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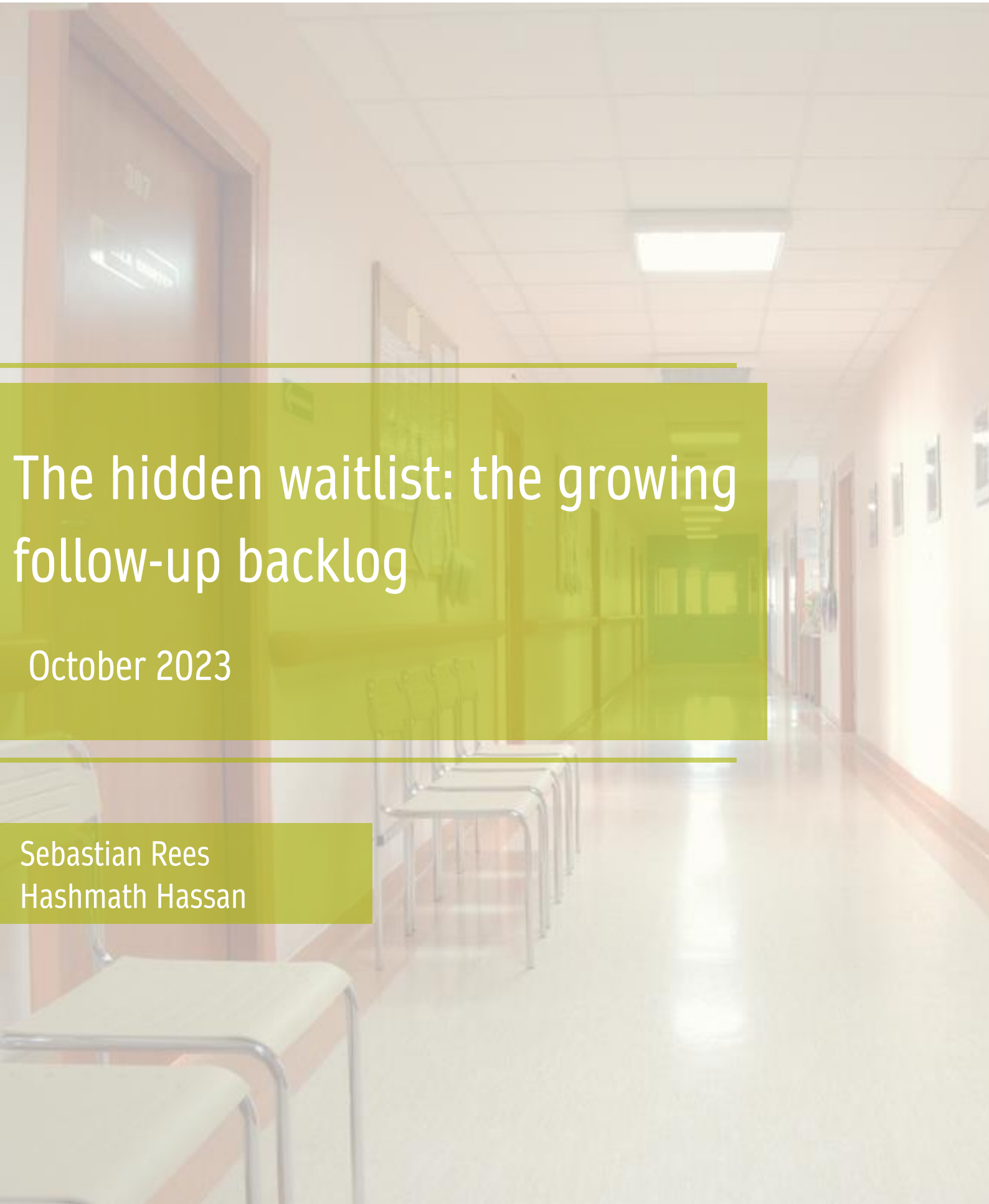

The hidden waitlist: the growing follow-up backlog

October 2023

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ABOUT REFORM

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This paper is part of the *Reimagining Health* work stream. While at its inception the National Health Service was visionary, three quarters of a century later, with demand rising and outcomes deteriorating, a bold and urgent rethink is needed. *Reform* will explore how to transform England's approach to health, considering how we can move from a treatment-oriented model to one geared towards health creation, the changes necessary in healthcare to facilitate this, and how to build a fair and sustainable approach to funding.

As part of the research programme *Reform* is publishing a series of data-driven briefing notes to better understand the current state of the NHS. This paper is part of that series.

1. Introduction

The NHS is under severe pressure. More than 7.75 million people are now waiting for elective treatment[1] and A&E performance dropped to its lowest ever level during last year's Winter crisis.[2]

Reducing this elective backlog and improving A&E performance has taken the lion's share of attention. However, many other waits, such as those for mental health support and in community health services, are also high and growing.[3]

Even within secondary care settings, not all waiting lists are treated equally. Publicly reported referral-to-treatment (RTT) data – the elective waitlist – only accounts for patients who are waiting for their "first definitive treatment" following a referral to specialist care (usually by a GP).[4] However, many patients require ongoing care – follow-up appointments after a treatment or operation, guidance on medication, or support to manage a chronic condition – without which their recovery may stall and their health decline.

The number of people waiting for follow-up appointments is estimated to have grown rapidly since the pandemic.[5] However, worryingly, the full-scale of the problem is not known – hospital providers are not required to record or report this data even though more than 60 per cent of all outpatient appointments in the NHS are follow-ups.[6] This is the hidden waitlist.

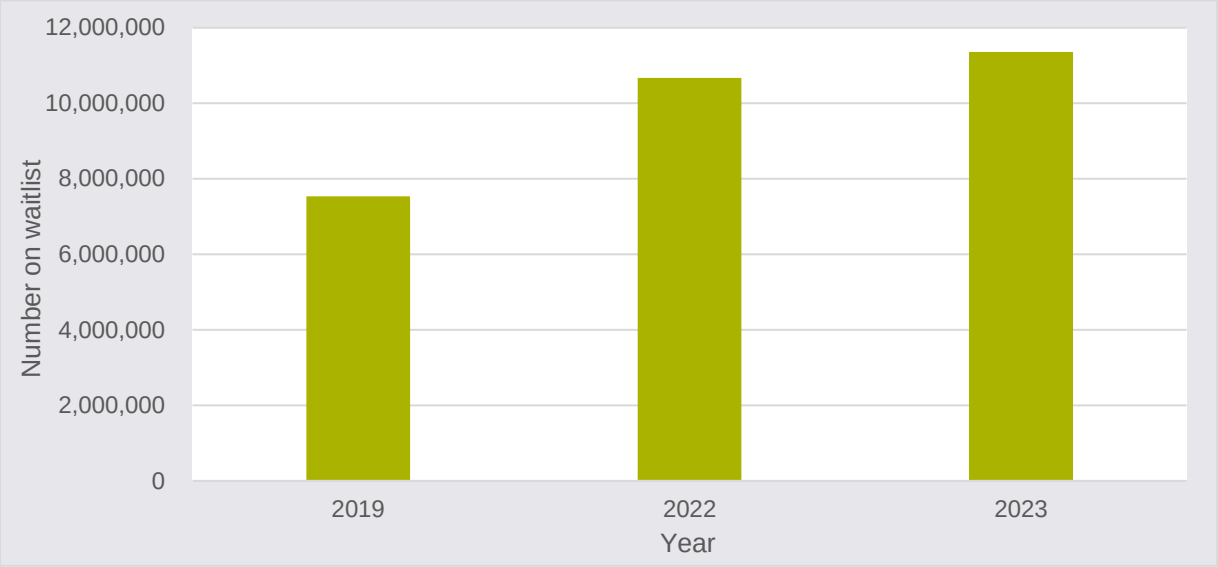
This short briefing paper, based on a freedom of information (FOI) request to all acute trusts in England, seeks to understand the length and composition of the follow-up waitlist.

