

Data gaps in healthcare statistics

March 2024

This report looks at the healthcare questions that are repeatedly asked by key statistics users outside of the Government, but cannot be answered by official healthcare statistics. We hope to raise awareness of the main data gaps in healthcare, so that important questions can be answered and care quality improved.

Summary	1
Methodology	2
Sources	3
Choosing our focus areas	4
Limitations	4
Key gaps in published statistics	4
The NHS workforce	5
Specialisms and skills	5
Vacancies	6
Entries, exits and reasons for leaving	6
Diagnoses	7
By patient demographics	8
By geography	9
Waiting times	10
By length of wait	11
By patient demographics	11
Ambulance service delays	11
Systemic gaps	12
Lack of geographic breakdowns	12
Lack of demographic breakdowns	12
Recommendations	13
Acknowledgements	14

Summary

- Certain health and social care statistics are needed to deliver high-quality care. Despite this, and despite calls from regulators and civil society, available statistics do not always cover key areas of the healthcare system.
- We spoke to ten charities, looked through nearly 200 major independent reports and analysed more than 2,500 PQs to identify patterns in healthcare data gaps.
- Our research revealed important areas of the health and social care system that charities, regulators and MPs have repeatedly asked for better information on.

- Three topics stood out as consistently missing important data:
 - **Data on the NHS workforce.** This data is important for workforce planning, ensuring safe staffing levels, and setting pay rates.
 - **Data on the prevalence of certain conditions.** Without this data, users cannot understand the populations affected by particular conditions, identify their unmet needs, or tackle inequalities in patient outcomes.
 - **Waiting times data.** Users need this data to understand the supply of and demand for services, plan provision effectively, and ensure high-quality care.
- And across the healthcare system, data is often lacking sufficient breakdowns by demography and geography. This stops charities and policymakers from identifying and acting on health inequalities.
- These gaps are not abstract problems. They mean charities have less money to spend on patient care, and can help fewer people. And they stop the Government from investing in the most urgent areas of health, meaning that people fall through the cracks. Ultimately these data gaps affect patients' lives.
- The Health and Social Care Statistics Leadership Forum recently opened a consultation into health and social care statistical outputs.¹ The Department of Health and Social Care needs to prioritise filling these gaps as part of this review so that care quality can be improved.

UPDATE March 2024: we have clarified the wording around some Parliamentary Questions to clarify where a question can be partially answered; we have also noted a couple of minor corrections in the footnotes.

Methodology

We define data gaps as areas where a lack of official data means that questions of significant public interest cannot be answered. Without quantitative data, internal and external stakeholders find it harder to understand where services are failing or succeeding, and campaigners struggle to advocate for patients' needs.

However, it is not always easy for statistics producers to identify gaps. As the UK statistics regulator notes, data gaps are best identified by users rather than by those responsible for compiling the statistics.²

Our report looks at the healthcare questions that are repeatedly asked by users outside of the Government, but cannot be answered by official healthcare statistics. In doing so, we hope to raise awareness of the main data gaps in healthcare, so that important questions can be answered and care quality improved.

¹ Health and Social Care Statistics Leadership Forum, '[Health and social care statistical outputs published by DHSC \(including OHID\), NHSBSA, UKHSA, ONS and NHS England](#)' (2023).

² Office for Statistics Regulation, '[Data gaps: no need to be daunted](#)'.

Sources

Our report draws on a range of sources chosen to reflect the variety of stakeholders whose work is affected by data gaps in healthcare statistics.

- **Unanswered Parliamentary Questions (PQs).** PQs allow MPs and peers to request information from government departments. We obtained the text of all written PQs addressed to the Department of Health and Social Care (DHSC) during this Parliament, and their answers, by web scraping. We then identified all questions which sought quantitative information, and which could not be answered due to a lack of data.³ These 2,806 questions were manually reviewed and analysed to pinpoint areas where healthcare data was consistently requested and denied. We ignored questions that were primarily about Covid-19, as we wanted our report to reflect current user needs as closely as possible.
- **Major independent reports** from the last five years. Given that we are focused on the needs of users outside Government, we looked at independent reports commissioned by DHSC⁴ as well as health and social care reports published by independent bodies with a statutory role. The independent bodies we studied are: the Care Quality Commission (CQC),⁵ the National Audit Office (NAO),⁶ and the Office for Statistics Regulation (OSR).⁷ After we had compiled 192 reports, we searched each of them for relevant phrases like ‘data’, ‘gap’, ‘lack’, ‘limited’, ‘FOI’ and others, to find references to data gaps.
- **Civil society reports** on data gaps. We compiled a list of major UK health charities and think tanks, and searched each organisation’s website for relevant phrases like those listed above to identify data gaps.
- **Interviews with civil society stakeholders.** We contacted the civil society groups on our list, and interviewed eight of them about the data gaps that most affect their work: Asthma and Lung UK, Breast Cancer Now, the British Geriatrics Society, the British Liver Trust, MS Society, the National Autistic Society, Prostate Cancer UK, and one charity that preferred to stay anonymous. We also received guidance from

