Delays to elective care

The experiences of waiting for nine people from Black, Asian or minority ethnic backgrounds

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VCSE Health and Wellbeing Alliance

This research has been conducted through the Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance). The HW Alliance is a partnership between voluntary sector representatives and the health and care system. Its purpose is to:

- provide a co-ordinated route for health and care organisations to reach a wide range of VCSE organisations
- support collaboration between VCSE organisations and provide a collective voice for issues related to VCSE partnerships in health and care
- enable health and care organisations and VCSE organisations to jointly improve ways of delivering services which are accessible to everyone by making it easier for all communities to access services will reduce health inequalities
- ensure health and care decision makers hear the views of communities which experience the greatest health inequalities
- bring the expertise of the VCSE sector and communities they work with into national policy making.

Background

Impact of the Covid-19 pandemic on waiting times

Already a challenge before the pandemic, waiting times have been significantly impacted by Covid-19.

The maximum waiting time target for non-urgent planned care in England is 18 weeks from referral to treatment with the standard set for at least 92% of patients to meet this target (NHS England, 2022). The 92% standard was last met in February 2016, and by January 2020, before the impact of the Covid-19 pandemic, more than one in six patients were waiting for more than 18 weeks (Charlesworth, Watt and Gardner, 2020).

The Covid-19 pandemic triggered system-wide changes in the NHS, with many resources diverted towards Covid-related services. Operating theatres and outpatient clinics were closed or repurposed and surgical staff were redeployed at scale (Carr et. al, 2021). This led to a sharp reduction in the number of elective care procedures, treatments and appointments taking place during the pandemic.

The number of people in England waiting for treatment for more than a year increased 185-fold between January 2020 and January 2021 (NHS England, 2021).

Health inequalities

- People from Black, Asian and ethnic minority backgrounds in England experience significant health inequalities (Cookson et. al, 2016). For example, people from these groups face a ‘markedly higher’ mortality risk from Covid-19. Research indicates a range of reasons including over-representation in lower socio-economic groups, disproportionate employment in lower-band key worker roles and co-morbidities (OCEBM, 2020).
- There is growing evidence that longer waiting times for elective care disproportionately affect the most socioeconomically deprived groups in England (Marmot et. al, 2020; Healthwatch, 2022).
- In May 2021, an NHS Trust found that patients from minority ethnic groups waited 7.8 weeks longer than white patients for elective care procedures (Discombe, 2022).
- In November 2021, Healthwatch England published the results from a survey of people currently waiting for treatment, or who had received treatment in the last 18 months. It found that non-white respondents were less likely to feel supported and to feel that they were given clear, accessible information than their white counterparts (Healthwatch, 2021).
- In June 2022, a Healthwatch England study found that people from ethnic minority backgrounds are more likely to have had their treatment delayed or cancelled than respondents from white British backgrounds (57% vs 42% respectively). The study also found that people from ethnic minority backgrounds were also more likely to have been given a week or less notice before their care was delayed or cancelled than people from white British backgrounds (51% vs 37% respectively) (Healthwatch, 2022).

Individuals from Black, Asian and minority ethnic backgrounds are underrepresented in much of the research which explores the impact and experience of waiting for elective care. This research makes a valuable contribution to existing literature in this area. The qualitative approach provides rich, subjective detail which compliments the quantitative data evidenced above, enhancing understanding about the lived experience and impact of waiting for elective care for this group.

Aims

To explore experiences of wating for elective care in England since the start of the Covid-19 pandemic, from the perspective of people from Black, Asian and ethnic minority backgrounds.

1. To understand how waiting for elective care impacted participants’ lives.
2. To explore factors which influenced participants’ experiences of waiting for elective care – either positively or negatively.
3. To understand what would have improved participants’ experiences of waiting for elective care.