The paper finds that the follow-up waitlist in acute trusts has grown significantly since the pandemic, and estimates that more than 11 million patients are waiting for ongoing care – around 3.5 million more people than the elective backlog.

Shockingly, 47 per cent of acute trusts (56 out of the 119) claim either not to hold this information, to be unable to present it in an accessible format or failed to respond to the FOI within 10 weeks of receiving the request (the statutory requirement is 20 days). This suggests that trusts themselves may be struggling to effectively understand and manage their waitlists.

[1] NHS England, *Consultant-Led Referral to Treatment Waiting Times Data 2023-24*.
[2] NHS England, *A&E Attendances and Emergency Admissions*.
[3] NHS England, *Mental Health Access, and Waiting Time Standards*, 2023.
[4] NHS England, *Recording and Reporting Referral to Treatment (RTT) Waiting Times for Consultant-Led Elective Care: Frequently Asked Questions*.
[5] Lay, Bello, and Willoughby, 'NHS Waiting Lists Hiding 10m Patients in Need of Follow-up Care'.
[6] NHS Digital, *Hospital Outpatient Activity 2021-22*.

Figure 1: Estimated number of total follow-up waiting list over time



Source: Author's calculations based on FOI responses (see Appendix 2 for more information).

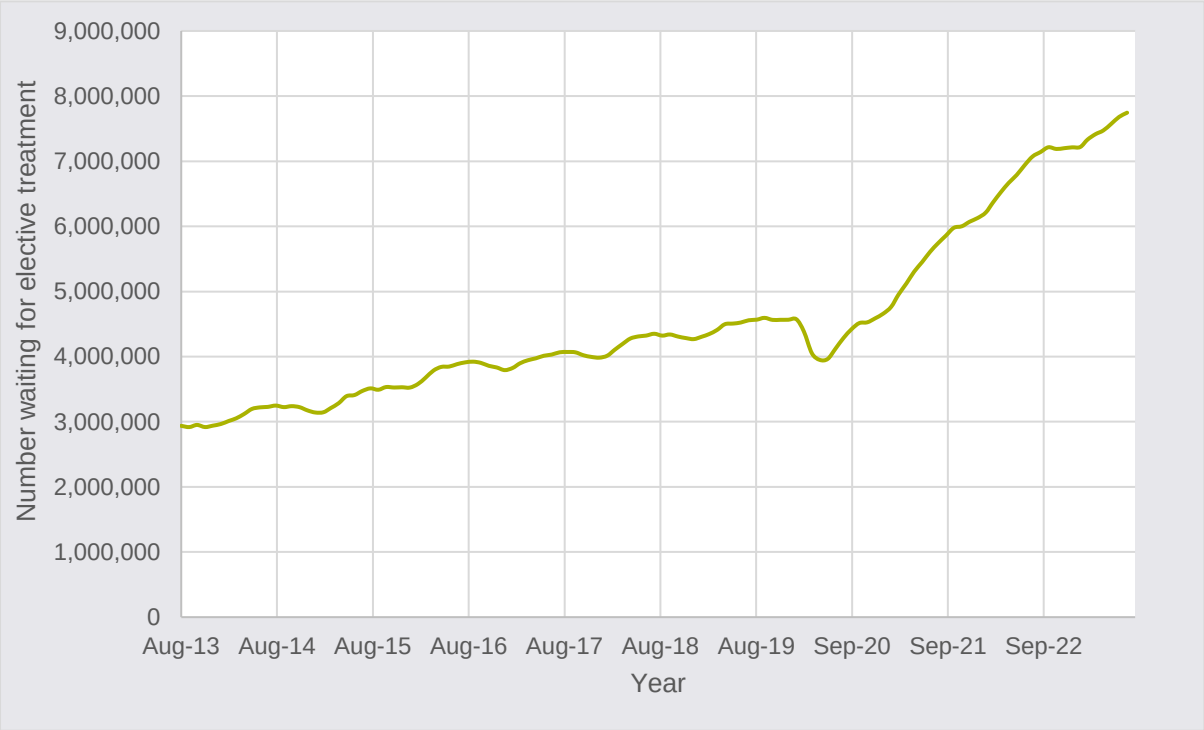
2. Waiting for the NHS

2.1 The RTT waitlist

Patients waiting for different services in the NHS are categorised in different ways. The NHS 'waitlist' tends to refer to those waiting for elective treatment, who are on a consultant-led 'referral to treatment' (RTT) pathway. A typical example of this kind of pathway would be a hip replacement pathway. A patient reporting persistent hip pain and severe problems with day-to-day functioning to their GP or physiotherapist may be referred to a rheumatologist and then on to an orthopaedic surgeon to carry out a replacement procedure.

The wait 'clock' for this kind of pathway starts when a referral sent by a medical practitioner (usually a GP) is received by a care provider (usually a hospital trust). The clock is stopped when "first definitive treatment" – "an intervention intended to manage a patient's disease, condition or injury and avoid further intervention" – occurs. In the case above, the clock would be stopped at the point that surgery had taken place.

