Cancelled care research

July 2023
About the research

We commissioned Yonder Data Solutions to run an online survey to learn about the impact of postponements and cancellations of recent or planned care or appointments in 2023.

This was against the context of the rising elective list, the ongoing impact of the pandemic and industrial action by NHS staff, and the proactive sharing of information by the public with the Healthwatch network about the impact of disrupted care caused by staff strikes.

Fieldwork was carried out between 26 June and 3 July 2023 in two phases:

1. An initial survey of 1,038 people, nationally representative (NAT REP) by age, gender, region, social grade and ethnicity, to understand: how many were NHS users and, of those, how many had care cancelled in 2023.

   Out of 1,038, 55% (568) confirmed they were an ‘NHS user’, which meant they either had an appointment for, had recently had an appointment for, or were on a waiting list for a diagnostic test/scan, operation/procedure, hospital outpatient appointment, or community hospital/service appointment. Of this group of 568 people, 141 people (25%, or 1 in 4) said they their care had been cancelled.

2. To look beyond the topline statistics in the initial sample, Yonder continued with fieldwork to BOOST the number of respondents to reach a total sample of 1,084 people whose care had been cancelled or postponed in 2023.

Where different demographic groups are compared in the findings, e.g. carer versus non-carer, only those where significant differences (5% risk level) have been found, are displayed.
Key findings

- Initial research identified that 55% of a nationally representative sample of 1,038 people, in 2023, had used or were waiting to use NHS services (planned elective care, outpatient appointments and community health appointments).

- 25% of those NHS users had had their care cancelled.

- To look beyond those topline statistics, we boosted the research to reach a total sample of 1,084 people whose care had been cancelled in 2023, to find:
  - 39% had had their care cancelled on two or more occasions.
  - 18% said their care was cancelled at the last minute (on the day or upon arrival).
  - Certain groups were more likely to report that their care had been cancelled multiple times. These included disabled people, 52%; neurodivergent people, 51%; and people on lower incomes, ethnic minorities and LGBTQ+ being affected the most, 49% respectively.
Key findings (continued)

• 66% reported significant impacts on their lives due to the cancelled care, such as worsening mental health, ongoing pain and disrupted sleep.

• Certain groups were more likely to report these impacts. These included unpaid carers, 84%, and neurodivergent people, 83%; followed by people on low incomes, 80%; and those from minority ethnic backgrounds, 75%.

• 25% had not been given a new date for their care.

• 79% said they had been offered 'very little' or 'no' support to manage mental health needs during their new wait.

• 15% said the NHS told them their cancellation was due to strikes, 25% believed this was the reason, 41% said another reason and 20% didn't know why.
Sample explained

- Not applicable, 45%
- At least one of the NHS services apply, 55%
- No, 75%
- Postpone cancel, 25%
- Postpone cancel, 100%
- Experienced postponement or cancellation, 100%

Nat rep sample* 1,038
NHS users 568
Experienced postponement or cancellation 141
Boost sample 1,084

Screen → Boost

* The sample used is randomly selected in accordance with a nationally representative make-up of the adult population within England. A 98.2% weighting efficiency was achieved meaning that the sample naturally matches the nationally representative population at a very high level, so very little weighting was needed on the data.

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Findings: The cancellation experience

- 39% of the 1,084 people who had care cancelled, said this happened on two or more occasions.
- 45% said the cancellation happened between one and seven days beforehand.
- 18% had had their care cancelled at the last minute (on the day or on arrival at their appointment, to use the NHS definition of last-minute cancelled elective care).
- The following slide shows which groups experienced two or more cancellations, more than others.
Two+ cancellation or postponements

Boost sample

Those more likely* to have had two or more NHS postponement or cancellations are:

- Base (cancelled or postponed): 39%
- Aged 25-34: 46%
- Not white: 49%
- Disabled: 52%
- Neurodivergent: 51%
- LGBTQ+: 49%
- Really struggling financially: 49%

* Some people (e.g. disabled people) may be higher users of the NHS generally so maybe more likely to experience cancellation or postponement
Consequences of delay
Boost sample

66% of those who’d had a cancellation or postponement for any reason, experienced consequences of some kind as a result

- It negatively impacted my mental health: 25%
- I suffered on-going pain: 26%
- My ability to sleep was affected: 19%
- My condition/symptoms got worse: 23%
- It negatively impacted my physical fitness: 15%
- It led to further problems/complications: 9%
- It negatively impacted my ability to work: 6%
- I needed additional care from friends: 6%
- I experienced loss of income or increased: 9%
- My ability to care for a loved one (e.g. child): 5%
- It negatively impacted my relationship: 5%
- I needed social care support: 2%
- There were no consequences: 34%
- Something else: 3%
- Don’t know: 1%

Base: 1,084 (have experienced a cancellation or postponement)
Consequences for communities

Boost sample

Those more likely to experience any consequences as a result of the NHS postponement or cancellations were:

- Base (cancelled or postponed): 65%
- Aged under 35: 74%
- Not white: 75%
- Carer: 84%
- Neurodivergent: 83%
- Really struggling financially: 80%
Consequences for carers

Boost sample

Consequences of the NHS postponement or cancellations: Carer versus non-carer.