Method

- The research took an in-depth, qualitative approach consisting of face-to-face interviews with nine participants, conducted in their homes. The interviews averaged two and a half hours long, allowing the participants time to open up about sensitive issues.
- The discussion guide was broad, with the twin goals of getting to know the person and their life experience and gathering details about their health problems and their experience of waiting for care.
- There were nine participants in total:
- three men, six women
- between ages 25-75
- living in different parts of England
- varying levels of severity of symptoms
- varying lengths of time waiting for elective care (from months to years)
- different ethnic backgrounds
- waiting for a range of elective care referrals.

The participants

- Amaya is a British Asian* woman in her late 30s. She lives in a big city in East Midlands. She is waiting for an appointment with a gynaecologist to explore severe period pains and bleeding post childbirth.
- Charlotte is a Black British* woman in her late 50s. She lives in North West London. She has been waiting to see a specialist at a lymphedema clinic where she hopes to receive treatment to help improve the symptoms of her condition.
- Elijah is a Black British* man in his early 50s. He lives in North West London. He has been waiting for over six months for an appointment with a consultant regarding his knee pain.
- Gia is a Trinbagonian* woman in her early 70s. She lives in North East London. She is waiting for neuromodulation treatment for her lower back pain and mobility issues.
- Jaz is a British African* woman in her late 40s. She lives in South East England. She recently waited over eight months to receive surgery to remove fibroids on her uterus.
- Saff is a British Pakistani* man in his mid 50s. He lives in a city in North West England. He has been waiting for over a year to receive in-person counselling for severe mental ill-health.

The participants (cont.)

- Simon is a Jewish* man in his 70s. He lives in a small town in South East England. After waiting over six months for a date for surgery to remove his kidney stones, he discovered he was not on any waiting list (it is unclear whether Simon was never put on a wait list or whether he was taken off within that time).
- Tulisa is a Black British* woman in her late 40s. She lives in a city in North East England. She is waiting for counselling, support for weight management, an x-ray for her spine, and physiotherapy to help manage pain.
- Yana is a mixed White/Black Caribbean* woman in her early 20s. She lives in a large city in South West England. She is waiting for surgery to repair a torn anterior cruciate ligament in her knee.

** Ethnicity was self-identified by the participants. Terms used reflect how the participants describe themselves, and how they want their ethnicity to be described in this report. All names are pseudonyms.*

1. The impact of waiting for care

Deterioration in existing health conditions

Deterioration in the condition or symptoms that participants were waiting to be treated for was often the first negative consequence of waiting that people mentioned. All participants who had experienced deterioration spoke about the tangible ways their health had deteriorated. For example:

- During her year-long wait for surgery to fix a tear in a ligament in her knee, Yana experienced deterioration in her condition, which involved frequent dislocations of her kneecap and increased pain. She was concerned that this could lead to permanent damage.

- Simon experienced significant deterioration of his condition and increased pain in the time he was waiting for his kidney stone removal surgery. Having initially been told surgery was urgent, Simon waited for six months to receive an update. In that time, he had called an ambulance twice due to the severity of the pain he was suffering.

"The pain just came back, and I'm still prescribed morphine solution. And when the pain is really bad, I can have up to four doses a day" (Simon, mid 70s)

The emergence or worsening of other health problems

Some respondents found that new health problems developed while waiting. For example:

- During her wait for weight management treatment, Tulisa experienced a rapid deterioration in other conditions which she had. Tulisa feared that this would continue to be the case whilst she waited, as she may continue to gain weight, and consequently, the pain in her legs and back would worsen.

> "*I'm a short woman. You don't see a lot of women my size with my weight. I know as I'll get bigger, everything will get worse…not just my knees*" (Tulisa, late 50s)

- Amaya reported that her mental health was deteriorating as a result of her wait to have a consultation with a gynaecologist.

> *"That's the worst thing… and it's been really making me struggle mentally too, because of the hormones going up and down, you know, and it's just horrible" (Amaya, late 30's)*

Impact on personal life

Reports of feeling uncertain, helpless, and frustrated were common among participants. Some felt that their future and their goals was dependent on receiving the treatment or procedure they were waiting for. Many reported feeling that their lives were ‘on hold’.

