September 2022

Prioritising the elective care waiting list in Coventry and Warwickshire

Executive Summary of Findings from a Public Deliberation

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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

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[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.

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