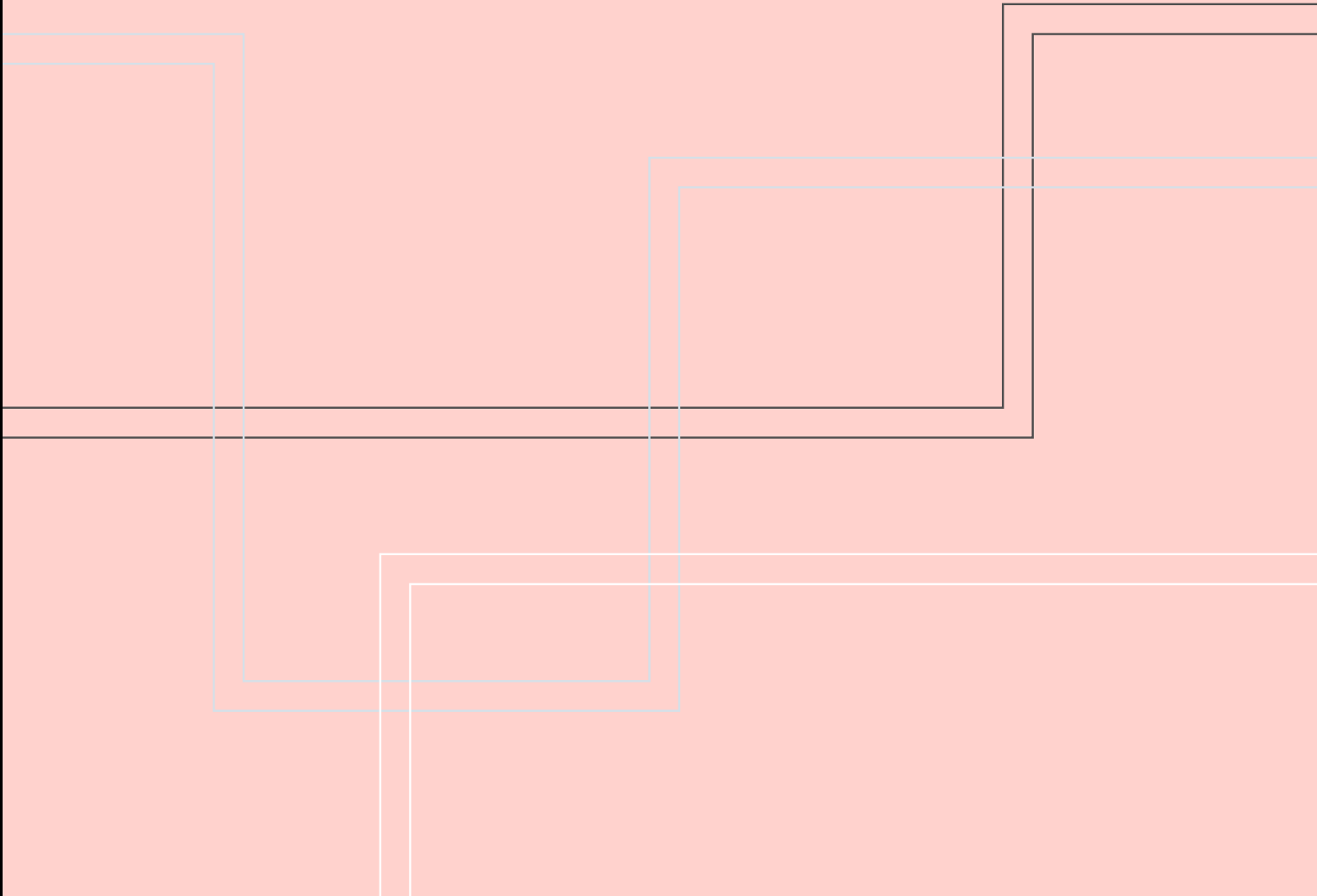


Discussion paper

‘The computer won’t do that’

Exploring the impact of clinical information systems in primary care on transgender and non-binary adults

September 2024



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Executive summary

High-quality, representative data is fundamental to the development and deployment of health systems. Research using – and technological innovations built on – health data can help to solve challenging health problems, from the diagnosis of rare diseases to more personalised care pathways.

But what happens when this data does not accurately represent the experience of certain people and groups accessing care? And what does that mean for equitable access to health services? In this report, we examine these questions by exploring the experiences of transgender and non-binary people interacting with clinical information systems in primary care.

Our research found that these clinical information systems (the umbrella term encompassing all technological systems used by primary care services in the UK, sometimes referred to by the NHS as 'IT systems' or as 'digital systems') are not consistently designed to accommodate gender diversity, and that they conflate gender with physiological sex characteristics. Furthermore, information about gender identity and sex is collected and recorded in different ways in different parts of the system.

This could have a number of harmful knock-on effects for transgender and nonbinary people seeking healthcare. It could mean that they are not treated with the same dignity and respect as cisgender patients. It could also threaten their continuity of care – as any patient who changes their gender marker in the system must also change their NHS number, which risks the loss of vital health records. And ultimately, it could result in the invisibility of transgender and nonbinary people in health data altogether.

The data journey of the NHS

NHS England has advanced a transformational vision for the health and care system, with data at the heart of it. In 2023, a year after the *Data Saves Lives* strategy was published, the NHS stated that it had delivered on over half of the commitments made in the strategy, including promoting common

data standards, shared care records for integrated care systems, and replacement of paper records with digital ones for most providers.¹

The NHS considers AI to hold great potential to make a positive difference in health and care settings due to the ability to quickly process vast quantities of data. AI technologies are already being used to help clinicians by, for example, analysing X-ray images or brain scans, reducing the time it takes for patients to receive treatment. In the coming years, we are likely to see the development and proliferation of many AI tools for diagnostic and other purposes – trained on datasets taken from, among other sources, primary care.

As AI becomes more commonplace and complex, it is ever more important that the datasets underpinning AI systems are a good reflection of the population and of our society. If the data present in these systems is not representative and free of bias, this could reinforce or widen inequalities and result in harmful effects for people and society.

Data disparities: the experience of transgender and non-binary people

Assumptions we make about people's identities and bodies and accompanying stereotypes, for example about race or gender, are reflected in the health systems we design and use. These assumptions result in systems being narrowly configured and, consequently, not universally accessible.

One essential piece of information that data-driven health systems collect about patients is their gender marker. In this exploratory research project, we examined the implications of using data-driven health systems that are not designed with the input – and do not fully reflect the experiences – of transgender and non-binary people.