³ For more on our methodology, see: Centre for Public Data, [‘Research paper: Data and statistical gaps in criminal justice’](#) (2023); and Centre for Public Data, [‘What are the questions MPs ask that don’t get answered?’](#) (2024).

⁴ We looked at the documents categorised as ‘Independent reports’ on DHSC’s publication page, with filters set to ‘All research and statistics’, and ‘Updated after 20 February 2019’. We excluded those with a Covid-19 focus, as we wanted our report to reflect current user needs as closely as possible. This left us with 82 reports. See GOV.UK, [‘Research and statistics’](#).

⁵ CQC is the health and adult social care regulator for England. We went through all of their publications since 20 February 2019, and excluded those that focused primarily on Covid-19. This left us with 68 reports. See Care Quality Commission, [‘Publications’](#).

⁶ NAO reports were selected by filtering publications by ‘Reports’, ‘Health and social care’, with a publication date of 2019 onwards. We excluded financial audits and reports focusing on Covid-19, leaving us with 26 reports. See National Audit Office, [‘Reports’](#).

⁷ OSR reports were selected by filtering publications by ‘Health and social care’ and ignoring those before 20 February 2019 and those primarily about Covid-19. This left us with 16 reports. See Office for Statistics Regulation, [‘Publications’](#).

Miscarriage Association and Parkinson's UK. These stakeholders represent a broad range of health conditions.

Choosing our focus areas

This document is not intended to be a comprehensive map of every data gap in health and social care statistics. Given that we found too many gaps for us to include in one report,⁸ we used the following criteria to prioritise areas to focus on:

1. A range of stakeholders expressed a clear desire for better data on the topic.
2. Stakeholders' ability to support patients is significantly impacted by the missing data; without the data, they cannot answer an important question about the health and care system.

Limitations

Our methodology has the following limitations, due to resource and time constraints:

- **It is restricted to health and social care statistics in England.** This is because the consultation on healthcare statistics has this scope.
- **It covers only certain stakeholders.** We focused on civil society perspectives, rather than other important user groups like journalists and academics. None of the organisations that we interviewed were dedicated primarily to social care, so our findings about statistical gaps in this area are similarly limited.
- **Some of the gaps we identify may have already been filled.** Although we have tried to ensure our analysis is up-to-date, in some cases a data gap may have been filled since the publication of the report or PQ that brought our attention to it.
- **We have a limited understanding of the underlying healthcare data** and so cannot yet say which gaps would be easiest to fill.

Key gaps in published statistics

We found evidence of persistent gaps in basic data that affect statistics users in three main areas: the NHS workforce, diagnoses, and waiting times.

⁸ The most significant data gap that we found evidence for, but did not include in this report, relates to value for money, i.e. the cost and effectiveness of different health and care programmes or treatments. This gap featured heavily in the major independent reports we reviewed, but little in civil society interviews and reports, likely as a result of these organisations' different functions.

The NHS workforce

NHS workforce data is important for workforce planning and ensuring a high quality of care. However, well-established gaps in these statistics are stopping the Government, the NHS, and regulatory bodies from understanding what is needed to meet workforce demand.

For example, the NAO has repeatedly noted that NHS workforce planning is impeded by a lack of workforce data.⁹ The Economist writes that the Government “has little idea how many doctors it will need next year, let alone in ten”.¹⁰

This data gap also impedes the work of health charities in the UK, causing them to struggle to identify and act on service gaps before they take a toll on the UK’s health. In 2022, nearly 100 health and care organisations formed a coalition to urge the Government to publish missing workforce data.¹¹

Specialisms and skills

Knowing how many NHS workers there are by specialism in each region is vital for workforce planning and to address regional variations in access to healthcare. Parkinson’s UK has been campaigning for better information on the number of Parkinson’s specialists in the NHS since 2022,¹² and in interviews, charities including Prostate Cancer UK and MS Society also expressed a need for data on specialist staff.

