unable to attend school / education while waiting	Can have a knock-on effect on future jobs/career prospects, causing a downward spiral for health.	Length of wait	Some say those who waited the longest should be prioritised (ie first come first served), others say length of wait does not correlate with severity of health condition.
Unable to work while waiting	Having financial means to live is vital, especially if patient is the breadwinner, and financial hardship can affect health outcomes.	NHS worker who is unable to work while waiting	Some groups mentioned this should be dependent on the type of role in the NHS; some say this can have an impact on the health system but then there are other key workers that should also be considered, as well.
		Disability	Some say prioritisation depends on the nature of disability because people can still function with a disability; some say they're disadvantaged regardless and should be prioritised.
		Carer for relative, friend or neighbour	Some say carers should be prioritised; some mentioned there are agencies that can provide care. Some say prioritisation depends on the level of care being provided, as caring can free us NHS resources.



Where you live

- Right now, some people are dying years younger than they should.
- Poverty, poor-quality housing, low paid or unstable jobs all impact on people's physical and mental health
- To have a healthy society we need the right building blocks in place
- Where you live matters to your health and wellbeing

Ethnic groups

- Some health issues are more common in some ethnic groups e.g. diabetes, heart disease
- More likely to live in more disadvantaged areas, experience poverty, poor quality housing etc.
- Racism and discrimination can make life even harder
- Social and economic conditions cause chronic stress, which directly affects health

NHS
University Hospitals
Coventry and Warwickshire
NHS Trust

Prioritisation of waiting lists

05.April.2022

Dr Mavis Machirori for:
Ipsos & UHCW public deliberation

Ada
Lovelace
Institute

List prioritisation and where data comes from

Waiting times - Elective care

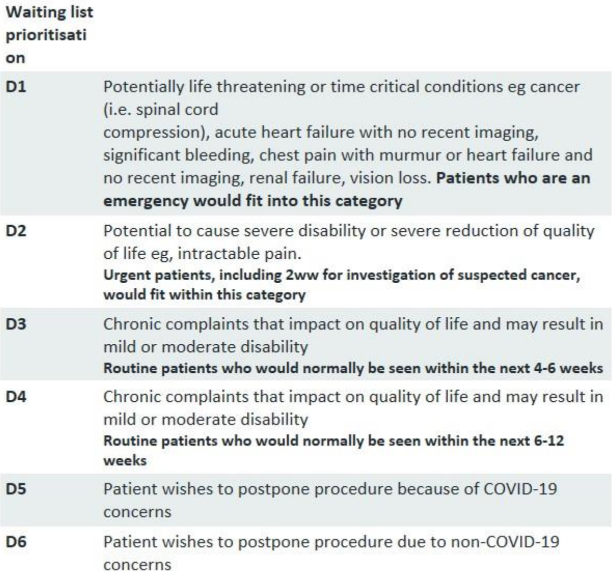
Covid-19 has placed challenges on our NHS services and we are delivering care differently to support patients across Scotland.

During the pandemic, patients have been seen and treated based on their clinical urgency and we will continue to do so whilst we remobilise our NHS.

Patients are being classified in the following groups:

- Priority Level 1a Emergency – operation needed within 24 hours
- Priority Level 1b Urgent – operation needed within 72 hours
- Priority Level 2 Surgery – scheduled within 4 weeks
- Priority Level 3 Surgery – scheduled within 12 weeks
- Priority Level 4 Surgery – may be safely scheduled after 12 weeks

Surgical vs diagnostic lists



Waiting list prioritisation	
D1	Potentially life threatening or time critical conditions eg cancer (i.e. spinal cord compression), acute heart failure with no recent imaging, significant bleeding, chest pain with murmur or heart failure and no recent imaging, renal failure, vision loss. **Patients who are an emergency would fit into this category**
D2	Potential to cause severe disability or severe reduction of quality of life eg, intractable pain. **Urgent patients, including 2ww for investigation of suspected cancer, would fit within this category**
D3	Chronic complaints that impact on quality of life and may result in mild or moderate disability **Routine patients who would normally be seen within the next 4-6 weeks**
D4	Chronic complaints that impact on quality of life and may result in mild or moderate disability **Routine patients who would normally be seen within the next 6-12 weeks**
D5	Patient wishes to postpone procedure because of COVID-19 concerns
D6	Patient wishes to postpone procedure due to non-COVID-19 concerns

Factors to consider in prioritisation – aims, data, contexts (and ethics?)

What are the issues in the UK?