To inform this research, we examined scholarship in the gender, health, data and AI spaces to identify gaps in the existing research. We found that transgender and non-binary people's experiences of the healthcare system are gaining visibility, but there is a gap in the situating of these experiences in the context of data and AI.

1 M Tang and L Greenrod, 'Data Saves Lives: One Year On' (NHS England, 28 June 2023) www.england.nhs.uk/blog/data-saves-lives-one-year-on accessed 25 July 2024.

To interrogate and address this evidence gap, we convened roundtables with academics, policymakers and independent researchers working in this space, and we drew on conversations with general practitioners (GPs) and organisations advocating for transgender and non-binary people. Finally, we conducted a workshop and one-to-one interviews with a small number of transgender and non-binary people to understand and document their lived experiences (see our [methodology](#) for more details and discussion of necessary limitations). We also held a second workshop with the same participants to present research findings and to gather feedback on our insights.

GPs and other NHS services often rely on data about a person's sex characteristics in order to make diagnoses or invite them to screenings. For some people, gender identity does not correspond with their sex assigned at birth. Under the Gender Recognition Act, individuals can change their health record to accurately reflect their gender identity.² However, the health record linking to the Spine – the national database that holds important health information in electronic records – includes only the binary categories of male and female, and links pronouns and titles with gender in a rigid and binary way. This can cause problems for those who are transgender, non-binary or intersex.

Data about a person's gender identity and how they wish to be addressed (pronouns, titles) is also crucial for providing care that is respectful and compassionate to all people. Being misgendered by clinical staff or in letters from health services can be a very distressing experience.

But currently the only process to change one's gender in the record is to assign a new NHS number and establish a new record with no link to the previous one. GPs are tasked with transferring relevant information between the records, but this process is complicated and time consuming, which results in data being lost.

Interview participants informed us that when they asked their GP about making changes, they were told that the system could not accommodate this. For example, a person who is registered as female cannot have a request to be addressed as 'Mr' noted in their health record.

2 'Gender Identity' (NHS England Digital) <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/submit-data/data-quality-of-protected-characteristics-and-other-vulnerable-groups/gender-identity> accessed 14 August 2024

This research focuses on primary care – which includes general practice, dental and optometry services, and pharmacy services – because this is often the first instance of a person interacting with the healthcare system. Within primary care, the research focuses on GP surgeries, which, for the transgender and non-binary people we spoke to, can be challenging to navigate.³ The research refers to the two principal clinical information systems used by GP surgeries to manage patient health records: SystemOne (a product of the Phoenix Partnership, TPP) and EMIS.

The lived reality of transgender and non-binary people having to navigate the NHS data systems and services can be challenging. While our sample was small, our research shows the real-world impact on people, and on continuity of care, when clinical information systems and the policies that guide their use fail to capture data accurately or fail to keep people's health records together.

Key findings

An analysis of the interviews, workshops and stakeholder conversations revealed indicative findings grouped under these broad themes:

- **Clinical information systems do not consistently allow for a range of options when recording gender identity and sex.** Noting physiological sex characteristics is necessary for medical purposes, but transgender and non-binary people also require care that is compassionate and respects their identity. Most data-driven systems currently used by the NHS operate within a binary framework that does not accommodate this, and this can have a negative impact on individuals' access to care and their wellbeing.
- **The NHS number change process disrupts people's continuity of care.** When patients ask to change their gender marker in their medical record, they are assigned a new NHS number (and accompanying new record). GPs, other clinical staff, and transgender and non-binary people themselves are not always clear on the guidelines for doing this, and the process can be difficult to understand and implement. This can lead to a loss of data such as information about vaccinations or previous test results, clinical history related to complex

3 TransActual, 'Trans Lives Survey 2021: Enduring the UK's Hostile Environment' (2021) <https://transactual.org.uk/trans-lives-21> accessed 25 July 2024.

medical conditions, and in some instances even safeguarding information. Additionally, GPs are often left without sufficient support or resources when attempting to provide care.

- **Legacy systems in the NHS are difficult to navigate and change.** The vision of a 'modern' digital NHS is frustrated by the reality of a lack of basic functional IT equipment. This finding is reflected in other research, and in the 2023 report *Digital Transformation in the NHS* by the House of Commons Health and Social Care Committee.⁴

Our analysis suggested that the current state of affairs broadly causes, or could cause, three levels of harm:

- **An immediate harm is the impact on transgender and non-binary people's health and wellbeing.** All people deserve healthcare that is respectful of their identity and experiences. For transgender and non-binary people, this includes addressing them with the names, titles and pronouns that they use. The NHS and its systems operate with the assumption that a person's gender identity, sex assigned at birth and anatomy all map neatly onto each other, which conflicts with many people's understanding and experiences of themselves and their bodies. If a patient is unable to receive the care they need or experiences distress due to the inability of clinical information systems to record all of the relevant data, this is a flaw that warrants attention.
- **A medium to long-term harm is the loss of medical information and the potential for many people to be missed in cancer screenings or diagnostic tests.** People are assigned a new NHS number when they change their gender in the health record, and the system typically treats this as their sex assigned at birth for purposes of diagnoses and invitations for screenings. A change in a person's NHS number can lead to a cascade of problems such as medical history being unavailable to the patient or their clinician. This leads to a disruption in the continuity of care.
- **A potential future harm is that without change to the current clinical information systems, transgender and non-binary people are lost from overall health data.** This could happen because the lack of options beyond binary male/female categories mean that people are

4 Health and Social Care Committee, 'Digital transformation in the NHS: Eight Report of Session 2022–23' (House of Commons 2023) <https://publications.parliament.uk/pa/cm5803/cmselect/cmhealth/223/report.html> accessed 21 August 2024.

not fully and accurately represented in the data. This means that the NHS has little to no data on how many people are transgender or non-binary and how their gender may impact their health. This could also have far-reaching effects on health research: the erasure of any link between the old and new record could make longitudinal research using participant records biased or more complicated.⁵

We found that the design and functioning of clinical information systems results in an overarching harm to health services: NHS clinicians and support staff, such as records management professionals, are already stretched beyond capacity and the processes currently in place are an unnecessary burden that prevent effective care.

AI systems are only as good as the data they are built on. If clinical information systems are not designed to hold *all* necessary data about a patient, any clinical decision making that relies on this data and any complex technologies built on it will be inaccurate. It is necessary to understand and account for diverse experiences of health systems, and to understand the biases implicit in datasets, in order to eventually co-develop and deploy inclusive data-driven systems – for healthcare and in other sectors.