However, with the exception of doctors and consultants, who account for just 10% of the workforce, we do not have national figures for the number of workers in particular specialisms.¹³ In Parliament, DHSC was unable to answer the question:

1. How many multiple sclerosis specialist nurses work in the NHS?¹⁴

And even more fundamentally:

2. How many full-time equivalent GPs are there in England, and by region, per head of population?¹⁵

Charity interviews and our analysis of PQs identified data gaps in the number and location of a much broader range of specialists than just those mentioned above. The specialists include, but are not limited to: anaesthesia associates, people qualified to perform autism diagnoses, bladder and bowel continence nurses, cancer nurses, nurses and doctors with critical care training, dermatology nurses, eating disorder specialists, geriatric specialists,

⁹ National Audit Office, [‘The NHS nursing workforce’](#) (2020).

¹⁰ The Economist, [‘The NHS is in seriously poor shape’](#) (2022).

¹¹ Royal College of Physicians, [‘Strengthening workforce planning in the health and care bill: coalition principles’](#) (2021).

¹² Parkinson’s UK, [‘Can’t Wait’](#).

¹³ The Carer UK, [‘People with Parkinson’s Waiting Years for Care Due to NHS Workforce Crisis’](#) (2022).

¹⁴ [HL Deb](#), 28 April 2022, cW.

¹⁵ [HC Deb](#), 11 April 2022, cW. Note March 2024: we have learned that GP counts by ICB and sub-ICB locations are available. See NHS Digital, [‘General Practice Workforce Official Statistics’](#).

motor neurone disease nurses, osteoporosis nurses, podiatric care specialists, radiology nurses, renal counsellors, respiratory community nurses, and urology specialist nurses.

Vacancies

Vacancy information is important for workforce planning, for ensuring safe staffing levels, and for setting salaries. However, current statistics are not granular enough for these purposes, as they do not provide breakdowns by specialty or region.

The British Medical Association warned in 2021 that this lack of data was affecting services:

“Without knowing where [staff] shortages exist, ie the staff grade/speciality and the region, it is impossible to ensure sufficient supply or fill existing rota gaps and vacancies. This leaves services dangerously understaffed.”¹⁶

An independent report on the social care sector also flagged that the lack of detailed data on vacancies can affect care quality, noting that “there should be up-to-date information on the number of services lacking registered managers, given the important impact that [they] have on care quality”.¹⁷

The data gap also makes it hard to set pay rates accurately. In 2023, the official body that sets doctors’ and dentists’ salaries said it would benefit from breakdowns of vacancy rates by specialty and geography, and the body responsible for other NHS salaries similarly requested more granular data.¹⁸

However, the gap remains. In Parliament, DHSC was unable to answer questions like:

1. How many vacancies in the NHS are there for hepatologists?¹⁹
2. How many NHS hospitals have had vacancies for medical staff unfilled for more than a year?²⁰

Entries, exits and reasons for leaving

Information on the number of staff recruited is also important for workforce planning. However, it seems that the only available central recruitment figures are for staff in hospital trusts and clinical commissioning groups, meaning there is limited information on recruitment patterns into primary care, local authorities, and other providers.

¹⁶ British Medical Association, [‘Medical staffing in England: a defining moment for doctors and patients’](#) (2021).

¹⁷ Baroness Cavendish, [‘Social care reform: an independent review by Baroness Cavendish’](#) (2022).

¹⁸ Review Body on Doctors’ and Dentists’ Remuneration, Office of Manpower Economics, and Department of Health and Social Care, [‘Review Body on Doctors’ and Dentists’ Remuneration 51st Report: 2023’](#) (2023); NHS Pay Review Body, Office of Manpower Economics, and Department of Health and Social Care, [‘NHS Pay Review Body Thirty-Fifth Report: 2022’](#) (2022); NHS Pay Review Body, Office of Manpower Economics, and Department of Health and Social Care, [‘NHS Pay Review Body Thirty-Sixth Report: 2023’](#) (2023).

¹⁹ [HC Deb](#), 18 June 2020, cW.

²⁰ [HC Deb](#), 8 October 2020, cW.