Figure 2: Number of patients waiting for elective treatment since August 2013

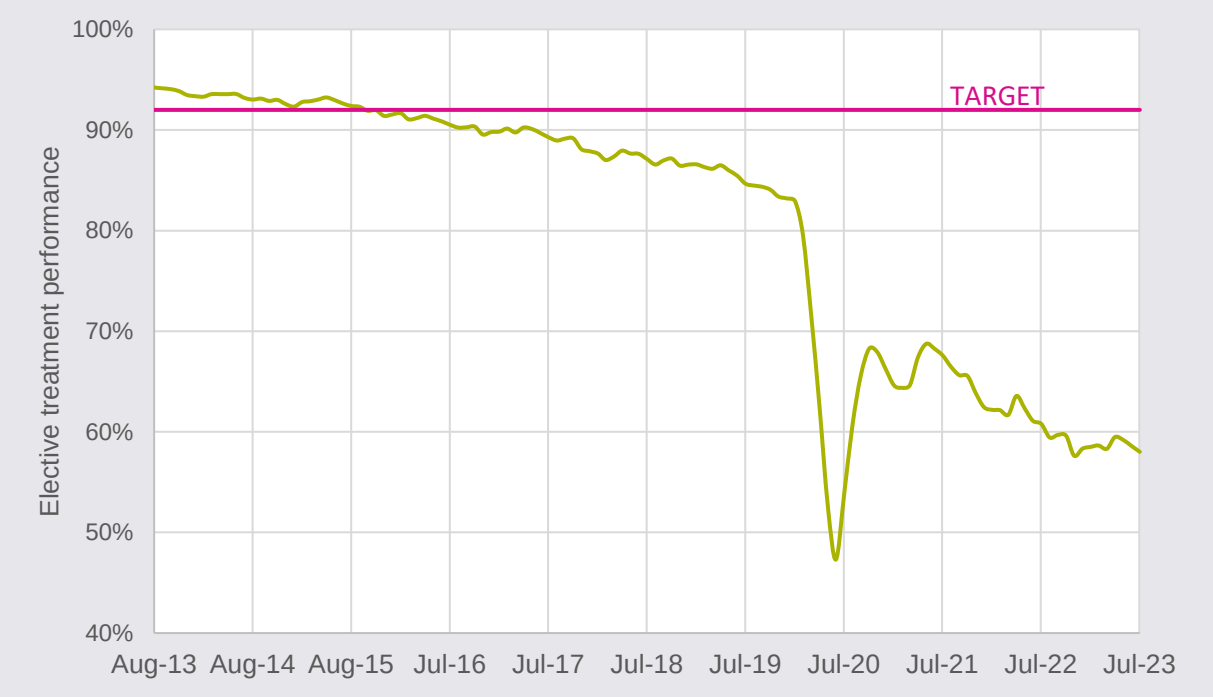


Source: NHS England, *Referral to Treatment (RTT) Waiting Times*, 2023.

There are currently 7.75 million waiters (Figure 2) on the RTT pathway. According to the NHS Constitution, it is a statutory requirement that at least 92 per cent of patients should receive their elective treatment within 18 weeks of first referral. September 2015 was the last time this standard was met (see Figure 3).

During the pandemic, performance declined precipitously as elective activity was postponed to free up staff and beds.[7] Though there has been some improvement since this point, in August 2023 (the latest month that we have data for), almost 400,000 people were waiting over 52 weeks – an entire year or more – for elective care. In January 2020, that number stood at 1,875.

Figure 3: Percentage of patients who received elective treatment within 18 weeks of referral since August 2013



Source: NHS England, *Referral to Treatment (RTT) Waiting Times*, 2023.

Addressing the elective backlog is a key system goal – long waits for elective care worsen patient experience, risk the deterioration of health outcomes and provide additional burdens on other healthcare providers (such as primary care providers) who have to manage symptoms until treatment can occur.

Given the scale of the issue, it is no surprise that bringing down the elective waitlist is a top NHS (and Prime Ministerial) priority: the elective recovery plan was published in February 2022,[8] an elective recovery taskforce was set up in December 2022,[9] and £14 billion of funding and capital has been allocated to tackle elective and cancer services over two years.[10]

[7] Harwich et al., *What's next for the NHS? Building the Resilience of the Health and Care System*.
[8] NHS England, 'News: NHS Publishes Electives Recovery Plan to Boost Capacity and Give Power to Patients'.
[9] GOV.UK, 'Elective Recovery Taskforce'.
[10] House of Commons and Committee of Public Accounts, *Managing NHS Backlogs and Waiting Times in England Thirty-Eighth Report of Session 2022–23*.

2.2 ‘Hidden’ waitlists

However, the RTT waitlist is not the only area in which system performance is declining. Non-RTT waits – those for non-consultant-led services, some planned care, and follow-up care – are also thought to have grown to unprecedented levels.[11]

Non-RTT services refer to multiple pathways including both non-consultant-led services (where a consultant does not retain overall clinical responsibility for the patient care) and planned services (patients waiting for a treatment on a specific clinical date), and account for over 60 per cent of all hospital appointments.[12] Non-RTT pathways include those for emergency care, cancer treatments, mental health services, diagnostic tests, rehabilitation services, and follow-up appointments.

Despite the obvious fact that delays to care lead to poor outcomes for patients, many hospitals do not collect consistent and reliable non-RTT waitlist data or validate that data effectively.[13]

Reporting standards for *some* non-RTT waits are, thankfully, improving – the NHS now publishes waiting time metrics for three mental health pathways (talking therapies for anxiety and depression, services for children and young people with eating disorders, and early intervention in psychosis),[14] and since 2022 has published data on waitlists for community health services.[15]

However, patients waiting on other non-RTT pathways, such as for follow-up appointments, are only recorded at the discretion of individual trusts. No statutory obligation exists to publish this data and there are no constitutional standards around wait times, helping explain why these lists are ‘hidden’.

Therefore, while all non-RTT treatment pathways need to be explored in detail to fully understand the pressures on the system, given the lack of visibility in the policy debate and the serious risks to patients of neglecting follow-up waitlists, this is the focus of the paper.

2.3 Follow-up waitlists

Follow-up appointments can be scheduled after ‘first definitive treatment’ has occurred with a specialist (i.e., after the RTT clock has stopped). They can serve a variety of purposes, outlined in Figure 4.

[11] BMA, ‘NHS Backlog Data Analysis’.
[12] NHS Digital, *Hospital Outpatient Activity 2021-22*.
[13] Mulholland, *RTT Rules Made Easy: A Guide to Managing RTT in Hospitals*.
[14] NHS England, *Mental Health Access and Waiting Time Standards*.
[15] NHS England, *Community Health Services Waiting Lists*.

Figure 4: Types of follow-up appointments

Function	Description
Post-treatment monitoring	After patients have undergone treatment, a follow-up may be scheduled to monitor recovery. This may involve wound checks, assessing pain levels, and ensuring the healing process is proceeding as expected.
Chronic condition monitoring	Patients with long-term conditions may require regular follow-up appointments to manage their health. Appointments may involve medication adjustments, the monitoring of symptoms and discussions about lifestyle change to improve health.
Cancer monitoring	Follow-ups are crucial for monitoring patients who have completed initial cancer treatment and are used to detect any signs of recurrence and manage potential side effects of treatment.
Medication management	Patients on long-term medications prescribed by specialists may have follow-up appointments to assess a medication's effectiveness, manage side effects, and adjust dosage. For instance, a patient on anti-retroviral medication for HIV may book a follow-up appointment with a gastro-urinary physician for this purpose.

Performing the functions outlined above in a timely manner is clearly vital to providing comprehensive and safe healthcare. Failing to carry out adequate monitoring of long-term conditions, manage medicines appropriately, and follow-up to ensure that treatments such as surgery have been effective provides significant clinical risks.

Further, failures to provide follow-up care may cause pressures across the wider health system. Patients who require ongoing support may re-present in primary care or emergency settings in order to have their needs met.

While trade-offs exist over the use of resources in the NHS – providing more follow-up care may redirect resources away from clearing the backlog of new patients – it is vital that we develop a full picture of what prioritisation is occurring, where the greatest risks to safety and health lie, and what the optimal prioritisation of appointments is in a whole system view.

3. Data from the Freedom of Information (FOI) request

To determine the length of the follow-up waiting list, we sent an FOI request to all acute trusts (see Appendix 1 for a copy of the FOI request) requesting the number of patients waiting for follow-up care in May 2019, May 2022, and May 2023, capturing pre- and post-pandemic levels.

3.1 How many hospitals collect this data?

The FOI request was sent to 119 acute trusts. The table below shows how many trusts collected follow-up waiting list data for at least one of the years requested (2019, 2022, 2023). If they did not carry snapshot data, they were asked how many patients were currently waiting for follow-up treatment.