The aims…

“UHC is the ultimate expression of fairness” and defined it as “ensuring that everyone can obtain essential health services of high quality without suffering financial hardship”
WHO Director General

The potential barriers…

Resources
- People e.g. staff
- Space e.g. beds
- Technologies (opportunities)

Covid
- Adding to previous health issues
- Creating new health vulnerable
- Covid mitigation measures

Winter
- Future beyond winter
- Future beyond Covid

Pr

Shielc
NHS I

Costanza P
29 June 202

https://
inform-l

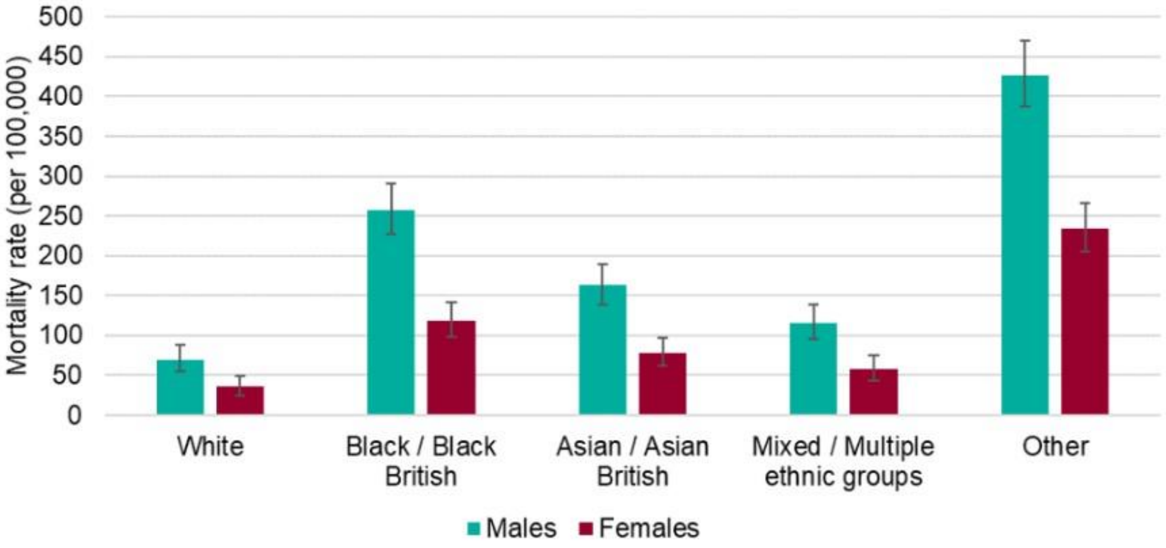


Figure 4.5. Age standardised mortality rates in laboratory confirmed COVID-19 cases by ethnicity and sex, as of 13 May, England. Source: Public Health England: COVID-19 Specific Mortality Surveillance System.

How do you rank?

A reflection on case studies

W visible

a

- tened to
- y, asylum
  funds)
  ng daytime
  inner, caring
- ivate renters-
  h
- l exclusion

Money and resources

1 IN 5 of the UK population live in poverty. Over half of these people live in working households. Poverty damages health and poor health increases the risk of poverty.

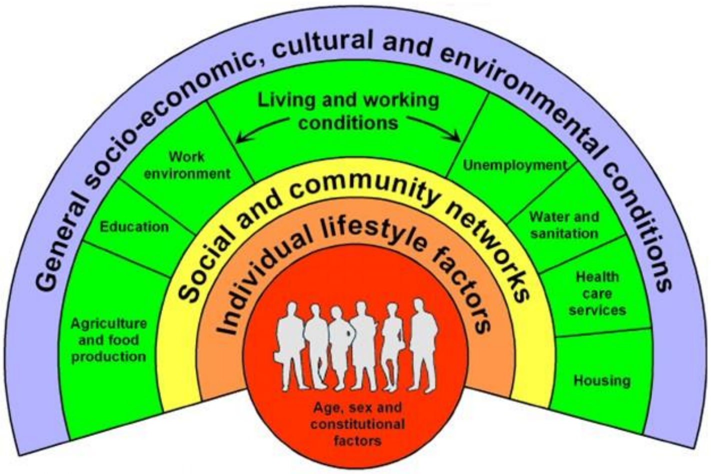
An inadequate income can cause poor health because it is more difficult to:

Avoid stress and feel in control	Access experiences and material resources	Adopt and maintain healthy behaviours	Feel supported by a financial safety net
Living with the day-to-day stresses of poverty in early childhood can have damaging consequences for long-term health	Money can allow people to access the basics they need to fully participate in society. Yet, 48% of 21-24 year-olds earn less than the living wage	Healthy behaviours can feel unattainable. It is 3 times more expensive to get the energy we need from healthy foods than unhealthy foods	A safety net enables people to invest in their future. In a recent study, 40% of people with unmanageable debt said they were less likely to study or retrain

The Health Foundation

References available at www.health.org.uk/healthy-lives-infographics

What makes a health experience? Contexts visible and invisible from data



Source: Dahlgren and Whitehead, 1991

- Changes by demographics or disease?