Glossary of terms

AI: an umbrella term for a range of algorithm-based technologies that solve complex tasks by carrying out functions that previously required human intelligence.⁶

Algorithm: a sequence of well-defined instructions for solving a problem or task using data.

Biological sex: the categorisation of people as male, female or intersex depending on their biological and physiological characteristics, such as chromosomes, hormones and reproductive organs.⁷

5 A Boyd and others, 'NHS Number and the Systems Used to Manage Them: An Overview for Research Users' (Closer, UCL Institute of Education, April 2018) www.closer.ac.uk/wp-content/uploads/CLOSER-NHS-ID-Resource-Report-Apr2018.pdf.

6 We acknowledge that the term 'intelligence' and how it is defined is itself contested and that intelligence is constructed through a racialised and gendered lens. For more, see: S Cave, 'The Problem with Intelligence: Its Value-Laden History and the Future of AI' (2020) 7 February, 29 AIES '20: Proceedings of the AAAI/ACM Conference on AI Ethics and Society <https://doi.org/10.1145/3375627.3375813>.

7 WHO, 'Gender and Health' www.who.int/health-topics/gender#tab=tab_1 accessed 24 July 2024.

Cisgender: refers to a person whose gender identity corresponds with their sex assigned at birth.⁸

Clinical information systems: computer-based systems, sometimes also called 'IT systems', which can collect, store and alter clinical data on patients. Electronic health records are stored in these systems.

Data-driven systems: technologies that collect, process and analyse data about people to present information in new ways, make predictions or reach a particular outcome (including data dashboards and diagnostics tools).⁹

Health and social care system: the collection of organisations that provide health and social care support to people, including GP practices, hospitals, dentists and care homes.¹⁰

Gender: the socially constructed characteristics, norms, behaviours and roles generally associated with being a man, woman or gender-diverse person. Gender also influences how people perceive themselves and each other, how they act and interact, and the distribution of power and resources in society.¹¹

Gender binary: the construction of gender into two strict and distinct categories of male or female.¹²

Gender-diverse: refers to people whose gender identity is at odds with what is perceived as the gender norm in a particular context at a particular point in time, including those who do not place themselves in the male/female binary.¹³

8 Merriam-Webster, 'Cisgender' www.merriam-webster.com/dictionary/cisgender accessed 24 July 2024.

9 A Studman, *Access denied? Socioeconomic inequalities in digital health services* (Ada Lovelace Institute 2023) www.adalovelaceinstitute.org/report/healthcare-access-denied accessed 24 July 2024.

10 Studman, *Access denied?* (n 9).

11 WHO, 'Gender and Health' (n 7); Canadian Institutes of Health Research, 'What Is Gender? What Is Sex?' (8 May 2023) <https://cihr-irsc.gc.ca/e/48642.html> accessed 24 July 2024.

12 Human Rights Campaign 'Glossary of Terms' (31 May 2023) www.hrc.org/resources/glossary-of-terms accessed 24 July 2024.

13 Independent Expert on sexual orientation and gender identity, 'The Struggle of Trans and Gender-Diverse Persons' (UN OHCHR) www.ohchr.org/en/special-procedures/ie-sexual-orientation-and-gender-identity/struggle-trans-and-gender-diverse-persons accessed 2 August 2024.

Gender identity: a person's innate, deeply felt and individual sense of their own gender. This may or may not correspond to their physiology or sex assigned at birth.¹⁴

Intersex: an umbrella term for individuals born with natural variations in biological or physiological characteristics (including sexual anatomy, reproductive organs and/or chromosomal patterns) that do not fit traditional definitions of male or female.¹⁵

Non-binary: an umbrella term for people whose gender identity does not sit comfortably or exclusively within the gender binary. It can encompass identities such as agender, bigender, genderqueer or gender fluid.¹⁶

Sex assigned at birth: the sex recorded at a person's birth, such as in their birth certificate. It is typically based on physical characteristics such as visible sex organs but may include chromosomes and hormones. This may also be referred to as 'assigned sex'. The NHS *Digital Service Manual* notes: 'We use the phrase "sex assigned at birth" when we're talking about trans health and gender dysphoria, as this is the language our audience uses. In other cases, we use "the sex someone was registered with at birth" because user research shows that most people understand this better as it refers to an actual event.'¹⁷

Sex characteristics: each person's physical characteristics relating to sex, including genitalia and other reproductive anatomy, chromosomes and hormones, and secondary physical characteristics emerging from puberty.¹⁸

Transgender/trans/TGD (trans and gender-diverse): umbrella terms to describe people whose gender is not the same as, or does not sit comfortably with, the cultural expectations based on the sex they were assigned at birth.¹⁹

14 Human Rights Campaign, 'Sexual Orientation and Gender Identity Definitions' www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions accessed 24 July 2024; NSPCC, 'Gender Identity' www.nspcc.org.uk/keeping-children-safe/sex-relationships/gender-identity accessed 24 July 2024; WHO 'Gender and Health: Q&A' (24 May 2021) www.who.int/news-room/questions-and-answers/item/gender-and-health accessed 24 July 2024.

15 WHO, 'Gender and Health: Q&A' (n 7).

16 Human Rights Campaign, 'Transgender and Non-Binary People FAQ' www.hrc.org/resources/transgender-and-non-binary-faq accessed 24 July 2024; BMA, 'Inclusive Care of Trans and Non-Binary Patients' (28 June 2024) www.bma.org.uk/advice-and-support/equality-and-diversity-guidance/lgbtplus-equality-in-medicine/inclusive-care-of-trans-and-non-binary-patients accessed 24 July 2024.

17 Statistics Canada, 'Sex at Birth of Person' (1 October 2021) www23.statcan.gc.ca/imdb/p3Var.pl?Function=DEC&Id=24101 accessed 2 August 2024; NHS Digital, 'Sex, Gender and Sexuality' (NHS Digital service manual) <https://service-manual.nhs.uk/content/inclusive-content/sex-gender-and-sexuality> accessed 2 August 2024.

18 UN OHCHR, 'Born Free and Equal: Sexual Orientation, Gender Identity and Sex Characteristics in International Human Rights Law' (2019) www.ohchr.org/sites/default/files/Documents/Publications/Born_Free_and_Equal_WEB.pdf.

19 BMA, 'Inclusive Care' (n 16); Human Rights Campaign, 'Sexual Orientation and Gender Identity' (n 14); TransActual, 'Glossary' <https://transactual.org.uk/glossary> accessed 24 July 2024.