Because of this, DHSC could not answer questions in Parliament on how many radiotherapy staff retired or resigned across the NHS in the last year,²¹ nor how many nurses had been recruited across the NHS since December 2019.²²

DHSC also needs to understand what drives health and social care workers to leave their jobs, especially given that 2022 was a record year for NHS staff departure in England.²³ But the department could not say how many junior doctors, consultants and nurses had left the NHS to work in private healthcare in each of the last five years.²⁴

In 2023, the NHS Pay Review Body flagged that this was a significant data gap:

“Over the last few years, we have repeatedly asked for leaver data which effectively records reasons for leaving at a system level. That this remains unsolved is of significant concern.”²⁵

Diagnoses

Charities need data on diagnoses to understand the patient communities they serve, and identify unmet needs so that they can advocate for increased service provision.

However, many charities cannot even access data on the national prevalence of relevant conditions, often due to unavailable data from primary care. Asthma and Lung UK, for example, told us that they cannot find out how many respiratory diseases are diagnosed every year, which limits their ability to plan services and make the case for greater investment in treatments.

Moreover, Parkinson’s UK and MS Society have both paid for data so that they can estimate how many people have Parkinson’s or multiple sclerosis respectively.²⁶ Accessing this data requires money and time that the charities could be spending on care, and generates only a rough national picture.

The lack of national statistics on certain diagnoses also affects public health bodies, who need to understand the prevalence of a condition to provide high-quality care and plan services.²⁷ A recent independent report commissioned by DHSC recommends that NHS England introduce consistent data collection on pregnancy loss so that they can better

²¹ [HC Deb](#), 31 January 2022, cW.

²² [HC Deb](#), 20 July 2022, cW.

²³ The Guardian, [‘Revealed: record 170,000 staff leave NHS in England as stress and workload take toll’](#) (2023).

²⁴ [HC Deb](#), 20 March 2023, cW.

²⁵ NHS Pay Review Body, Office of Manpower Economics, and Department of Health and Social Care, [‘NHS Pay Review Body Thirty-Sixth Report: 2023’](#) (2023).

²⁶ Parkinson’s UK uses data from Clinical Practice Research Datalink and MS Society uses data from The Health Improvement Network.

²⁷ For example, see Care Quality Commission, [‘Assessment of mental health services in acute trusts’](#) (2020).

understand the true scale of the problem, and “to prevent patients from being notified of outstanding maternity appointments and scans in error”.²⁸

Despite the importance of this data, DHSC could not answer:

1. How many people were diagnosed with anxiety or depression in the last five years?²⁹
2. How many people have been diagnosed with a terminal illness in the last decade?³⁰
3. How many people were diagnosed with chickenpox in the last five years?³¹

Charity interviews and our PQ analysis identified a wide range of conditions for which questions on national prevalence rates could not be answered, beyond those above. These include, but are not limited to: alopecia, asbestosis, brain haemorrhage, chronic bronchitis, colour blindness, Crohn’s disease, dyslexia, dysphagia, ectopic pregnancies, eczema, endometriosis, eyesight loss, fibromyalgia, gout, irritable bowel syndrome, metastatic breast cancer, miscarriage, motor neurone disease, molar pregnancy, myocarditis, osteoporosis, pericarditis, polycystic ovary syndrome, restless leg syndrome, spinal disorders, and ulcerative colitis.

By patient demographics

Limited data on the demographic distribution of conditions prevents charities and public health bodies from being aware of and tackling disparities in treatment. We have identified particular demand for breakdowns of diagnoses by age, gender, and ethnicity.

In 2023, the UK’s Chief Medical Officer highlighted how a lack of breakdowns by age in diagnosis data means that public health bodies struggle to meet older people’s needs:

"The health and care needs of older adults are often not recognised because the relevant data are not systematically collected or aggregated in one place. For example, epidemiological data on health conditions contributing to disability such as hearing loss and mental health is not routinely available for older adults. To plan appropriately, organisations including the NHS, Office for National Statistics (ONS), and central and local government need systematically to collect and share data on the health and care needs of older adults, including by ethnicity, sex and other protected characteristics."

Likewise, given that the understanding of autism in women has historically been very poor, the National Autistic Society told us about the importance of monitoring this gender gap and evaluating progress in awareness of autism in women. This requires gender breakdowns in autism diagnoses, which currently are not published.

²⁸ Department of Health and Social Care, [‘Pregnancy Loss Review’](#) (2023).

²⁹ [HL Deb](#), 28 July 2022, cW.

³⁰ [HC Deb](#), 22 February 2023, cW.