- Increasing attendance to AnE
  - Not attending prior screening
  - Not having health concerns listened to
  - Not able to see GP
    - No GP (e.g. migrant community, asylum seeker – no recourse to public funds)
  - Cannot take time off work (e.g. zero-contract hrs, breadwinner, caring responsibilities → can't time off for recovery
  - Covid
    - Increased mental health
    - New socially vulnerable e.g. private renters – earning enough but not enough
    - Digital exclusion – technological exclusion
    - Increased use of foodbanks
    - Increased unemployment
    - BME 2-3x mortality – even 'well off' like Drs

Some questions – what is the aim?

- **Economic recovery?**
  - The fittest to be treated first?
    - William > Norman based on perceived health status
    - Norman > William based on social support needs
- **Age priority**
  - Extend years lived or improve years left?
    - Sakesh > Lucy if years of life
    - Sakesh or Lucy if considering mental health impact
      - Don't know what kind of opportunities Sakesh has and has Lucy maximised hers?
    - Lucy or Sakesh if wider family support needs?

- ***How do you rate the worth and value of each of those factors? Individual or collective approach?***

- **Equity and correction of inequalities**
  - **What metric e.g. gender? Ethnicity? A mix?**
    - Reece or Sakesh if earnings and family support?
    - Sakesh's **mum** has to take time off
    - What of the obesity and bullying – state of mental health? Should we deal with that first?
- **Health behaviours**
  - Are we rewarding or punishing one's lifestyle
  - Wayne vs Norman?
    - Both have health issues
    - Both social issues which increase their need for mental health
    - Which of those takes precedent?

- ***What external non-health support is necessary if they are not prioritised?***

Ethical knots – and what if we agree? Should we automate waiting list decisions?