How to read this paper

...if you are a policymaker or regulator concerned with data-driven health systems:

The first part of this paper summarises the infrastructure of data-driven systems in the NHS and the operation of clinical information systems used in primary care to manage patient health records. This section also lays out the binary gender framework embedded in these systems that prevents GPs and other healthcare professionals from providing good care to all patients.

In the second part of the paper, we highlight the findings drawn from conversations with various stakeholders, including a small sample of transgender and non-binary people. Our insights in this section are aimed at supporting policymakers to understand the impact that incomplete or unrepresentative data can have on people, and the dangers of using this data as the foundation for more complex technologies such as AI.

...if you are a developer or designer building data-driven systems or clinical information systems:

Read the 'Findings' and 'Overall implications' chapters to understand how the design of health systems can make access to and provision of care extremely challenging for certain groups of people, particularly transgender and non-binary people.

We hope that this paper will spark more conversation on the need to include patients, especially from marginalised groups, in the design and development process from the very start.

...if you are a researcher, civil society organisation or member of the public interested in technology and society:

The 'Findings' chapter indicates that research in this field is missing a crucial component of understanding and documenting the lived experience of those who will be most impacted by the deployment of data-driven systems.

The second part of this paper offers crucial insights from interviews on the parallel experiences of navigating data-driven health systems of healthcare professionals trying to best serve all patients, and of patients seeking care regardless of gender identity. We hope this paper will add to existing literature and ongoing research on the various barriers to healthcare that transgender and non-binary people face.

Introduction

Good data is foundational to the effective application of AI and data-driven systems, especially in healthcare. The NHS relies on data to improve population health and address unequal health outcomes²⁰ by targeting resources towards the people who need them most.²¹

Collecting, processing and interpreting data about millions of people, as a population, can be used to improve healthcare in significant ways. Recent developments in research suggest that AI-assisted tools could help diagnose COVID-19,²² assist in guiding antibiotic treatment²³ or analyse images to detect skin cancer.²⁴ NHS England also notes that algorithms have been used for many years in general practice, in calculating risk scores or switching prescriptions.²⁵

According to the NHS, information contained about us in health and care records 'can be put together to create a set of data that is unmatched anywhere else in the world'.²⁶ NHS guidance on AI also notes the capacity of machine learning to use 'objective data' held by general practice (GP) or primary care networks, and to help to 'segment and risk stratify all patients'.²⁷ This assumption about objectivity underpins much of the design and development process for data-driven systems in healthcare.

However, data has its limitations, particularly if it is incomplete or omits certain groups of people.

20 DHSC, 'Data Saves Lives: Reshaping Health and Social Care with Data' (GOV.UK, 15 June 2022) www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data accessed 25 July 2024.

21 NHS England, 'How Data Is Used to Improve Health and Care' (15 June 2021) <https://digital.nhs.uk/your-data/how-health-and-care-data-is-used> accessed 25 July 2024.

22 D Cushnan, 'Using Chest Imaging AI to Support COVID-19 Research and Development' (NHS England, 18 January 2021) <https://transform.england.nhs.uk/blogs/using-chest-imaging-ai-support-covid-19-research-and-development> accessed 25 July 2024.

23 UCL Institute of Health Informatics, 'Stewardship of Antimicrobials using Real-Time Artificial Intelligence (Samurai)' www.ucl.ac.uk/health-informatics/stewardship-antimicrobials-using-real-time-artificial-intelligence-samurai accessed 25 July 2024.

24 H Marsden and others, 'Effectiveness of an Image Analyzing AI-Based Digital Health Technology to Identify Non-Melanoma Skin Cancer and Other Skin Lesions: Results of the DERM-003 Study' (2023) 10, 1288521 *Frontiers in Medicine*.

25 NHS England 'Artificial Intelligence (AI) and Machine Learning' (Version 1.1, 14 June 2023) www.england.nhs.uk/long-read/artificial-intelligence-ai-and-machine-learning accessed 25 July 2024.

26 NHS England, 'How Data Is Used' (n 21).

27 NHS England, 'Artificial intelligence (AI) and Machine Learning' (n 25).

Unrepresentative health datasets risk replicating existing societal inequalities in data-driven systems

Primary care, specifically general practice, is the first point of health-related data collection for most people. GP surgeries use clinical information systems – systems that help to manage patient data/electronic health records – to collect and store large quantities of patient data, including demographic information, administrative notes, and medical details such as test results, diagnoses and medications.

The way data is coded and the people who are represented (or not represented) in datasets affect the functioning of other systems – such as those which make use of complex algorithms to aid in clinical decision making.

If datasets are not representative, this risks replicating existing inequalities in society in data-driven systems. This can lead to poorer outcomes for people and society, especially for marginalised groups of people.

When complex algorithms or AI tools are developed using datasets wrongly assumed to contain 'objective data', this can lead to poor health outcomes for some groups of people.

Inequalities present in the UK healthcare system – based on factors such as social exclusion, age, socioeconomic position, disability, gender and ethnicity – can affect both a person's health status and the quality of care they receive.²⁸

The *2023 Equity in Medical Devices: Independent Review* noted how perceptions of race can influence the treatment that people receive.²⁹ Similarly, a study found that facial recognition algorithms have higher error rates when classifying darker-skinned men and women due to the datasets being overwhelmingly composed of lighter-skinned people.³⁰

28 E Williams and others, 'What Are Health Inequalities?' (The King's Fund, 17 June 2022) www.kingsfund.org.uk/publications/what-are-health-inequalities accessed 25 July 2024.

29 'Equity in Medical Devices: Independent Review' (11 March 2024) <https://assets.publishing.service.gov.uk/media/65e89e9e62ff48001a87b2d8/equity-in-medical-devices-independent-review-report-web-accessible.pdf>.

30 J Buolamwini and T Gebru, 'Gender Shades: Intersectional Accuracy Disparities in Commercial Gender Classification' (2018) 1 Foundations of Machine Learning Research.

The way data is collected in the NHS invisibilises gender-diverse identities and experiences

Gender is another key factor that impacts health outcomes. Currently, however, clinical information systems used by GPs make it extremely challenging for people to receive care that is respectful and compassionate, due to stereotypes about gender and outdated notions of sex and gender identity that are reflected in and reinforced by these systems.

Such underlying assumptions about sex, gender identity and bodies have been extremely detrimental to the provision of inclusive healthcare. The healthcare system has typically set a male (often white and able-bodied) standard as the default against which to measure all others. In addition, the construction of 'womanhood' has historically taken place through a specific racialised and gendered lens. Research has shown, for example, that Black women may be 'perceived and constructed as non-prototypical' for their gender: when presented with images of Black and white men and women, respondents often miscategorised Black women as men.³¹ Treating 'women' as a uniform category therefore makes for bad analysis.