Almost 50 per cent of acute trusts did not provide any follow-up data either because the provider did not hold this information in a reportable way or did not reply to the request. Those trusts that did not reply within the statutory time limit of 20 days were provided with additional time to collect information, and were thereafter reported to the Information Commissioner's Office for non-compliance.

Disturbingly, a third of trusts reported they did not hold this information or could not easily retrieve it, making it hard to see how they are monitoring their follow-up waitlist.

Figure 5: Acute trust responses

	Total	Provided data	Does not hold this information[16]	Did not reply	Section 22[17]
Number	119	62	39	17	1
Percentage	100	52	33	14	1

3.2 Length of follow-up waitlists

Figure 6 shows the number of trusts that provided data for each year, the length of the waiting list from reported data and the average number of those waiting per trust.

[16] Or cannot easily retrieve this information.
[17] The information is intended for future publication.

Figure 6: Data from acute trusts that responded to the FOI

	May 2019	May 2022	May 2023
Number of trusts reporting data	37	49	56[18]
Total number of patients reported waiting	2,289,978	4,277,452	5,100,439
Average number of patients waiting per trust	61,891	87,295	91,079
% change from 2019	-	41	47

The FOI data shows that the average number of patients waiting per trust has increased significantly since the pandemic. In May 2023, the average number of patients waiting per trust is 47 per cent higher than it was before the pandemic in May 2019. After the pandemic, data coverage also improves as more trusts hold follow-up backlog information.

Figure 7: Acute trusts that provided data for all three years

	May 2019	May 2022	May 2023
Total number of patients reported waiting	2,289,978	3,112,513	3,413,346
Average number of patients waiting per trust	61,891	84,122	92,253
% change from 2019	-	36	49

Out of the 62 trusts that provided data, only 37 trusts provided data for all years requested (2019, 2022 and 2023). Figure 7 provides the total number of patients reported waiting, the average number waiting and the percentage change of the average from 2019 of trusts that provided data for all three years.

[18] This is different from the number of trusts that provided data (62) because some trusts were unable to provide snapshot data for May 2023.

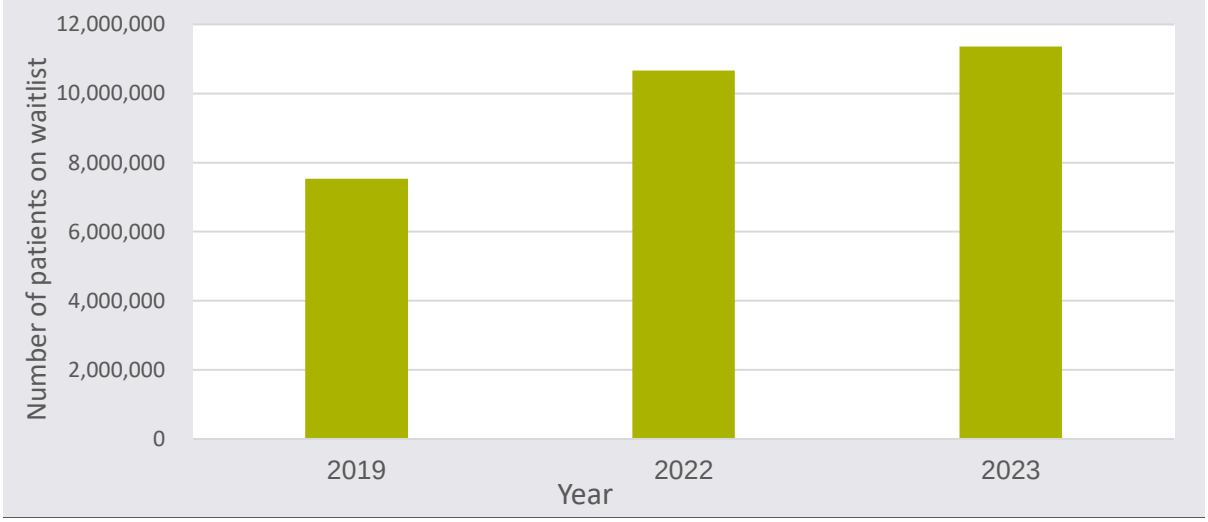
Figures 6 and 7 show that the percentage increase (from 2019) of the backlog is lower in 2022 for trusts that were able to provide data for all three years compared to trusts who only provided data for one or two of the years requested. The percentage increase in May 2022 and May 2023 in Figure 7 is 36 per cent and 49 per cent respectively compared to 41 per cent and 47 per cent in Figure 6.

3.3 Total estimated size of waitlist

Ideally, it would be possible to collect data from all trusts and thereby establish a clear figure for the total number of patients waiting for follow-up appointments. However, the inability, or failure, of all trusts to report on their follow-up waitlists means that estimating the total number of patients waiting requires extrapolation. Similar analyses on follow-up waitlists, notably by *The Times* (50 per cent of trusts)[19] and Medefer (15 per cent of trusts), have used data from a smaller sample of reporting hospitals to develop estimates of its size.[20]

Based on the data received, *Reform* estimates the total length of the follow-up waitlist using the number of outpatient referrals a trust receives in each of the corresponding snapshot months (for full information on how this was calculated, please see Appendix 2). Outpatient referrals were used to estimate the follow-up waitlist as they provided some information about the trust type, such as the overall level of activity and the clinical services it provides. Figure 8 represents the estimated follow-up backlog in the years 2019, 2022 and 2023.

Figure 8: Estimated total of the follow-up backlog over time



Source: Author's calculations based on FOI responses (see Appendix 2 for more information).

The total estimated number of people waiting for follow-up appointments in May 2023 was 11,355,922. That is an estimated increase of 50 per cent from 2019 when 7,533,696 people were waiting. This hidden waitlist has around 3.5 million more patients on it than the elective backlog. On average, more than 90,000 people were waiting for follow-up appointments per

[19] Lay, Bello, and Willoughby, 'NHS Waiting Lists Hiding 10m Patients in Need of Follow-up Care'.
[20] Health Business, '15.3 Million on NHS Hidden Waiting List'.

acute trust in 2023. Figure 9 shows that the follow-up backlog has increased significantly since the pandemic.

Figure 9: Total estimated follow-up backlog and average per trust

	May 2019	May 2022	May 2023
Total estimated	7,533,696	10,667,434	11,355,922
Estimated waiting per trust	63,308	89,641	95,428
% increase from 2019	-	42	51

Source: *Reform* calculations based on NHS England, *Monthly Outpatient Referrals Data*, 2023

3.4 Do trusts with follow-up backlog data perform better than trusts without?

The methodology used to calculate the total follow-up waitlist does not factor in the fact that higher-performing trusts may be better able to account for their waitlists than lower performing trusts.

Though it is not possible to definitively determine this from the available data, overall trust performance does not appear to be associated with a trust's ability to report on follow-up appointments.

Figure 10 shows that the average performance – measured by the number of patients receiving elective treatment within 18 weeks and the percentage of patients seen within 4 hours in A&E settings – between trusts that reported data in response to the FOI and trusts that did not are roughly the same. This suggests that trusts who provided data are not routinely higher performing than trusts who did not.

Figure 10: Average performance (in May 2023) of acute trusts that reported data compared to trusts that did not report data

	Elective treatment performance (% seen in 18 weeks)	A&E performance (% seen in 4 hours or less, type 1)
Trusts that provided data	59.79	59.91
Trusts that did not provide data	60.96	59.78

Source: NHS England, *A&E Attendances and Emergency Admissions 2023-24,* 2023; NHS England, *Referral to Treatment (RTT) Waiting Times,* 2023.