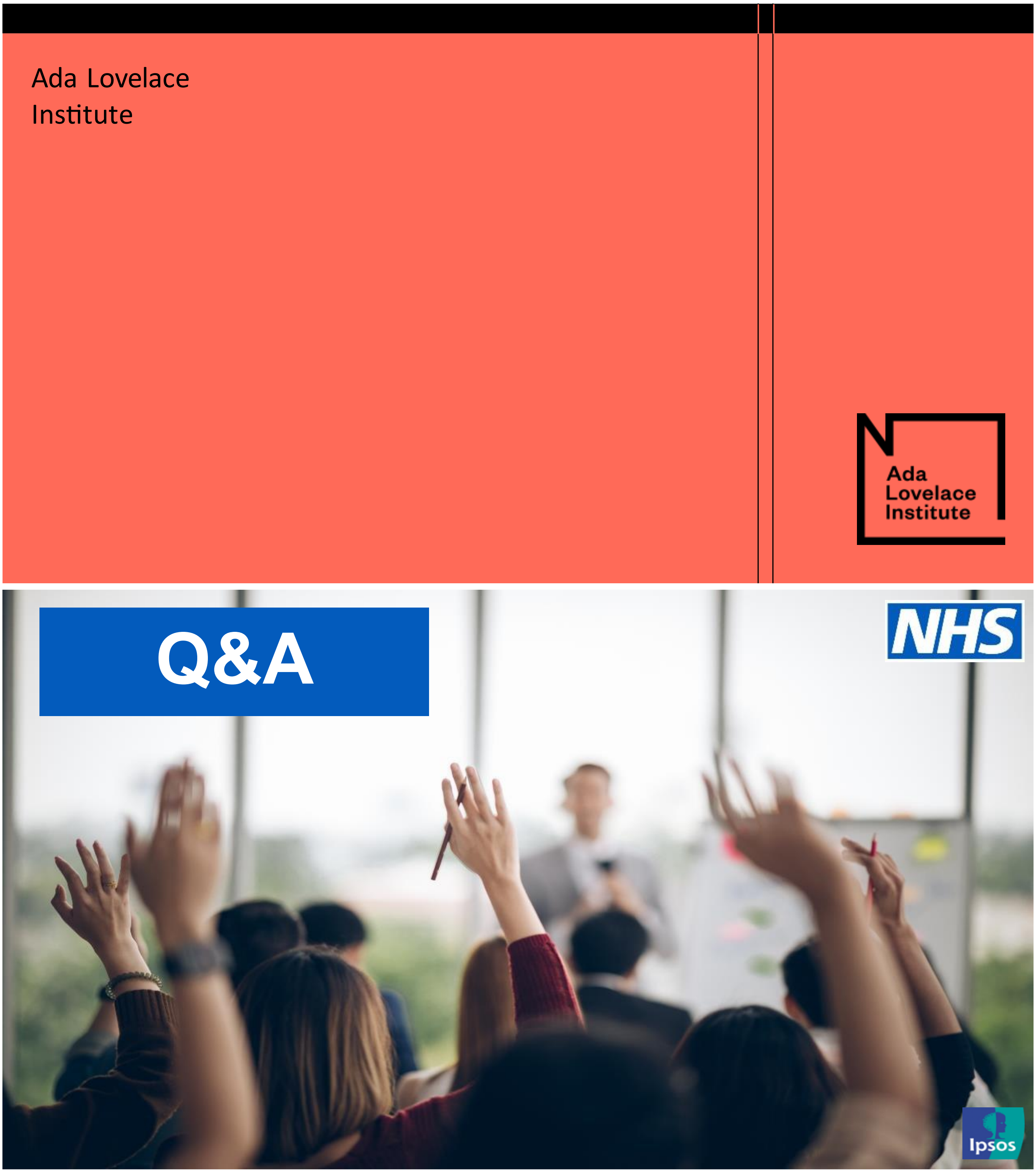
Further reflections

- Support structures needed
    - Voluntary sector
    - Social care system
    - General practice

- New tools on old structures?
    - Data accuracy and quality?
    - Data sharing across health and social care
        - Not all want this

- Can decisions be contested? By whom? How?