³¹ [HC Deb](#), 22 April 2020, cW.

In Parliament, DHSC could not say how many people had been diagnosed, by age and gender, with Alzheimer's, bi-polar disorder, chronic fatigue syndrome, cystic fibrosis, epilepsy, multiple sclerosis, and Tourette's syndrome, to name a few.³²

Both the British Liver Trust and Prostate Cancer UK told us that they lack diagnosis data on the populations who are most affected by liver disease and prostate cancer respectively. People from deprived communities are disproportionately likely to develop liver disease,³³ and research suggests that Black men are twice as likely to be diagnosed with prostate cancer as other men.³⁴ However, the relevant breakdowns of these conditions by level of deprivation and ethnicity are not publicly available.³⁵ This makes it difficult to monitor, manage, and further research these health inequalities.

By geography

Some conditions lack area-level data on diagnoses. As above, this data gap prevents charities and public health bodies from recognising and tackling health inequalities.

For example, a lack of regional data on musculoskeletal conditions means that charity Versus Arthritis has to estimate area-level prevalence from its own statistical model, which again takes considerable resources that it must divert from patient care.³⁶ Versus Arthritis explain that limited local data on the number of people with these conditions was affecting service planning and the quality of care:

“By not measuring these conditions, it became difficult for local planners to take them into account when planning their services and risked the conditions being overlooked. A lot of power in the healthcare system, in particular public health, rests at a local level, so allowing estimates to be produced at this level was especially important.”³⁷

Similarly, the British Liver Trust told us that if they had better oversight of which areas had higher burdens of alcohol misuse or obesity, for example, they would be better able to target interventions that could prevent the development of liver diseases.

³² [HC Deb](#), 17 May 2021, cW; [HC Deb](#), 21 March 2022, cW; [HC Deb](#), 4 December 2020, cW; [HC Deb](#), 4 December 2020, cW; [HC Deb](#), 29 January 2021, cW; [HC Deb](#), 15 June 2023, cW; [HC Deb](#), 4 December 2020, cW.

³³ British Liver Trust, '[Liver disease in numbers - key facts and statistics](#)'.

³⁴ Therese Lloyd, Luke Hounsome, Anita Mehay, Sarah Mee, Julia Verne, and Alison Cooper, '[Lifetime risk of being diagnosed with, or dying from, prostate cancer by major ethnic group in England 2008-2010](#)' (2015).

³⁵ Prostate Cancer UK mentioned to us that they are particularly in need of breakdowns of prostate cancer by ethnicity, by stage at diagnosis. They could then, for example, evaluate their awareness-raising campaigns and identify groups that are more likely to experience poor prostate cancer outcomes.

³⁶ It is worth noting that the Musculoskeletal Calculator relies on datasets that lie behind a paywall. See: Versus Arthritis, '[Musculoskeletal Calculator](#)'.

³⁷ Versus Arthritis, '[MSK Calculator FAQ](#)'.

Since December 2019, a large number of PQs have asked for breakdowns of conditions' prevalence by region of England - and not been answered. This includes, but is not limited to breakdowns for: ADHD, chronic bronchitis, Crohn's disease and liver disease.³⁸

Waiting times

Charities and healthcare providers alike need to understand how long people are waiting for appointments, diagnoses, and treatments, both nationally and regionally. Without this information, insight into the demand for and supply of care is limited, making it difficult for organisations to plan services effectively, measure care quality, and identify inequalities in access to care. Granular data on waiting times is only becoming more important as NHS backlogs grow to unprecedented levels.³⁹

Despite this, waiting times statistics are often not available. For example, data on waiting times for ADHD diagnoses is not held centrally, so there is no oversight of average waiting times, nor the number of people in line.⁴⁰ And according to Freedom of Information requests that the charity ADHD UK made to each diagnosis service, 75% of NHS providers did not even know their own waiting times.⁴¹

Data on waiting times between diagnosis and treatment are similarly important. For example, if people with multiple sclerosis receive treatment soon after diagnosis, their disease progression is slowed. However, MS Society observes that there is limited data on waiting times between diagnosis and treatment, meaning they cannot monitor a crucial measure of care quality.