If operational capacity is not the reason that trusts do not routinely collect or validate follow-up waitlist data, it may instead be the case that particular trusts do not see follow-up waitlist management as an organisational priority. This poses significant risks, explored below.

3.5 Backlog treatment functions

Beyond the total number waiting, it is important to understand the type of patients waiting for follow-up treatment and the level of clinical risk posed by growing backlogs. As part of the FOI request, *Reform* asked for follow-up waitlists to be broken down by treatment function. Figure 11 shows the number of acute trusts that provided follow-up waitlist data broken down by treatment function type.

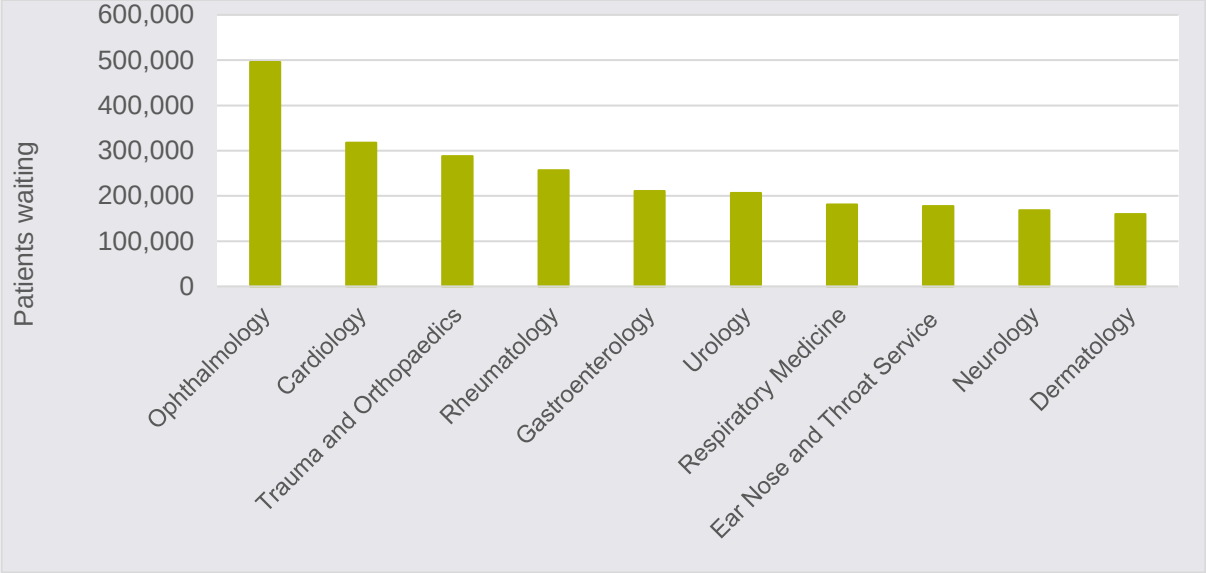
Figure 11: Acute trusts that provided FOI data on follow-up waitlist treatment functions

	May 2019	May 2022	May 2023
Number of trusts that provided waitlist data	37	49	56
Number that provided treatment function data	34	45	53
% of trusts that provided treatment function data	92	92	93

Understanding the level of risk involved in failing to adequately address growing follow-up backlogs is vital for informing the strategic decisions taken by NHS providers. Currently, NHS trusts are incentivised to allocate more of their resources to clearing RTT backlogs which are measured and reported on, but this may overlook the high level of risk associated with de-prioritising follow-ups.

It is not possible to determine risk levels without access to granular data relating to patient demographics and clinical need. However, breaking down follow-up waiting lists by treatment functions gives a general indication of areas that require investigation. Figure 12 shows the top ten treatment functions with the largest follow-up backlog in 2023 (for those trusts which reported data).

Figure 12: Top ten treatment functions by volume in 2023



Source: Author's calculations based on FOI responses (see Appendix 2 for more information).

Figure 13 shows the top ten treatment functions over time per trust. Figure 13 only includes trusts that provided data for all three years (May 2019, May 2022 and May 2023).

Figure 13: Top 10 treatment functions by average number waiting per trust over time

Source: Author's calculations based on FOI responses (see Appendix 2 for more information).

Ophthalmology, the treatment function with the highest average number of waiters per trust, has had consistently high follow-up waitlists since 2019. Other top specialities include cardiology, trauma and orthopaedics, rheumatology, gastroenterology, and urology – all high-risk medical specialities.

Delays in follow-up care in ophthalmology can be very risky. A report by The Royal College of Ophthalmologists found that delays in follow-up appointments has resulted in patients suffering permanent visual loss.[21] In 2017, 22 patients per month were at risk of losing their vision due to delays in treatment and permanent harm from avoidable visual loss is 9 times more likely in follow-up patients than in new patients.[22] There are now about 30% more patients on ophthalmology waitlists as pre-pandemic, meaning the number of people at risk of sight loss may have increased.

Patients with chronic ophthalmological conditions such as glaucoma, age-related macular degeneration and diabetic retinopathy are most likely to be associated with loss of vision as they require long-term routine follow-ups and are particularly vulnerable.[23] This is likely to worsen as the population continues to age.

The table below, Figure 14, gives the top (by number waiting) treatment functions in the three years for which data was requested. The top treatment functions have remained largely consistent – although the number of patients waiting for each treatment has increased.

Figure 14: Top ten treatment functions in 2019, 2022 and 2023 for trusts that provided data for all three years

Rank	May 2019	May 2022	May 2023
1	Ophthalmology	Ophthalmology	Ophthalmology
2	Trauma and Orthopaedics	Trauma and Orthopaedics	Trauma and Orthopaedics
3	Rheumatology	Diagnostic Imaging	Diagnostic Imaging
4	Cardiology	Cardiology	Cardiology
5	Diagnostic Imaging	Rheumatology	Rheumatology
6	Urology	Respiratory Medicine	Gastroenterology
7	Respiratory Medicine	Gastroenterology	Respiratory Medicine
8	Gastroenterology	Neurology	Urology
9	Acute internal medicine	Urology	Neurology
10	Audiology	Ear, Nose and Throat Service	Ear, Nose and Throat Service

[21] The Royal College of Ophthalmologists, 'BOSU Report Shows Patients Losing Sight to Follow-up Appointment Delays'.
[22] The Royal College of Ophthalmologists.
[23] The Royal College of Ophthalmologists.

Long waits for paediatric care should be of particular concern for the NHS. Long waits for care are particularly harmful for children, as they can impair mental and physical development at a critical time, causing suffering for patients and their families and storing up additional system costs in the long run.