People's health outcomes should not depend on how closely they align with gender norms,³² as this approach affects ethnic minority women as well as transgender and non-binary people.

The expectation that a person's gender identity must align with the sex they were assigned at birth, or that gender identity must map neatly onto specific anatomical or bodily configurations, is flawed.

Transgender and non-binary people encounter significant challenges of bias or discrimination due to stereotypes about gender. Additionally, transgender and non-binary people's access to and experiences of healthcare are poorly documented because the way data is currently being collected invisibilises gender-diverse identities and experiences.

The NHS exists to improve everyone's health and wellbeing, and is guided by certain principles laid out in the NHS Constitution. First among these is that the NHS is 'available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and

31 NOA Kwate and S Threadcraft, 'Perceiving the Black Female Body: Race and Gender in Police Constructions of Body Weight' (2015) 7(3), 123 *Race and Social Problems* <https://doi.org/10.1007%2Fs12552-015-9152-7>.

32 E Cleghorn, 'Medical Myths about Gender Roles Go Back to Ancient Greece: Women Are Still Paying the Price Today' *Time* (17 June 2021) <https://time.com/6074224/gender-medicine-history> accessed 16 August 2024.

It is challenging for GPs to accurately record information about and their transgender and non-binary patients in clinical information systems

maternity or marital or civil partnership status' and that it has a duty to serve every individual and respect their human rights.³³

A key finding from the literature is that one barrier to healthcare service delivery is how challenging NHS clinical information systems currently make it for GPs to accurately record information about and effectively serve their transgender and non-binary patients.³⁴

These systems operate based on outdated notions of gender identity and sex. They are able to record legal gender only as a binary male/female category and do not allow for a range of different options, such as 'sex assigned at birth', 'physiological sex characteristics' and 'gender identity', which, for some people, do not align. The current conflation of this terminology causes confusion.

While GPs need to record information about a person's physiological sex characteristics in order to make accurate decisions regarding care (such as preventative screenings, testing and treatment), it is also vital for them to know and record information about a person's gender identity and how they wish to be addressed. Patients can request that the gender recorded in NHS systems be changed to reflect their identity: the NHS recognises this and enables a process to do so. The NHS also acknowledges that data on how a person defines their gender is important for providing personalised care and, significantly, that 'how patients tell providers they would like their gender to be recorded and referred to' is important for their mental health.³⁵

Currently, people's recorded gender identity is strictly tied to expected norms for pronouns and titles – so a person registered as female is not able to have the system address them as 'Mr'. Requesting a change to gender in the health record triggers a process that involves getting a new NHS number and a new record without a link to the old one. In practice, this is complicated and often leads to loss of medical history. In turn, this results in people having to choose between keeping their data and receiving care that is affirming of their gender identity.

33 DHSC, 'The NHS Constitution for England' (GOV.UK, 17 August 2023) www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england accessed 16 August 2024.

34 London Assembly Health Committee, 'Trans Health Matters: Improving Access to Healthcare for Trans and Gender-Diverse Londoners' (2022) www.london.gov.uk/sites/default/files/health_committee_-_report_-_trans_health_matters.pdf.

35 NHS England, 'Guidance on Collecting and Submitting Data for the Data Items on Gender within the Mental Health Services Data Set (MHSDS) v5.0' <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/guidance-on-collecting-and-submitting-data-for-data-items-on-gender> accessed 16 August 2024.

Furthermore, our analysis shows that when GPs record a person's 'gender' in their electronic health record, it is treated for medical purposes by the system as equivalent to their sex assigned at birth. The risk of harm here is great: screening invitations (such as those for cervical cancer) may be sent out based on the person's gender identity rather than their sex characteristics. This can also result in inaccurate test results or diagnoses, when labs and GPs do not have all the relevant information about a person.

The main concern with changing a person's NHS number and record is the disruption to their continuity of care.

This is a challenge not only for people who want to change the gender in their health record but also for adopted children, who are assigned a new NHS number and record upon their legal adoption, and for their adoptive parents.³⁶ The GP who registers the child as a patient is meant to transfer information from the previous record, but, as we heard from interviewees, in practice this is a complicated process that may result in loss of data.

Anecdotally, adoptive parents are aware of this and talk about it on blog and advice sites. CoramBAAF – a membership organisation for professionals working across adoption, fostering and kinship care – is campaigning to end the practice of changing the NHS number when a child is adopted.³⁷

It is necessary to look at how different aspects of a person's identity may overlap and affect health outcomes. Given the rising numbers of people with complex health and care needs, and the NHS vision of digital transformation, it is crucial that we take the time now to fundamentally rethink and redesign clinical information systems used across primary care – to make them better work for people and society.

36 PCSE, 'Adoption and Gender Reassignment Processes' <https://pcse.england.nhs.uk/help/patient-registrations/adoption-and-gender-reassignment-processes#:~:text=Adoption%20process&text=When%20a%20patient%20is%20adopted%2C%20they%20are%20given%20a%20new,a%20newly%20created%20medical%20record> accessed 16 August 2024.

37 CoramBAAF Adoption & Fostering Academy, 'Review of 2020' (2021) <https://corambaaf.org.uk/sites/default/files/Review%20of%202020.pdf>.

Project aims and methodology

This was an exploratory project which aimed to:

- map the landscape of clinical information systems used in general practice, and to understand what data is collected about patients and why
- expand the evidence base around transgender and non-binary adults' lived experiences of accessing primary care services in the UK, in the context of systems that operate within a binary framework
- better understand the experiences of clinicians and other NHS staff navigating clinical information systems
- analyse how these systems encode gender and whether this makes it challenging to record information about those outside of what the system understands as 'typical'.

The scope of this project focused on how GPs use the clinical information systems EMIS and SystmOne, what data they collect from patients and why, and an examination of the gender norms and biases embedded in the operation of these systems.

This project comprised both desk research and primary qualitative research with a range of experts, key stakeholders and those with lived experience of being represented inadequately in datasets and clinical information systems.

The desk research included information about health systems and wider literature from relevant disciplines, as well as scholars exploring the intersections of technology, gender, society and health, including the feminist science and technology studies (STS) field.

We held an expert roundtable comprised of academics, policymakers and transgender and non-binary researchers. Participants discussed gaps in existing research, the impact that various data-driven systems and AI tools might have on transgender and non-binary people, and what a gender-inclusive approach to developing technology might look like.