- My ability to care for a loved one (e.g. child or elderly parent) was affected: 21% (Carer) vs 2% (Not carer)
- It led to further problems/complications: 17% (Carer) vs 7% (Not carer)
- I experienced loss of income or increased costs: 14% (Carer) vs 8% (Not carer)
- It negatively impacted my relationship: 10% (Carer) vs 4% (Not carer)
- I needed additional care from friends/family: 11% (Carer) vs 5% (Not carer)
- It negatively impacted my ability to work (paid or voluntary): 9% (Carer) vs 5% (Not carer)

When carers are impacted, so are the people they care for.

Base: not carer 923, carer 161
Consequences for neurodivergent

Boost sample

Consequences of the NHS postponement or cancellations: Neurodivergent versus not neurodivergent.

<table>
<thead>
<tr>
<th>Consequence</th>
<th>Neurodivergent*</th>
<th>Not ND</th>
</tr>
</thead>
<tbody>
<tr>
<td>It negatively impacted my mental health</td>
<td>23%</td>
<td>52%</td>
</tr>
<tr>
<td>I suffered on-going pain</td>
<td>24%</td>
<td>40%</td>
</tr>
<tr>
<td>My condition/ symptoms got worse</td>
<td>22%</td>
<td>37%</td>
</tr>
<tr>
<td>I experienced loss of income or increased</td>
<td>7%</td>
<td>22%</td>
</tr>
<tr>
<td>It led to further problems/complications</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>It negatively impacted my relationship</td>
<td>4%</td>
<td>11%</td>
</tr>
<tr>
<td>I needed additional care from friends/ family</td>
<td>5%</td>
<td>12%</td>
</tr>
</tbody>
</table>

Neurodivergent people were more impacted overall than other groups and the heaviest impact was on their mental health.

*Caution as this was a small base – further research recommended for this group.

Note: Neurodivergent people were more likely to be struggling financially and/or be LGBT+.

Base: not neurodiverse 1,001, neurodiverse 83* (small base)
Consequences by financial status

Boost sample

Consequences of the NHS postponement or cancellations: Financial status.

Those really struggling financially, also experienced high impact compared to other groups.

- It negatively impacted my mental health
- My condition/symptoms got worse
- My ability to sleep was affected
- I suffered on-going pain
- It negatively impacted my physical fitness
- It led to further problems/complications
- I experienced loss of income or increased costs

Base: very comfortable 85* (small base), quite comfortable 437, just getting by 440, really struggling financially 116

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Consequences by ethnicity

Boost sample

Consequences of the NHS postponement or cancellations: Ethnicity.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Not white</th>
<th>White</th>
<th>Impacts more on life factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>I experienced loss of income or increased costs</td>
<td>7%</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>It negatively impacted my ability to work (paid or voluntary)</td>
<td>5%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>It negatively impacted my relationship</td>
<td>5%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>My ability to care for a loved one (e.g. child or elderly parent) was been affected</td>
<td>4%</td>
<td>8%</td>
<td></td>
</tr>
</tbody>
</table>

Base: white 804, non-white 280
Consequences for disabled people

Boost sample

Consequences of the NHS postponement or cancellations: Disabled versus not disabled.

Base: Not disabled 868, disabled 216

- My condition/ symptoms got worse: 38% (Disabled) vs 19% (Not disabled)
- I suffered on-going pain: 38% (Disabled) vs 23% (Not disabled)
- It negatively impacted my mental health: 36% (Disabled) vs 22% (Not disabled)
- My ability to sleep was affected: 26% (Disabled) vs 17% (Not disabled)
- It negatively impacted my physical fitness: 24% (Disabled) vs 13% (Not disabled)
- It negatively impacted my relationship: 10% (Disabled) vs 4% (Not disabled)
- I needed additional care from friends/ family: 10% (Disabled) vs 5% (Not disabled)

Impacts more on their physical and mental wellbeing
Consequences if you’ve a long-term condition

Boost sample

Consequences of the NHS postponement or cancellations: Long-term condition versus no long-term condition.