Figure 15 shows the treatment functions with the largest percentage increase since 2019. Backlogs in paediatric treatment functions are among the fastest growing in the NHS – three of the fastest growing backlog functions relate to child and maternity care. Although the starting baseline for these numbers is very small, given recent high-profile failings in these care settings, growth in follow-up appointment backlogs should be urgently addressed.[24]

Figure 15: Top ten treatment functions with the largest percentage increase from 2019 for trusts that included data for all three years

Rank	Treatment Function	Percentage increase from 2019	Number of people waiting in 2019 to Number waiting in 2023
1	Learning Disability	12243%	7 to 864
2	Vascular Studies	10750%	2 to 217
3	Haematology	2746%	138 to 3928
4	Programmed Pulmonary Rehabilitation	1370%	20 to 294
5	Paediatric Pain Management Service	1150%	6 to 75
6	Fetal Medicine	967%	3 to 32
7	Trauma	845%	33 to 312
8	Clinical Neurophysiology	486%	210 to 1231
9	Bariatric Surgery	407%	252 to 1278
10	Public Health Medicine	400%	1 to 5

Alongside growing backlogs for paediatric care, the significant growth in patients awaiting support for learning disability services should also be a major cause for concern. Evidence shows that those living with learning disabilities have poorer health and have poorer experiences with, and outcomes from, healthcare.[25]

[24] Parkin, Balogun, and Harker, *Quality and Safety of Maternity Care (England)*.
[25] NHS England, *University of Bristol LeDeR Annual Report 2020*.

3.6 Descriptive statistics

The follow-up data (the number of patients waiting for a follow-up appointment) in 2019, 2022, 2023 consists of 37, 49 and 55 observations respectively. The descriptive statistics of the data set are summarised in the table below.

Figure 16: Descriptive statistics of reported data

	May 2019	May 2022	May 2023
Smallest follow-up backlog from reported data	783	936	1008
Largest follow-up backlog from reported data	392,640	446,904	516,919
Average follow-up backlog from reported data	61,891	87,295	91,079
Number of responses	37	49	56

The average in 2019 is 61,891 and increases significantly to 87,295 in 2022 and increases further to 93,093 in 2023. Data for each year have large ranges with the minimum and maximum in 2023 varying drastically – Nottingham University Hospitals has a follow-up backlog of 1,008 whilst East Kent Hospitals has a backlog of 516,919.

The total outpatient referrals, an indication of trust size, for Nottingham University Hospitals is 30,083 and for East Kent Hospitals 56,840. East Kent therefore has double the referrals of Nottingham, suggesting that it is a bigger acute trust, but their follow-up backlog is 513 times that of Nottingham. This suggests that there is a high degree of unwarranted variation at play.

The boxplot in Figure 17 shows that there is large variation between trusts in every year data was collected. The range increases significantly over time suggesting that the large variation between trusts is increasing over time.

Figure 17: Boxplots of reported FOI follow-up data in May 2019, May 2022 and May 2023

A high degree of unwarranted variation between trusts when it comes to follow-up waitlist management should be an urgent cause of concern. It suggests that patients are receiving an unacceptably poor care offer, based either on the decision by their trust to deprioritise follow-up appointments or, even more worryingly, to neglect follow-up waitlist management altogether. Closing a large and growing gap between trusts' abilities to provide follow-up care management requires substantial policy focus.

3.7 Known unknowns

The above sections show the likely total length of waitlists and the types of care for which patients are waiting. However, worryingly, many trusts responded to our FOI request without

data. This suggests that trusts either lack the capacity to collect information on waits in an easily identifiable format, or do not see this as a priority – both are deeply worrying.

This makes appropriately auditing trusts difficult – without knowledge of the length of follow-up waitlists, it is difficult to tell whether resources are being appropriately allocated and patient care improved.

The data presented in this report is also only one part of the story. Firstly, this report only examines follow-up waits in acute trusts. It does not take into account waits in mental health, specialist and community trusts which would further increase the follow-up backlog. Secondly, it does not provide granular detail on patient demographics and clinical need (aside from treatment functions). This makes establishing the level of clinical risk posed by growing backlogs difficult to determine. Finally, unlike with available RTT data, it is not possible to ascertain the length of patient waits for follow-up care. As is the case with data on the elective backlog, establishing how long patients have waited is vital for informing decisions on resource allocation.

In all, trusts' inability to provide crucial data on follow-up waits, and a lack of requirement for them to report on these, risks significant erosion of care quality and patient safety.

Conclusion and recommendation

The NHS' publicly reported waitlist stands at more than 7.75 million. However, this paper has shown that many millions more are waiting for follow-up appointments. In May 2023, more than 11.4 million people were awaiting follow-up care, a number which has grown by 50 per cent in the last four years. The follow-up backlog is rarely discussed, with issues such as A&E wait times and the elective backlog at the forefront of NHS priorities. This lack of emphasis placed on follow-up waits relates partially to the fact that there is no requirement for trusts to record and publish data on follow-up waiting times.

Follow-up care is an essential part of a patient's recovery and ongoing management. Failing to provide adequate follow-up care can have negative impacts on patient outcomes and brings long-term system costs. Deprioritising follow-up care can lead to patients' conditions deteriorating, increased anxiety as a result of being 'lost' in the system, and potentially greater use of primary care and emergency services. It is also likely contributing to the rise in sickness-driven economic activity.

With the NHS facing multiple crises, it is essential that trusts have detailed data on demand and patient need across all pathways. Without this, they cannot effectively manage their resources, nor properly serve their patients. The necessary trade-offs over resource allocation and priorities cannot be made transparently. The fact that almost half of all acute trusts could not provide information on their follow-up backlogs should be a particular cause for concern.

Though this paper does not suggest ways in which the large and growing follow-up care backlog can be dealt with, this journey must begin with transparency about its size and the level of clinical risk it poses. Only by properly scrutinising *all* NHS waitlists can performance decay start to be addressed.

Recommendation: NHS England should mandate all provider trusts to publish monthly snapshots of the number of patients waiting for follow-up outpatient appointments along with the treatment function they are waiting for.

NHS should provide digital support for trusts struggling to provide this data in reportable format and assist with the transformation of trusts' central digital system if so required.

Appendix 1: FOI Request

I am writing to you under the Freedom of Information Act 2000 to request the following information:

1) The number of patients waiting for a follow up appointment in your trust that were not captured in the official Referral to Treatment monthly statistics in the following months: May 2019, May 2022 and May 2023.
2) Please break this information down by:
a. Treatment function.
b. Month and year patients were placed on a follow up appointment list.
c. Month and year of due date for patients to be seen. If due dates are not in place, please state this by volume.

If this request is unclear, please contact me – under the Act, you are required to advise and assist requesters.

I would like to receive my response electronically at: hashmath.hassan@reform.uk

I would be grateful if you could confirm that you have received this request.

Yours faithfully,

Hashmath Hassan
Reform
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The FOI request was sent in July 2023.

Not enough trusts provided data on when patients were put on the waiting list and when they were due to be seen (question 2b and 2c) for meaningful analysis to be conducted in these areas.

Out of the 62 trusts that provided us with data, five trusts were not able to provide snapshot data for May 2019, May 2022 and May 2023 and were only able to provide their follow-up backlog when the FOI request was processed.

Appendix 2: Estimated total follow-up waitlist calculation

This paper calculated the total follow-up waitlist using three methods: mean imputation, deterministic and stochastic regression imputation. The estimated follow-up for each method is shown below.

Mean imputation, the easiest way to deal with missing data, involves calculating the average or the mean of the reported data. For example, for May 2019 37 trusts provided the length of their follow-up waitlist. To estimate the total waitlist of all acute trusts in May 2019 using mean imputation, the average of the 37 trusts should be calculated and that average is multiplied by the number of acute trusts.