Expertise can come from people's personal knowledge of and interactions with a system of service

This was supplemented with in-depth interviews with experts and practitioners across the healthcare system, including:

- GPs from various NHS Trusts across England
- representatives from healthtech platforms and NHS clinical information systems
- NHS staff including informatics professionals
- policy experts
- academics.

We also conducted workshops and interviews with six transgender and non-binary adults to build evidence from those with lived experience of this issue and to ensure the research was shaped by affected individuals. This included a review of terminology and findings.

Participants were recruited through social media and calls for participation were distributed through our networks (including emails and newsletters). Their participation allowed us to gain insights into the various experiences of designing, navigating and interacting with data-driven health systems. We spoke in depth with transgender and non-binary people as a means of documenting experiences that have not previously been reflected in academic or other research, and as evidence of the disproportionate impacts of gendered data-driven systems.

The argument for considering lived experience is that expertise comes not only from years of training or academic study: it can also come from people's personal knowledge of and regular interactions with a particular system or service. Lived-experience research values these interactions and the meanings people that derive from them as highly as any other form of evidence.³⁸

This is an exploratory piece of research and as such has limitations, in particular from recruiting a small sample of those with lived experience through informal networks and snowball sampling. The research originally

³⁸ L Chikwira, 'Back to Basics: Understanding Lived Experience and Intersectionality in Health and Care' (The King's Fund, 8 August 2023) www.kingsfund.org.uk/blog/2023/08/back-to-basics%E2%80%93understanding-lived-experience-and-intersectionality-health-and-care accessed 25 July 2024.

intended to include a larger sample, but this was not possible within the timeframe. We were therefore not able to represent many intersecting experiences of inequalities or a spectrum of views across wider geographies and demographics. As such, the findings should be treated as indicative and illustrative rather than representative.

These initial findings reinforce the importance of the topic and the need for more research on this subject, particularly in documenting the experiences of a larger and more representative sample of transgender and non-binary people.

Direct quotes have been used where possible and relevant, but without identifiable attribution to protect individual contributors.

Context: Intersections of data and gender

Data-driven systems are not value-neutral: they are designed, built and deployed by people who carry cultural interpretations into the work they do.³⁹ These cultural and social values are inscribed in technologies, and they also shape discourses that portray these technologies as neutral or inevitable. The bias encoded into technology reproduces existing social hierarchies and, consequently, inequalities – including gendered ones.

Gender, healthcare and data

As a lens of analysis, gender is one of the ways we can understand the structuring of society and social relations. Various academic disciplines have defined gender as a social construct that is open to change and contestation, and not a stable category.⁴⁰ The World Health Organization also takes this view, stating that: 'Gender varies from society to society.'⁴¹

The structural understanding of gender is related to but different from that of 'gender identity', which refers to a person's internal and individual experience of gender. This means that although people may exercise agency in determining their gender identity, they are still subject to the gender-based norms and values within which our society is ordered. Understanding gender bias in the context of power relations, as a systemic issue, allows us to think beyond binary identities and focus on the experiences of all gendered groups of people.

Gender stereotypes influence our analyses and interpretations; these stereotypes are constructed as facts and deeply embedded in our institutions.

39 E Simpson and others, 'For You, or For "You"?: Everyday LGBTQ+ Encounters with TikTok' (2021) 4(CSW3), 252 Proceedings of the ACM on Human-Computer Interaction.

40 Many feminist and queer theorists, including Judith Butler, Patricia Hill Collins, Os Keyes and Surya Monro, have discussed the social construction of gender and challenged the idea of 'gender' or 'woman' as stable and universal categories.

41 WHO, 'Gender and health' (n 7).

Historically, women could be registered as medical professionals from 1876, but until well into the twentieth century, the profession was still dominated by men.⁴² In the *Women's Health Strategy for England*, the Department for Health and Social Care (DHSC) acknowledges that 'the health and care system has been designed by men for men' and that gaps in the data and evidence mean that women are being failed by the system.⁴³

Women have often been excluded from clinical trials or been subject to treatment tested to the male standard – with even popular television programmes like *Grey's Anatomy* addressing the issue of doctors not taking women seriously when they face medical issues.⁴⁴ For example, datasets used to predict cardiovascular risk have had a history of being trained primarily on male patient data, which can lead to inaccurate risk assessment for female patients who may present with different symptoms.⁴⁵

In the 1960s and 1970s, activists began to fight against gender and racial bias in clinical research. The British Women's Health Movement campaigned for, among other things, the expansion of Well Woman Clinics.⁴⁶ The Movement was also concerned with challenging the 'objective' clinical knowledge that underpinned much of healthcare, and it pushed for consideration of women's subjective knowledge of their own bodies.

Slowly the need for greater research on women's health is being recognised, with scholarship highlighting the impact of gender bias in medicine. However, we still have a long way to go before we can fully understand and address the gender disparities in healthcare for groups that face systemic gender-based discrimination. This is reflected in datasets and in the advanced technologies trained on the data; if women's issues are not taken seriously, then women are not accurately represented in the data and in interventions based on the data.

42 Z Strimpel, 'Spare Rib, the British Women's Health Movement and the Empowerment of Misery' (2022) 35(1), 217 <https://doi.org/10.1093/shm/hkab016>.

43 DHSC, 'Women's Health Strategy for England' (GOV.UK, 30 August 2022) www.gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england accessed 25 July 2024.

44 L Denninger, 'What Happened to Miranda Bailey on "Grey's Anatomy" Will Make You So Emotional' (Bustle, 2 February 2018) www.bustle.com/p/what-happened-to-miranda-bailey-on-greys-anatomy-her-heart-attack-highlighted-important-feminist-issue-8097363 accessed 25 July 2024.

45 D Ueda and others, 'Fairness of Artificial Intelligence in Healthcare: Review and Recommendations' (2024) 42(1), 3 Japanese Journal of Radiology. We note here that this disparity in diagnosis is not exclusive to AI systems; research has shown that for cardiovascular disease, 'traditional diagnostic methods are not optimal for women', and that heart attacks in women often go undetected or are misdiagnosed. For more, see: AHEM Maas and YEA Appelman, 'Gender Differences in Coronary Heart Disease' (2010) 18(12), 598 Netherlands Heart Journal.

46 Strimpel, 'Spare Rib' (n 42).

The systemic nature of discrimination based on gender is acute for transgender and non-binary people, for whom data is missing because it is not collected except in specific circumstances. Society largely treats gender as a static concept and this is reflected in legislation and technology infrastructure. The traditional view of gender as 'immutable and physiological' is, as Os Keyes has stated, extremely limited in its ability to capture the 'biological and cultural range of humanity' but has been 'codified into everything nonetheless'⁴⁷ – from our language to the products we buy to the design of various technologies.