https://www.publicdomainpictures.net/en/view-image.php?image=20644

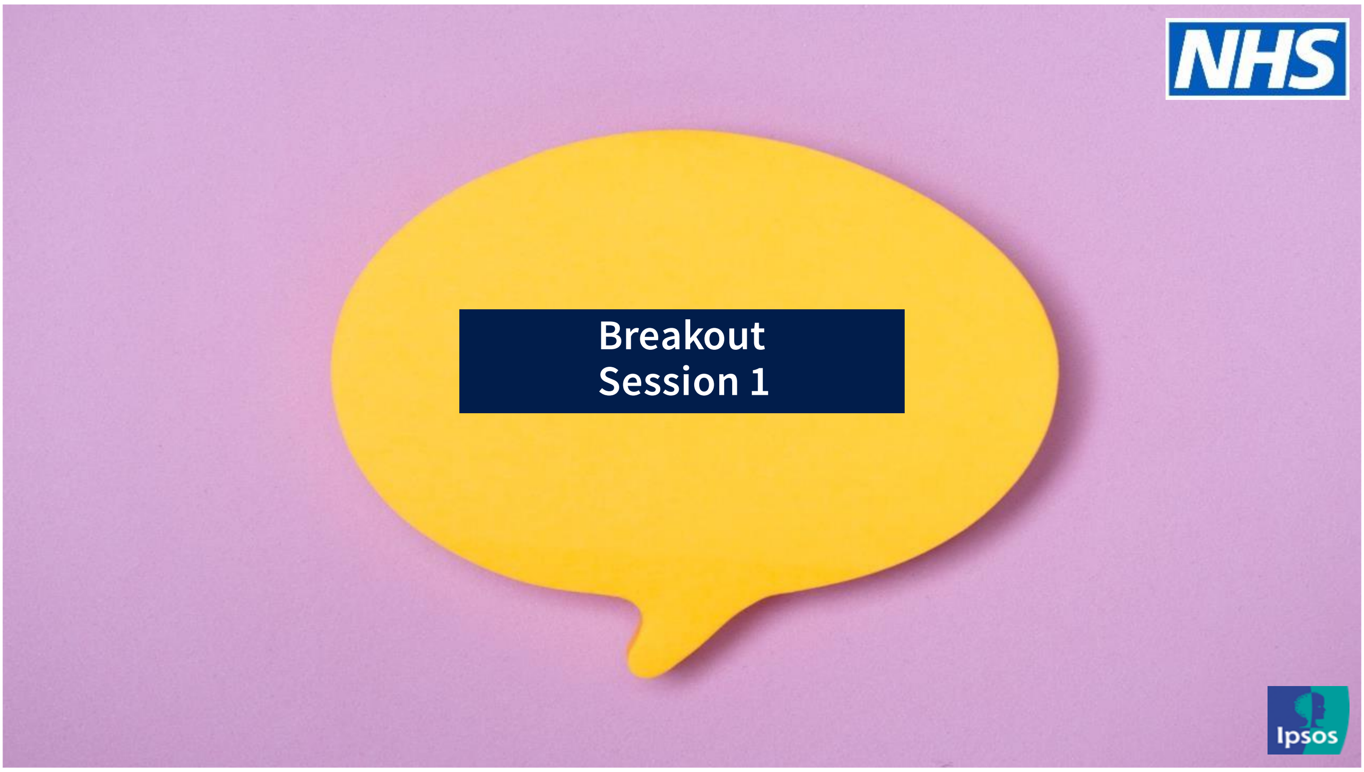


Ada Lovelace
Institute

Q&A

Comfort break: 10 minutes

Please be back for 7.05!



Breakout Session 1

Comfort break: 10 minutes

Please be back for 8.10!

Summary of waiting list prioritisation task


THANK YOU

Workshop 4

A deliberation on Coventry and Warwickshire's Waiting List Prioritisation

Workshop 4 - Thursday 7th April

This evening's agenda

Time	Discussion
6.00pm - 6.15pm	Welcome and presentation of draft expectations
6.15pm - 6.55pm	Group discussions
6.55pm - 7.05pm	Break
7.05pm - 7.45pm	Group discussions
7.45pm - 7.55pm	Break
7.55pm - 8.45pm	Presentations from each of the groups
8.45pm - 8.55pm	Specialist response on presentations from groups
8.55pm - 9.00pm	Next steps, thank you and close

What is deliberation & why are we doing it?

A partnership between policy and the public

- Deliberation – convenes a 'mini public' – you (of C&W)!
- Process of education and exploration – you as citizens working together not just individuals!
- Lived experience centred
- Dialogue with specialists (health + technical) to help you think through, with the support of stimulus materials (eg case studies and exercises) the key issues, explore and deliberate trade - offs associated with this.

This method ensures the NHS can understand public views that are carefully considered over a period of time, thus leading to more trusted and supported policy in the longer term.

Informed by your discussions, we pull together a report of the key themes for sharing. We are keen that this work influences how the NHS generally thinks about waiting times.

Review of the last workshop

Key themes

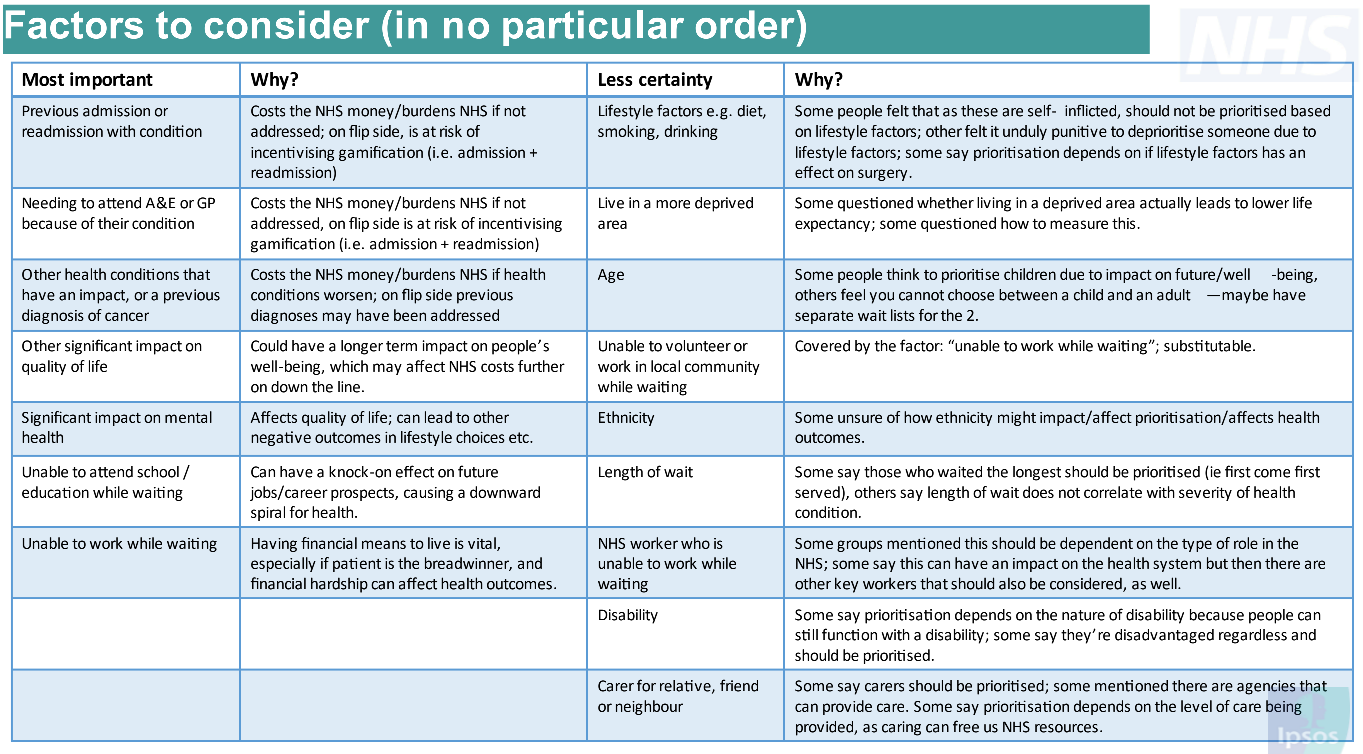
- Gamification is a risk to consider but most people feel this is not a huge risk, as it only applies to a small number of people
- Deprioritisation – are there factors (income/wealth) that could deprioritise someone from a waiting list?
- What about people we don't have enough information about?
- Some factors are interconnected
- We need to think more about how some factors interact with wait times, such as age, area of deprivation, ethnicity
- Inclusivity of groups i.e. elderly, retirees, those not tech savvy