However, mean imputation does not take into account variation in trust types such as trust size and its catchment area and assumes that the trusts that did not provide data are roughly similar to the trusts that did. To avoid making this assumption, this paper also estimates the total using deterministic and stochastic regression.

Both deterministic and stochastic regression uses the number of outpatient referrals[26] a trust receives for each of the snapshot months (May 2019, May 2022, May 2023) as a predictor or a weighting for a trust's follow-up backlog to avoid assuming that trusts that provided data and trusts that did not are the largely the same.

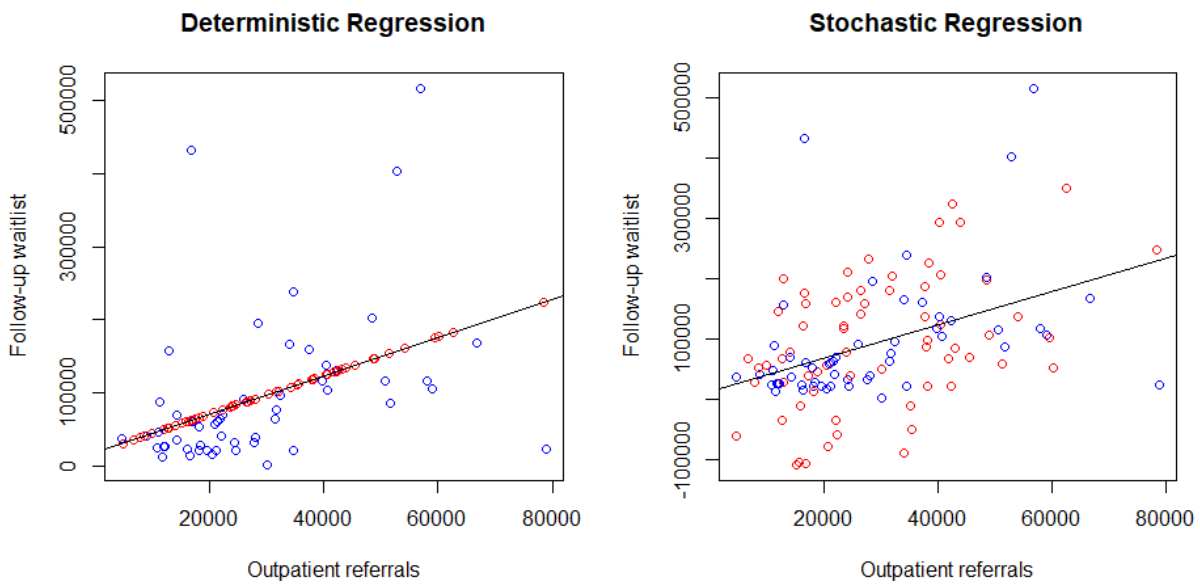
Outpatient referrals is used as the predictor because it is a good indication of the trust type: it provides some information on the size of the trust because it provides the overall level of activity in the trust and the clinical services a trust provides.

Both deterministic and stochastic regression establishes a relationship between the follow-up backlog (the dependent variable) and the number of referrals (the independent variable) based on a line of best fit.

The two regression imputations differ on how they estimate missing values. Deterministic regression imputation replaces missing values with the exact prediction from the regression model (see Figure 18). Stochastic regression on the other hand, adds a random error term to the predicted value (see Figure 18) to estimate some of the randomness of the relationship.

[26] NHS England, *Monthly Outpatient Referrals Data*.

Figure 18: Deterministic regression compared to stochastic regression



Stochastic regression is considered more robust than deterministic regression imputation as its prediction does not solely rely on the independent variable — avoiding imputation that is too precise and overestimating the correlation.

Figure 19 provides the total estimate of the follow-up backlog for all acute trusts in May 2019, May 2022 and May 2023 using the mean, deterministic regression, and stochastic regression imputation. Figure 19 shows the total estimate does not vary significantly by imputation method.

Figure 19: Waitlist using mean, deterministic regression and stochastic regression imputation

	Mean	Deterministic regression	Stochastic regression
May 2019	7,365,064	8,185,146	7,533,696
May 2022	10,388,098	10,571,160	10,667,434
May 2023	10,838,433	11,164,963	11,355,922

Source: Author's calculations based on NHS England, *Monthly Outpatient Referrals Data*, 2023

Appendix 3: Acute trust response status

Trusts highlighted in red are trusts that either could not or did not provide data for May 2019, May 2022 and May 2023. Trusts highlighted in grey are trusts who were not able to provide snapshot data (for May 2019, May 2022 and May 2023) but were able to provide their current follow-up backlog when the FOI request was processed (e.g., August 2023 and September 2023).

Acute trust name	Provided data for at least one year	Provided data for all three years	Provided treatment function data
Airedale NHS Foundation Trust	YES	YES	YES
Ashford and St. Peter's Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Barking, Havering and Redbridge University Hospitals NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Barnsley Hospital NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Barts Health NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Bedfordshire Hospital NHS Trust	YES	NO	YES
Blackpool Teaching Hospitals NHS Foundation Trust	YES	NO	YES
Bolton NHS Foundation Trust	YES	YES	YES
Bradford teaching hospitals	YES	YES	YES
Buckinghamshire Healthcare NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Calderdale and Huddersfield NHS Foundation Trust	YES	YES	YES
Cambridge University Hospitals NHS Foundation Trust	YES	YES	YES
Chelsea and Westminster Hospital NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Chesterfield Royal Hospital NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
Countess Of Chester Hospital NHS Foundation Trust	SECTION 22	NO	NO
County Durham and Darlington NHS Foundation Trust	YES	NO	YES
Croydon Health Services NHS Trust	DID NOT RESPOND IN TIME	NO	NO
Dartford and Gravesham NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO

Dorset County Hospital NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
East and North Hertfordshire NHS Trust	DID NOT RESPOND IN TIME	NO	NO
East Cheshire NHS Trust	YES	NO	YES
East Kent Hospitals University NHS Foundation Trust	YES	YES	NO
East Lancashire Hospitals NHS Trust	YES	YES	YES
East Suffolk and North Essex NHS Foundation Trust	YES	YES	YES
East Sussex Healthcare NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Epsom and St Helier University Hospitals NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Frimley Health NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
Gateshead Health NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
George Eliot Hospital NHS Trust	DID NOT RESPOND IN TIME	NO	NO
Gloucestershire Hospitals NHS Foundation Trust	YES	YES	YES
Great Western Hospitals NHS Foundation Trust	YES	YES	YES
Guy's and St Thomas' NHS Foundation Trust	YES	NO	YES
Hampshire Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Harrogate and District NHS Foundation Trust	YES	NO	YES
Homerton Healthcare NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Hull University Teaching Hospitals NHS Trust	YES	YES	YES
Imperial College Healthcare NHS Trust	DID NOT RESPOND IN TIME	NO	NO
Isle Of Wight NHS Trust	YES	YES	YES
James Paget University Hospitals NHS Foundation Trust	YES	YES	YES
Kettering General Hospital NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
King's College Hospital NHS Foundation Trust	YES	NO	NO
Kingston Hospital NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Lancashire Teaching Hospitals NHS Foundation Trust	YES	NO	YES