UK law does not recognise non-binary genders,⁴⁸ which means that 'male' and 'female' are the only available choices on official documents.

In a narrow sense, 'male' and 'female' capture physiological sex characteristics – although this still excludes intersex people – but do not and cannot capture gender identity. While the Equality Act 2010 includes gender reassignment as a protected characteristic, and the Gender Recognition Act 2004 allows adults to have their affirmed gender legally recognised, fluidity and gender-diverse experiences are not accommodated within the law. Additionally, researchers 'often treat their populations of interest as implicitly cisgender – as opposed to transgender'. This parallels the general treatment of gender in computing research, including feminist computing research, which 'has been largely inattentive to trans issues'.⁴⁹

There is growing evidence that transgender and non-binary people experience significant challenges when accessing healthcare.⁵⁰ NHS England provided written evidence to Parliament's Women and Equalities Committee enquiry in 2015 on transgender equality, stating that: 'Historically, transgender and non-binary people have reported poor experience of engagement, with the group becoming hidden.'⁵¹

47 O Keyes, 'The Misgendering Machines: Trans/HCI Implications of Automatic Gender Recognition' (2018) 2(OSCW), 88 Proceedings of the ACM on Human-Computer Interaction.

48 C Fairbairn, C Barton and D Pyper, 'Non-Binary Gender Recognition: Law and Policy' (House of Commons Library, 31 March 2022) <https://researchbriefings.files.parliament.uk/documents/CBP-9515/CBP-9515.pdf>.

49 C Rincon, O Keyes and C Cath, 'Speaking from Experience: Trans/Non-Binary Requirements for Voice-Activated AI' (2021) 5(OSCW1), 132 Proceedings of the ACM on Human-Computer Interaction.

50 London Assembly Health Committee, 'Trans Health Matters' (n 33); T Wright and others, 'Accessing and Utilising Gender-Affirming Healthcare in England and Wales: Trans and Non-Binary People's Accounts of Navigating Gender Identity Clinics' (2021) 21, 609 BMC Health Services Research.

51 Women and Equalities Committee, 'Transgender Equality: First Report of Session 2015-16' (House of Commons, 8 December 2014) <https://publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf>.

There are many contributing factors to poor health outcomes for transgender and non-binary people, such as long waiting lists and insensitive language used by healthcare professionals.⁵² Dr James Barrett, President of the British Association of Gender Identity Specialists (BAGIS), has stated: 'The casual, sometimes unthinking trans-phobia of primary care, accident and emergency services and inpatient surgical admissions continue[s] to be striking'.⁵³

These issues are exacerbated by the use in general practice of clinical information systems which historically have been set up to operate only within a gender binary framework. Clinical information systems are typically designed with the assumption that all people fit perfectly into one of the two binary sex categories of male or female. This has been set as the standard despite wider scientific and social recognition that people's anatomy, hormones, and other internal or external features do not always conform with their sex assigned at birth. When these systems are not designed to capture all of this information, we risk not being able to provide everyone with good healthcare.

People bring gendered expectations to all things they encounter. Since gender shapes how people relate to each other, how they understand themselves and how they interact with the world, including with technology, it would be impossible to imagine a data-driven system that does not encode *any* gender-based assumptions.

As these systems, including applications of AI, become more integral to the delivery of public services in the UK, it is critical that we explore these concerns in greater detail and with research that centres the affected people.

A digital NHS

The role of digital transformation in the NHS is an important one, particularly in its potential to improve access to healthcare for millions of people. This includes applications of AI systems and complex algorithms that range from improving diagnostics to machine learning techniques, monitoring

⁵² Ibid.

⁵³ Ibid.

patient health by collecting biometric data through apps, and automating administrative tasks.⁵⁴

Healthcare innovations such as diagnostic tools that can spot malignant tumours or predict the progression of a disease are promising applications of AI that everyone should stand to benefit from.⁵⁵ A hope for AI is that it can help to improve both the quality of care and the efficiency of services: using AI to analyse mammograms, for example, may improve early diagnosis and free up time for radiologists to spend with patients.

In its 2023 report *Digital Transformation in the NHS*, the Health and Social Care Committee identified digital transformation as a key priority for the DHSC and the NHS, encompassing both digitising paper-based services and 'greater reliance on more innovative approaches to care that are enabled by advances in technology'.⁵⁶ The Committee acknowledged that a shift to digital would be important for reducing care backlogs, improving access to care, and developing cutting-edge diagnostics and treatments.

However, there are concerns that AI might reinforce societal biases and thus result in harmful effects on people, especially marginalised groups. NHS guidance on AI and machine learning acknowledges that many types of bias can exist, including 'through the prejudices of the people developing the algorithm, or carelessness in the way training data is collected or processed'.⁵⁷

The Health and Social Care Committee also highlighted that past attempts at digital transformation have been frustrated by factors such as 'legacy' IT systems and hardware that are unable to handle the demands of a digital health service.⁵⁸ An overstretched workforce may also consider this kind of change an imposition, especially if a new IT system comes with a steep learning curve or without sufficient engagement with staff to address concerns around its use.

Finally, digital healthcare runs the risk of excluding many groups of people – especially those who may already experience digital or other forms of exclusion from health services. The trend of digital transformation

54 UK Parliament, 'AI and Healthcare' (PostNote 637, December 2020) <https://researchbriefings.files.parliament.uk/documents/POST-PN-0637/POST-PN-0637.pdf>.

55 National Institute for Health and Care Research, 'Artificial Intelligence: 10 Promising Interventions for Healthcare' (28 July 2023) <https://evidence.nihr.ac.uk/collection/artificial-intelligence-10-promising-interventions-for-healthcare> accessed 25 July 2024.

56 Health and Social Care Committee, 'Digital transformation in the NHS: Eight Report of Session 2022–23' (n 4)

57 NHS England, 'Artificial intelligence (AI) and Machine Learning' (n 25).

58 Health and Social Care Committee, 'Digital transformation in the NHS: Eight Report of Session 2022–23' (n 4)

has necessitated a closer look the role that data plays in research and healthcare service delivery, and what the implications might be of unrepresentative or biased data and data-driven systems, especially for marginalised groups such as transgender and non-binary people.