House keeping

- Recording and note-taking
- Confidentiality
- Quotes in final report, no attribution
- Respect each others' views and be polite
- Turn off mobile or put on silent
- Breaks
- Minimise interruptions
- Grab a pen and some paper

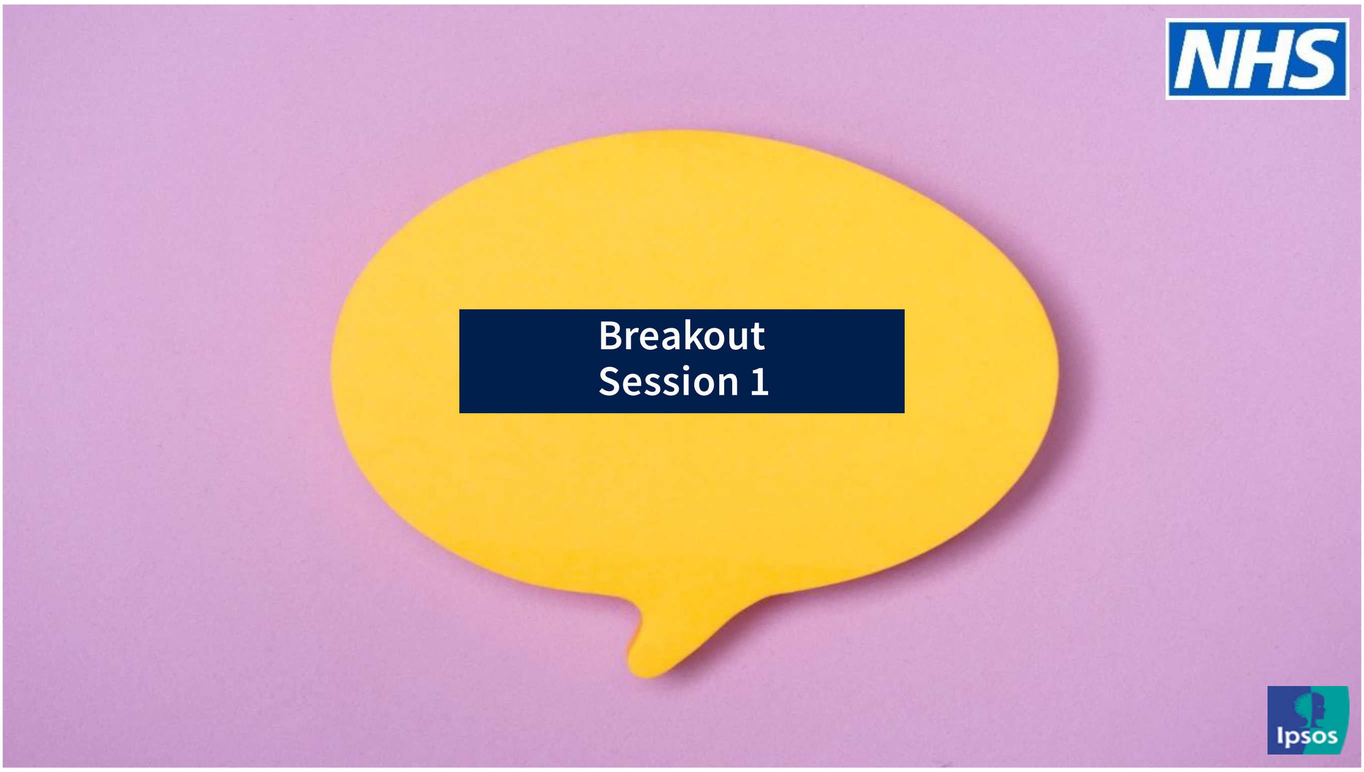
Ground Rules

1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. **Be patient** with other participants and the team – we have a lot of information to get through.
11. Feel free to share your thoughts about this event with **friends and family**.
12. If posting **about this event on social media** please do not share any detail of the discussions.



Factors to consider (in no particular order)

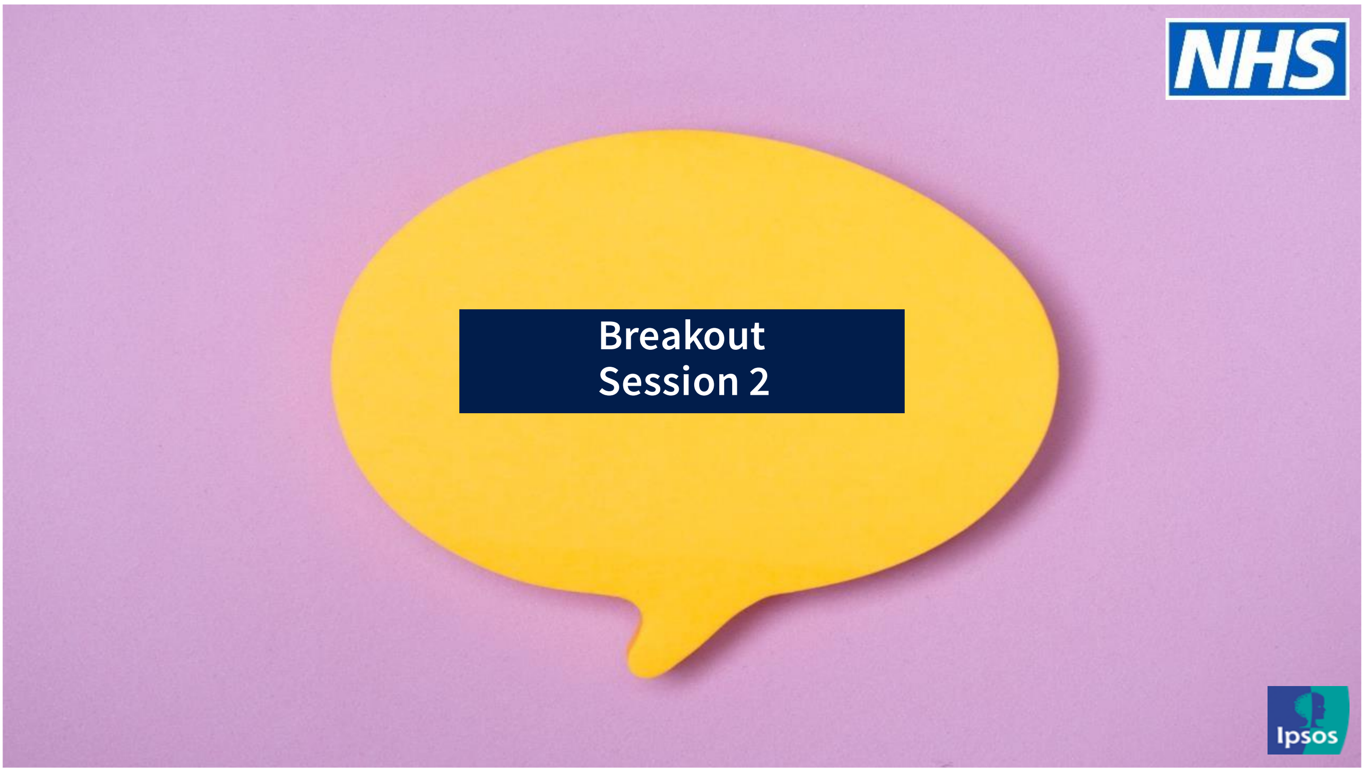
Most important	Why?	Less certainty	Why?
Previous admission or readmission with condition	Costs the NHS money/burdens NHS if not addressed; on flip side, is at risk of incentivising gamification (i.e. admission + readmission)	Lifestyle factors e.g. diet, smoking, drinking	Some people felt that as these are self- inflicted, should not be prioritised based on lifestyle factors; other felt it unduly punitive to deprioritise someone due to lifestyle factors; some say prioritisation depends on if lifestyle factors has an effect on surgery.
Needing to attend A&E or GP because of their condition	Costs the NHS money/burdens NHS if not addressed, on flip side is at risk of incentivising gamification (i.e. admission + readmission)	Live in a more deprived area	Some questioned whether living in a deprived area actually leads to lower life expectancy; some questioned how to measure this.
Other health conditions that have an impact, or a previous diagnosis of cancer	Costs the NHS money/burdens NHS if health conditions worsen; on flip side previous diagnoses may have been addressed	Age	Some people think to prioritise children due to impact on future/well -being, others feel you cannot choose between a child and an adult —maybe have separate wait lists for the 2.