In Parliament, DHSC was unable to answer questions including:

1. What is the average wait time for an in-person GP appointment in England?⁴²
2. What is the average waiting time for treatment in Child and Adolescent Mental Health Services in England?⁴³
3. How many patients are waiting to be seen for cancer treatment in Hull, East Yorkshire and England?⁴⁴

Our interviews and PQ analysis identified a wide range of areas for which there was limited data on the average waiting times or number of people in line for appointments, diagnoses, or treatment. These areas include, but are not limited to: bowel cancer screenings, children's speech and language therapy, Crohn's diagnosis, dyspraxia diagnosis,

³⁸ [HC Deb](#), 21 November 2023, cW; [HC Deb](#), 11 May 2020, cW; [HC Deb](#), 20 November 2020, cW; [HC Deb](#), 27 January 2021, cW.

³⁹ British Medical Association, '[NHS backlog data analysis](#)' (2024).

⁴⁰ [HC Deb](#), 19 April 2023, cW.

⁴¹ ADHD UK, '[Lobbying to Reduce ADHD Diagnosis Waiting Times](#)'.

⁴² [HC Deb](#), 28 February 2022, cW.

⁴³ [HC Deb](#), 26 July 2022, cW.

⁴⁴ [HC Deb](#), 11 November 2020, cW.

endometriosis diagnosis, treatment for specific gynaecological conditions,⁴⁵ hip and knee replacements, neurology appointments, orthodontic procedures, orthopaedic surgery, psychological treatments for eating disorders, specialist weight management services, spirometry asthma assessments, treatment at an NHS gender identity clinic, and ulcerative colitis diagnosis.

By length of wait

Data is often only published on the proportion of waiting times targets that have been met, and not on how long people actually waited for services. The NAO, for example, has noted that it cannot find out how many A&E patients are waiting significantly longer than the 12-hour target to be admitted to a ward.⁴⁶

This gap also inhibits the operations of health charities in the UK. For instance, Prostate Cancer UK knows that a significant proportion of patients in the UK are not being treated within the 62-day standard window, but this is of little help in identifying and intervening where the longest waiting times are.

Some charities have attempted to obtain the relevant data via other routes, but this is resource-intensive: the National Autistic Society told us that it is possible to get further breakdowns by making an FOI request of every single autism diagnosis service, but they do not have the capacity to do so.

By patient demographics

Waiting times data often lacks demographic breakdowns, meaning that regulators have no oversight of inequalities in waiting times, and charities cannot identify groups that need extra outreach. The NAO identified this problem in 2019, reporting that NHS England had a limited understanding of variations in waiting times across different population groups.⁴⁷

Statistics on waiting times for autism diagnosis, for example, are not broken down by gender, so DHSC does not know the average waiting time for autism diagnosis in women.⁴⁸ This is particularly concerning given that historically, women have been greatly underdiagnosed.

Ambulance service delays

Understanding the harm caused by the current crisis in ambulance waiting times is a matter of significant public interest. But information on the number of patients who have died while waiting for an emergency ambulance is not held centrally.⁴⁹ DHSC therefore does not know

⁴⁵ *Corrected 27 March 2024: we had previously written “gynaecology treatment”, but the NHS collects data on patients awaiting treatment for gynaecological conditions, it just does not break this data down by condition. See [HC Deb](#), 27 May 2022, cW.*

⁴⁶ National Audit Office, '[Access to unplanned or urgent care](#)' (2023).

⁴⁷ National Audit Office, '[NHS waiting times for elective and cancer treatment](#)' (2019).

⁴⁸ [HC Deb](#), 31 March 2022, cW.

⁴⁹ [HC Deb](#), 8 November 2021, cW.

how many patients have died due to ambulance delays in recent years, let alone the total number of serious incidents of avoidable harm that have been caused.⁵⁰

Systemic gaps

As established above, breakdowns by geography and demography are often missing from data on workforce, diagnoses, and waiting times. In fact, the unavailability of these breakdowns is a systemic problem across healthcare statistics, which prevents policymakers and charities from understanding and acting on health inequalities.

Lack of geographic breakdowns

Healthcare statistics often do not contain sufficient data at granular levels of geography, making it difficult for charities and the Government to pinpoint localities with poor health outcomes.

For example, this was described as a “key challenge” by the Chief Medical Officer in his report on coastal communities, which found that poor health outcomes at the coast can be masked by superior outcomes inland when the only available data is at a relatively high level of geography.⁵¹ The report judged that more granular data would be crucial for policymakers trying to improve the health of coastal communities.