Many participants reported an impact on their ability to socialise and maintain relationships. For example:

- Whilst waiting for treatment for his knee, Elijah was unable to play football in the park with his son, due to pain and immobility. Feeling that he could not offer his son something which he wanted, Elijah worried about missing out on time of bonding and connection and felt that that he would struggle to make up for lost time together.

  “You see fathers and sons playing in the park all the time but that’s not us and I don’t know when it will be” (Elijah, early 50s)

- Charlotte reported paying £50 weekly for massages to manage her lymphedema while waiting for treatment at the specialist lymphedema clinic. While she considers this to be ‘essential’ for managing her symptoms, the cost has meant ‘sacrificing’ her social life. She listed the things that she previously enjoyed such as going out for dinner and going to concerts with friends as activities that she was no longer able to afford. With a lack of participation in these social events, Charlotte felt she was losing her friends.

  “I don’t see my friends as much as I’d like to these days because I can’t afford to. I’ve got my daughters, but I guess they will move out soon” (Charlotte, late 50s)

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Impact on professional life

Some participants reported that their wait for care was having an impact on their career. For example:

- Elijah’s career ambitions were on hold due to the uncertainty of not knowing when his specialist appointment would be, and what would happen after it. He wanted to change career, but was unable to apply for jobs that would require him to travel to the office regularly due to his knee pain.

*“Imagine if I moved jobs then have to go into surgery in my first week with time off to recover. Would look bad, wouldn’t it?” (*Elijah, early 50s)

- Whilst waiting for treatment for her knee injury, Yana was unable to keep her job because it required standing up for long periods which exacerbated the condition. This had huge financial repercussions for Yana, who eventually had to apply for Universal Credit. She wished she could have had someone to talk to about the impact of the wait on her finances and work, and to get advice about how to manage this.

“*No-one asked how I was or gave me advice on the other things happening in my life… what am I meant to do if I can’t work for 2 months*?” - Yana, mid 20s

2. Factors influencing the experience of waiting

Communication and information

- Time spent waiting for treatment was a period of uncertainty for all participants. Many reported feeling anxious about what was to come and feeling that they'd lost some control of their lives.
- Participants who felt that they had received good communication about their wait and care felt more confident about where in the waiting journey they were. Knowing what was to come gave participants a greater sense of control and certainty. This sense of control allowed participants to feel more comfortable and relaxed as they went about their day-to-day lives, devoting a relatively small part of their day spent thinking about their waiting time.
- Many participants, however, felt there was a lack of communication from healthcare professionals about essential information.

"Communication seems not to exist. It works like friends when you have those who are happy for you to ring them, but they never seem to ring you. We are made to feel that they are so busy, and we shouldn't disturb them" (Simon, mid 70s)

"*I was given no information, nothing to read, nothing to go home and study*" (Gia, early 70s)

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Problems with communication

- Often, participants were unaware of who was responsible for their care at any given point. This could make it difficult to know who to contact for updates about how far along they were in their wait journey.

- The point at which the referral was made from the GP to the hospital/specialist service was the point that participants found most unclear.

> "*Yeah, there was a period where I didn't know where I stood. I tried ringing my old GP, but they didn't know anymore... My new GP was confident that he passed details along to the hospital but I ain't heard anything from them in a while*" – (Elijah, early 50s)

- Some participants who had received communication about their wait and condition felt that the way it was communicated to them was not appropriate. This included the information being rapidly communicated, with limited opportunity to reflect or ask questions, and communications which used inaccessible and complicated medical terminology.

- Those who received little or confusing communication tended to spend more time worrying about the uncertainties of their wait time and the care they were going to receive.

Expectation management and information about outcomes

- Most people understood that there could be no guarantees about the outcome of treatments and procedures, but many felt they knew very little about what the possible outcomes could be.

“Best case scenario, they tell me it won’t get worse. Worst-case scenario, it spreads to my other knee, gets worse and they have to operate… I just don’t know what’s going to happen” (Elijah, early 50s)

- Yana had similarly received little information about what the outcomes could be of the surgery she was waiting for. She began to worry about the lasting impacts of the procedure. Being unsure about who to ask about this she had resorted to watching videos of the surgery on YouTube.