I suffered on-going pain

- Long-term condition: 34%
- No LTC: 21%

My condition/ symptoms got worse

- Long-term condition: 32%
- No LTC: 18%

It negatively impacted my mental health

- Long-term condition: 30%
- No LTC: 22%

Impacts more on their physical and mental wellbeing

Base: no long-term condition 694, long-term condition 390
Information and support while waiting

- 24% of the 1,084 people whose care had been cancelled, had not been given a new appointment or procedure date and of this group, 82% said the NHS hadn’t told them when they would receive a date.
- 79% said they had been offered 'very little' or 'no support' by the NHS to manage mental health needs during their wait.
- 52% said they had not been offered support by the NHS to manage their medical symptoms during their wait.
- 24% said they had a 'a lot of support' during their wait to manage needs.
- 21% said they had received 'a little support'.
Reasons for cancelled care

Boost sample

▪ 15% of 1,084 people said the NHS told them that their cancellation was due to strike action.
▪ A further 24% of people thought strike action was the reason.
▪ 41% said the cancellation was for another reason.
▪ 20% didn’t know why.
Solutions
Our calls for change

NHS England, Integrated Care Boards and NHS providers should do more to:

- Collect and publish official data on cancellations to understand what is driving non-clinical, clinical and/or patient-led reasons for delay.

- Use this data to reduce the high number of last-minute cancellations.

- Offer more significant support to those most affected by new delays, especially with mental health needs.

- Improve admin and communication to close the gap for those who are left in limbo with no new date.

- We also renew calls to government and unions to reach a resolution to mitigate the impact of strikes on cancellations or postponements.
Appendices
Appendix 1: what we asked

• Which of these NHS services have you (a) recently had in 2023, (b) currently have a scheduled appointment for or (c) are on a waiting list for.

• Have any of the NHS services you’ve had or are due to have, been CANCELLED or POSTPONED in 2023?

• How many times was the NHS service you’ve had or are due to have been CANCELLED or POSTPONED?

• How much notice were you given that your NHS service was being CANCELLED or POSTPONED? (If there is more than one, please consider the most important one to you)

• Did the NHS strikes have anything to do with the POSTPONEMENT or CANCELLATION of your NHS service?

• What were the consequences of the POSTPONEMENT or CANCELLATION?

• Were you given a new date?

• Has the NHS kept you informed about when you’re likely to get a new date?

• What level of support were you given to help manage your medical condition while you were waiting (or are currently waiting) for your appointment?

• What level of support were you given to help with your mental wellbeing while you were waiting (or are currently waiting) for your appointment?
Appendix 2: defining NHS patients

Q9. Which of these NHS services have you (a) recently had in 2023, (b) currently have a scheduled appointment for or (c) are on a waiting list for.

Those ticking any of the relevant boxes were considered users of NHS services in 2023 and potentially affected by the strikes. 55% of the nat rep sample fall into this category.

<table>
<thead>
<tr>
<th>Service</th>
<th>(a) I have recently (2023) had an NHS...</th>
<th>(b) I have an NHS appointment scheduled for...</th>
<th>(c) I am on an NHS waiting list for...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic test/ scan</td>
<td>21%</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>Operation/ procedure</td>
<td>6%</td>
<td>3%</td>
<td>7%</td>
</tr>
<tr>
<td>Hospital outpatient appointment</td>
<td>25%</td>
<td>19%</td>
<td>7%</td>
</tr>
<tr>
<td>Community hospital/ service appointment</td>
<td>9%</td>
<td>5%</td>
<td>1%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>55%</td>
<td>68%</td>
<td>82%</td>
</tr>
<tr>
<td>Base</td>
<td>1038</td>
<td>1038</td>
<td>1038</td>
</tr>
</tbody>
</table>

Applicable: 45% 
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Appendix 3: Comparing samples

We used screening questions to reach the relevant people in the NAT REP sample who have experienced cancellation or postponement in 2023.

In order to look beyond the topline statistics in the NAT REP sample, we continued with fieldwork to BOOST the number of respondents who experienced cancellation or postponement to over 1,000 – allowing meaningful comparison between different demographics. We also attempted to include greater numbers of ethnic minority and lower financial status respondents.

<table>
<thead>
<tr>
<th></th>
<th>Nat rep</th>
<th>Boost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total respondents</td>
<td>1038</td>
<td>1084</td>
</tr>
<tr>
<td>Used/using/waiting to use NHS services in 2023 (NHS patients):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NHS services you’ve had or are due to have, been CANCELLED or POSTPONED in 2023?</td>
<td>141</td>
<td>1084</td>
</tr>
</tbody>
</table>
Appendix 4: Confidence intervals

We can use Confidence intervals to help express how reliable a sample is with respect to the data we measure from it. Confidence intervals are a range, between which we can be 95% (typically) sure that the true population mean lies.

<table>
<thead>
<tr>
<th>Survey percentage</th>
<th>10%</th>
<th>30%</th>
<th>50%</th>
<th>70%</th>
<th>90%</th>
</tr>
</thead>
<tbody>
<tr>
<td>95% Confidence Interval for sample of 1,000</td>
<td>+/- 1.9%</td>
<td>+/- 2.8%</td>
<td>+/- 3.1%</td>
<td>+/- 2.8%</td>
<td>+/- 1.9%</td>
</tr>
</tbody>
</table>
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