Other significant impact on quality of life	Could have a longer term impact on people's well-being, which may affect NHS costs further on down the line.	Unable to volunteer or work in local community while waiting	Covered by the factor: "unable to work while waiting"; substitutable.
Significant impact on mental health	Affects quality of life; can lead to other negative outcomes in lifestyle choices etc.	Ethnicity	Some unsure of how ethnicity might impact/affect prioritisation/affects health outcomes.
Unable to attend school / education while waiting	Can have a knock-on effect on future jobs/career prospects, causing a downward spiral for health.	Length of wait	Some say those who waited the longest should be prioritised (ie first come first served), others say length of wait does not correlate with severity of health condition.
Unable to work while waiting	Having financial means to live is vital, especially if patient is the breadwinner, and financial hardship can affect health outcomes.	NHS worker who is unable to work while waiting	Some groups mentioned this should be dependent on the type of role in the NHS; some say this can have an impact on the health system but then there are other key workers that should also be considered, as well.
		Disability	Some say prioritisation depends on the nature of disability because people can still function with a disability; some say they're disadvantaged regardless and should be prioritised.
		Carer for relative, friend or neighbour	Some say carers should be prioritised; some mentioned there are agencies that can provide care. Some say prioritisation depends on the level of care being provided, as caring can free us NHS resources.