- Several participants suggested that clear and straightforward communication about the possible outcomes of their procedure or treatment would help them to feel less nervous and uncertain whilst waiting.

- For example, a nurse took the time to explain to Charlotte that her lymphedema was not as severe as others in the clinic and therefore, she was not a priority, and would wait longer. Whilst disappointed, this conversation meant that Charlotte felt informed and this reduced her feelings of uncertainty.

Ability to self-manage condition/s

Participants who were able to take an active role in managing their symptoms and conditions tended to have a better experience of waiting than those who could not. For example:

- Charlotte used YouTube to find ‘self massage’ techniques to alleviate her lymphedema swelling. She also managed her diet, limiting foods which were known to worsen the condition.
- Jaz spent time researching her condition and looking at pain management techniques while waiting.

Other participants were less able to actively manage their conditions and felt reliant on healthcare professionals for advice, recommendations and support. Where this support was not available from healthcare professionals, they struggled to access it elsewhere. Saff, for example, felt a lack of agency around being able to improve his situation or manage his mental health whilst he waited for face-to-face counselling. Consequently, he felt pessimistic about accessing other types of support such as remote counselling.

Financial position

- Some participants who could afford to, redirected their finances towards their health, paying for private additional health support such as massages and physiotherapy to help manage their symptoms whilst they waited.
- Some of these participants found that this had financial repercussions affecting other aspects of their life. Gia, for example, was able to pay for private physiotherapy, but this meant using her pension and resulted in her having to budget for groceries, which she had not previously had to do.
- Paying for additional private healthcare support was not a financially viable option for most of the participants, many of whom felt powerless to improve their position. Those who could afford to pay for private healthcare were in an advantageous position compared with those who could not access these routes and tended to have a better experience of waiting.

3. Opportunities for improvement:

Improving communication

- All nine participants suggested that communication was the main thing which would improve their experience of waiting.
- Participants said that they would value concise, clear information in multiple forms, including phone calls and letters. Many stressed the importance of this information being tailored to their specific needs.
- Although none of the participants referenced My Planned Care, the insights from the participants should support its ongoing development across England.
- Participants suggested that they would find the following information useful:
  - Information about their condition
  - Information about the medical investigation or treatment itself, including: what it might involve, what the possible complications might be, and what the likelihood of a ‘successful’ outcome is
  - More regular, proactive updates to confirm that they were still on the waitlist, give a rough sense of how long they would be waiting and reassure them that if anything was to change, they would be made aware
  - Clearer information about who to get in touch with, and how to get in touch if they had a query regarding their wait or health condition
  - Information about how to self-care which would enable them to take ownership of their own health
  - Information about how to get support with the wider impacts of their health condition on their life in general. (Emphasis here on *how* to do it rather than just *what* they need to do).

Formal support to manage condition/s

- Some participants felt that they would have benefitted from professional support to manage symptoms and/or motivate, encourage and support them to engage in activities would help them stay well and avoid a decline in their health condition whilst they wait.

- Some participants simply wanted to be asked how they were – to ‘check in’ about how they were coping during their wait.

- Some participants also mentioned that they would value being signposted to voluntary or community groups where they could get support for either their condition, or the knock-on effects of their condition (such as the personal and professional impacts outlined in this report).

Peer support

- There was some appetite for peer support and information, especially if individuals could be connected to others who had a similar healthcare experience to them and could help them to better understand what to expect. Some participants felt this might help them feel less alone with what they were going through.

Conclusion

- The aim of this research was to explore experiences of wating for elective care in England, from the perspective of people from Black, Asian and ethnic minority backgrounds.
- Participants reported a range of detrimental impacts of waiting for care. These included a deterioration existing health conditions, the emergence new health problems, and negative effects on their personal and professional lives.
- Participants' experiences of waiting were shaped by the quality of the communication and information they received, the extent to which they were able to manage their condition/s, and their financial position.
- Participants suggested a number of ways to improve patients' experiences of waiting for elective care. These were: improving communication, better support to manage symptoms, and access to informal and peer support.

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