This issue will soon gain even greater operational significance. NHS England plans to delegate the commissioning responsibility for many services to Integrated Care Boards (ICBs).⁵² It is important, therefore, that the Government and charities have ICB-level data so that they can demonstrate areas of unmet need to the boards and hold them to account. However, many charities we have spoken to, such as the British Liver Trust, have said that this data is missing.

Lack of demographic breakdowns

Several major independent reports have highlighted the systematic lack of demographic breakdowns in healthcare statistics, with particular focus on missing ethnicity data.⁵³ For example, in 2023 CQC reported that there was “no existing national data” on the protected characteristics of people in care settings.⁵⁴ This prevents regulators from understanding

⁵⁰ [HC Deb](#), 9 January 2023, cW.

⁵¹ Professor Chris Whitty, [‘Chief Medical Officer’s annual report 2021: health in coastal communities’](#) (2021).

⁵² NHS England, [‘Specialised commissioning 2024/25 – next steps with delegation to integrated care boards’](#) (2023).

⁵³ For examples, see: National Audit Office, [‘Managing NHS backlogs and waiting times in England’](#) (2022); Care Quality Commission, [‘CQC Insight: Issue 15’](#) (2022); Nuffield Trust, [‘Ethnicity coding in English health service datasets’](#) (2021); Care Quality Commission, [‘Provider collaboration review: Urgent and emergency care’](#) (2021); Office for Statistics Regulation, [‘Statistics on Cancer Survival in England’](#) (2019).

⁵⁴ Care Quality Commission, [‘Rapid literature review: Inequalities in dementia’](#) (2023).

how demographic factors impact a person's experience of social care, and evaluating the success of measures designed to tackle these inequalities.

Inequalities data is similarly lacking in cancer settings. CQC found that most cancer services do not record demographic data well enough:

“There is a risk of widening inequalities among cancer patients stemming from ... challenges around the capturing and sharing of people's demographic data.”⁵⁵

Healthcare charities also feel the impact of this missing inequalities data. According to Breast Cancer Now, this is the data gap that most affects their work. Without better demographic breakdowns, charities and healthcare providers cannot fill gaps in services and effectively tackle health inequalities.

Recommendations

A wide range of stakeholders have identified gaps in healthcare statistics that stop patients receiving high-quality care. The gaps mean that charities' ability to support patients is restricted, that regulators have limited oversight of the performance of the healthcare system, and that the Government does not know where their money is most needed. Despite repeated calls from healthcare regulators and civil society, and repeated questions from MPs, the necessary data is still not published.

Our research shows that a wide range of stakeholders need answers to the following important questions, broken down appropriately by demography and geography:

1. Workforce:
 - a. How many NHS workers are there in a particular specialism?
 - b. How many vacancies are there for a particular specialism?
 - c. How many NHS workers have left particular roles in the last year?
 - d. How many NHS workers have been recruited into particular roles in the last year?
 - e. What reasons and future destinations were given by NHS workers who left their jobs in the last year?
2. Diagnoses:
 - a. How many people have been diagnosed with a particular condition in the last year - particularly conditions diagnosed in primary care or specialist services?
3. Waiting times:
 - a. How many people are waiting for specific appointments, diagnoses and treatments?
 - b. What is the average waiting time for specific appointments, diagnoses and treatments?

⁵⁵ Care Quality Commission, [‘Provider collaboration review: ensuring the provision of cancer services’](#) (2021).

- c. How long are people waiting for specific appointments, diagnoses, and treatments beyond the NHS standards for waiting times?
- d. How many serious incidents of avoidable harm have been caused by ambulance delays in the last month or year?

We recommend that DHSC begin publishing statistics that can answer these important questions. As producers of official statistics, the department has a formal duty under the UK's Code of Practice for Statistics to ensure its statistics are relevant to users, and to consider whether to produce new statistics to fill identified information gaps.⁵⁶ The ongoing review of health and social care statistics is a prime opportunity for DHSC to do so.

Acknowledgements

The Centre for Public Data is a non-partisan, non-profit research and advocacy organisation that works to improve the quality of UK public data. We have a particular interest in data gaps - areas where a lack of publicly available data or statistics means that questions of significant public interest cannot be answered.

This report was written by Amber Dellar and Anna Powell-Smith. We welcome comments and corrections - please get in touch at contact@centreforpublicdata.org.

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- Sally Greenbrook (British Geriatrics Society)
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⁵⁶ Office for Statistics Regulation, '[Code of Practice for Statistics - V1: Relevance to users](#)'.