Breakout
Session 1

Comfort break: 10 minutes

Please be back for 7.05!



Breakout
Session 2

Comfort break: 10 minutes

Please be back for 7.55!

Presentations from groups/specialist response


THANK YOU

Citations

Duxbury, K. (2018). *Bringing the public along on the health tech revolution*. [online] Ipsos. Available at: https://www.ipsos.com/en-uk/bringing-public-along-health-tech-revolution.

GOV.UK (2021). *NHS Constitution for England*. [online] GOV.UK. Available at: https://www.gov.uk/government/publications/the-nhs-constitution-for-england.

Mackie, M. (2020). *Deliberative engagement with Londoners to steer the pandemic response*. [online] Ipsos. Available at: https://www.ipsos.com/en-uk/deliberative-engagement-londoners-steer-pandemic-response.

Public deliberation in the use of health and care data. (n.d.). [online] Available at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf [Accessed 28 May 2022].

The Strategy Unit. (2022). *Treating people on waiting lists: who decides what is fair?* [online] Available at: https://www.strategyunitwm.nhs.uk/news/treating-people-waiting-lists-who-decides-what-fair.

www.england.nhs.uk. (n.d.). *NHS England and NHS Improvement London» London COVID-19 Deliberation Report*. [online] Available at: https://www.england.nhs.uk/london/our-work/patient-and-public-involvement-reports/london-covid-19-deliberation-report/.

www.oecd.org. (n.d.). *Innovative Citizen Participation and New Democratic Institutions: Catching the Deliberative Wave | en | OECD*. [online] Available at: https://www.oecd.org/gov/innovative-citizen-participation-and-new-democratic-institutions-339306da-en.htm.

Our standards and accreditations

Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a "right first time" approach throughout our organisation.

ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation. We were the first company to sign up to the requirements and self-regulation of the MRS Code. More than 350 companies have followed our lead.

ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

This is the international standard for information security, designed to ensure the selection of adequate and proportionate security controls. Ipsos was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.

HMG Cyber Essentials

This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.

Fair Data

Ipsos is signed up as a "Fair Data" company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos.com/en-uk
http://twitter.com/IpsosUK

About Ipsos Public Affairs

Ipsos Public Affairs works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. Combined with our methods and communications expertise, this helps ensure that our research makes a difference for decision makers and communities.