Leeds Teaching Hospitals NHS Trust	YES	YES	NO
Lewisham and Greenwich NHS Trust	DID NOT RESPOND IN TIME	NO	NO
Liverpool University Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
London North West University Healthcare NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Maidstone and Tunbridge Wells NHS Trust	YES	NO	YES
Manchester University NHS Foundation Trust	YES	NO	YES
Medway NHS Foundation Trust	YES	YES	YES
Mersey and West Lancashire Teaching Hospitals	DID NOT RESPOND IN TIME	NO	NO
Mid and South Essex NHS Foundation Trust	YES	NO	YES
Mid Cheshire Hospitals NHS Foundation Trust	YES	YES	YES
Mid Yorkshire Hospitals NHS Trust	YES	YES	YES
Milton Keynes University Hospital NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Norfolk and Norwich University Hospitals NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
North Bristol NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
North Cumbria Integrated Care NHS Foundation Trust	YES	NO	YES
North Middlesex University Hospital NHS Trust	DID NOT RESPOND IN TIME	NO	NO
North Tees and Hartlepool NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
North West Anglia NHS Foundation Trust	YES	NO	YES
Northampton General Hospital NHS Trust	YES	NO	YES
Northern Care Alliance NHS Foundation Trust	YES	NO	YES
Northern Lincolnshire and Goole NHS Foundation Trust	YES	YES	YES
Northumbria Healthcare NHS Foundation Trust	YES	YES	YES
Nottingham University Hospitals NHS Trust	YES	YES	YES
Oxford University Hospitals NHS Foundation Trust	YES	YES	YES
Portsmouth Hospitals University NHS Trust	YES	YES	YES

Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	DID NOT RESPOND IN TIME	NO	NO
Royal Berkshire NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Royal Cornwall Hospitals NHS Trust	YES	YES	YES
Royal Devon University Healthcare NHS Foundation Trust	YES	NO	YES
Royal Free London NHS Foundation Trust	YES	NO	YES
Royal National Orthopaedic Hospital NHS Trust	YES	YES	YES
Royal Surrey County Hospital NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Royal United Hospitals Bath NHS Foundation Trust	YES	YES	YES
Salisbury NHS Foundation Trust	YES	YES	YES
Sandwell and West Birmingham Hospitals NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Sheffield Teaching Hospitals NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
Sherwood Forest Hospitals NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
Shrewsbury and Telford Hospital NHS Trust	YES	NO	YES
Somerset NHS Foundation Trust	YES	YES	YES
South Tees Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
South Tyneside and Sunderland NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
South Warwickshire NHS Foundation Trust	YES	YES	YES
St George's University Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Stockport NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Surrey and Sussex Healthcare NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Tameside and Glossop Integrated Care NHS Foundation Trust	YES	NO	YES
The Hillingdon Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
The Newcastle upon Tyne Hospitals NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
The Princess Alexandra Hospital NHS Trust	YES	YES	YES
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	YES	NO	YES
The Rotherham NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO

The Royal Wolverhampton NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Torbay and South Devon NHS Foundation Trust	YES	YES	YES
United Lincolnshire Hospitals NHS Trust	YES	NO	NO
University College London Hospitals NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
University Hospital Southampton NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
University Hospitals Birmingham NHS Foundation Trust	DID NOT RESPOND IN TIME	NO	NO
University Hospitals Bristol and Weston NHS Foundation Trust	YES	YES	YES
University Hospitals Coventry and Warwickshire NHS Trust	YES	YES	YES
University Hospitals Dorset NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
University Hospitals of Derby and Burton NHS Foundation Trust	YES	YES	NO
University Hospitals Of Leicester NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
University Hospitals of Morecambe Bay NHS Foundation Trust	YES	YES	YES
University Hospitals of North Midlands	YES	YES	YES
University Hospitals Plymouth NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
University Hospitals Sussex NHS Foundation Trust	YES	NO	YES
Warrington and Halton Hospitals NHS Foundation Trust	YES	NO	YES
West Hertfordshire Hospitals NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
West Suffolk NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Whittington Health NHS Trust	DOES NOT HOLD INFORMATION	NO	NO
Wirral University Teaching Hospital NHS Foundation Trust	YES	NO	YES
Worcestershire Acute Hospitals NHS Trust	YES	YES	YES
Wrightington, Wigan and Leigh NHS Foundation Trust	DOES NOT HOLD INFORMATION	NO	NO
Wye Valley NHS Trust	YES	YES	YES
York and Scarborough Teaching Hospitals NHS Foundation Trust	YES	NO	YES

Appendix 4: Follow-up waitlist of acute trusts in May 2023

Trust Name	Number
East Kent Hospitals University NHS Foundation Trust	516,919
Northumbria Healthcare NHS Foundation Trust	432,396
Guy's and St Thomas' NHS Foundation Trust	403,108
Cambridge University Hospitals NHS Foundation Trust	238,382
University Hospitals of North Midlands	201,372
Hull University Teaching Hospitals	195,035
Mid and South Essex NHS Foundation Trust	167,352
University Hospitals Sussex NHS Foundation Trust	165,861
Gloucestershire Hospitals NHS Foundation Trust	160,038
Wye Valley Trust	157,377
University Hospitals Bristol and Weston NHS Foundation Trust	137,775
North West Anglia NHS Foundation Trust	130,281
University Hospitals Coventry and Warwickshire NHS Trust	116,698
Oxford University Hospitals NHS Foundation Trust	116,374
Northern Care Alliance	115,447
Leeds Teaching Hospitals NHS Trust	105,304
Bedfordshire Hospitals NHS Foundation Trust	103,468
Royal Cornwall Hospitals	96,435
Royal Devon University Healthcare	90,413

Warrington and Halton Teaching Hospitals	87,925
University Hospital of Derby and Burton NHS Foundation Trust	85,747
Mid Yorkshire Hospitals NHS Trust	76,186
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	70,213
Great Western Hospitals	70,113
Worcestershire Acute	63,663
Portsmouth Hospitals University	63,538
Blackpool Teaching Hospitals	60,284
Mid Cheshire Hospitals	60,223
Royal Free London NHS Foundation Trust	59,807
Shrewsbury and Telford Hospital NHS Trust	57,632
Torbay and South Devon NHS Foundation Trust	52,392
Tameside and Glossop Integrated Care NHS Foundation Trust	46,423
University Hospitals of Morecambe Bay	40,974
Airedale NHS Foundation Trust	40,108
Lancashire Teaching Hospitals NHS Foundation Trust	39,372
Royal National Orthopaedic	37,171
Salisbury NHS Foundation Trust	35,716
Bradford Teaching Hospitals NHS Foundation Trust	32,526
Royal United Hospitals Bath NHS Foundation Trust	31,146
Bolton NHS Foundation Trust	28,936
James Paget University Hospitals NHS Foundation Trust	26,735
Calderdale and Huddersfield	26,489

South Warwickshire	26,439
Isle Of Wight NHS Trust	23,701
Manchester University Hospitals	23,353
Wirral University Teaching Hospital NHS Foundation Trust	22,692
Medway NHS Foundation Trust	21,717
East Suffolk and North Essex	21,028
Somerset NHS Foundation Trust	20,841
East Lancashire Hospitals	20,564
Northern Lincolnshire and Goole	20,238
Northampton General Hospital NHS Trust	15,939
North Cumbria Integrated Care	13,905
Harrogate and District NHS Foundation Trust	13,618
The Princess Alexandra Hospital NHS Trust	12,042
Nottingham University Hospitals	1,008

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