Data and inequalities

According to the DHSC's *Data Saves Lives* strategy paper, the NHS has an 'unparalleled longitudinal health data set' and an exceptional health and care research ecosystem.⁵⁹ The paper states that data helped the NHS to withstand the COVID-19 pandemic and predicts that data will improve population health and care, tackle unequal outcomes and access, enhance productivity and value for money, and support broader social and economic development.⁶⁰

We know from other research in this area, including our previous work on healthcare, that data pipelines are complex and have numerous 'knots', where data does not flow as it was intended to.⁶¹ Our research with the Health Foundation found that high-quality data is crucial to producing meaningful results and preventing unequal health outcomes. Missing or incomplete data – such as the data of migrants who may not regularly visit a GP or of people with mental health issues – is a significant issue.⁶² A Nuffield Trust review of NHS datasets showed that there is poor coverage of ethnicity data in primary care, as well as usage of outdated ethnicity codes and 'systematic differences in coding' between white and minority ethnic groups.⁶³

Inequalities are reflected in how data is collected, stored and processed in the various data-driven systems used across the NHS.

59 M Tang and L Greenrod, 'Data Saves Lives' (n 1).

60 Ibid.

61 M Machiori, *A Knotted Pipeline* (Ada Lovelace Institute 2023) www.adalovelaceinstitute.org/report/knotted-pipeline-health-data-inequalities.

62 Ibid.

63 S Scobie, J Spencer and V Raleigh, 'Ethnicity Coding in English Health Service Datasets' (Nuffield Trust, NHS Race and Health Observatory 2021) www.nuffieldtrust.org.uk/research/ethnicity-coding-in-english-health-service-datasets accessed 25 July 2024.

Interventions based on poor-quality data may disproportionately harm (or fail to equally benefit) people who are not represented

As our report *A Knotted Pipeline* notes, data gaps can 'create systems that do not comprehensively respond to inequalities on the ground'.⁶⁴ Significantly, interventions based on poor-quality data may disproportionately harm (or fail to equally benefit) people who are not represented.

Better data on specific inequalities should also help us to understand and design services around intersectional inequalities, building on the knowledge that inequalities intersect and compound each other. Thus, a person living with multiple disabilities who also wants to change their gender in their record will face a more difficult process than someone who is able-bodied; at the same time, the considerations of clinicians about the care they need to provide will also differ.

(Un)representative data

The collection and use of representative data is vital to reducing bias within the algorithmic and automated decision-making systems that are becoming more prevalent across the NHS.

There are growing concerns that 'non-diverse and non-representative data contribute to the creation of biased algorithms',⁶⁵ resulting in some groups of people not benefiting from healthcare innovations or potentially experiencing worse outcomes. This can lead to health data poverty – 'the inability for individuals, groups, or populations to benefit from a discovery or innovation due to the scarcity of representative data'.⁶⁶

Unrepresentative data can cause real-life harms, as evidenced by an analysis of racial bias in a healthcare algorithm applied to roughly 200 million people in the US that reduced, by more than half, the number of Black patients identified for extra care.⁶⁷ The algorithm used healthcare costs as a proxy for health needs: less money spent on Black patients meant that they were identified as being at lower levels of risk, despite being equally as sick as white patients or more so. This is a problem both

⁶⁴ Machirori, *A Knotted Pipeline* (n 61).

⁶⁵ A Arora and others, 'The Value of Standards for Health Datasets in Artificial Intelligence-Based Applications' (2023) 29(11), 2929 *Nature Medicine*.

⁶⁶ H Ibrahim and others, 'Health Data Poverty: An Assailable Barrier to Equitable Digital Health Care' (2021) 3(4), E260 *The Lancet Digital Health*; A Smith, 'Health Data Poverty in the Digital Era' (Health Data Research UK, 8 March 2021) www.hdruk.ac.uk/news/health-data-poverty-in-the-digital-era accessed 25 July 2024.

⁶⁷ Z Obermeyer and others, 'Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations' (2019) 366(6464), 447 *Science*.

of missing or inaccurately interpreted data (Black patients may generate lower medical expenses due to disparities such as poor access to care, experiences of direct discrimination or mistrust of the system) and of poor labelling choice (using costs instead of a different metric).

Another study in the USA found that an algorithm used by healthcare providers to predict the likelihood of a successful vaginal birth after caesarean delivery (VBAC) used race as the sole correction factor – despite race having no clear biological connection to the mechanisms of childbirth. This approach led to the algorithm predicting that Black and Latino women were less likely to have a successful VBAC than white women, causing doctors to perform more C-sections on them.⁶⁸

Data collection often begins at the primary care stages in the UK, when patients register with their local GP surgery. NHS England notes that: 'High-quality patient records are the foundation of good clinical care delivery.'⁶⁹ Patient records contain important information that is needed to provide good care. They are also important for research into and assessment of public health outcomes.⁷⁰ It therefore matters what basic information about a patient is included in these records and whether it fully captures aspects of their lived experience that might be risk factors for certain medical conditions.

As noted previously, the lack of data on transgender and non-binary people's access to health services means that many transgender and non-binary people are unlikely to be accurately represented in datasets. In 2021, the Census for England and Wales asked questions about gender identity for the first time. These 'official statistics in development' revealed that around 0.5% of people stated that they are transgender,⁷¹ which has been argued as showing that more people are transgender than had previously been estimated.⁷² The Office for National Statistics has stated that its national estimates were broadly consistent with the GP patient survey.⁷³

68 D Vyas and others, 'Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator' (2019) 29(3), 201 Women's Health Issues.

69 NHS England, 'High Quality Patient Records' (17 November 2022) www.england.nhs.uk/long-read/high-quality-patient-records accessed 25 July 2024.

70 Ibid.

71 Used as an umbrella term in the Census.

72 Mermaids, 'Census 2021: What Does It Mean for Young People?' (26 January 2023) <https://mermaidsuk.org.uk/news/census-2021-what-does-it-mean-for-young-people> accessed 25 July 2024.

73 Office for National Statistics, 'Quality of Census 2021 Gender Identity Data' (8 November 2023) <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/genderidentity/articles/qualityofcensus2021genderidentitydata/2023-11-13/> accessed 21 August 2024

Previous Ada research has found the need for better engagement with patients in the design and use of digital healthcare systems

The collection of this data in the Census for the first time indicates 'a shift away from the assumption that everyone is cisgender and straight'.⁷⁴ With the move to an increasingly digital and data-driven NHS, it is crucial that datasets contain complete and accurate information about all people.

When the lived reality of patients is not appropriately represented in datasets and data-driven systems, there is a risk of not telling the full story.

This can lead to misdiagnosis of health conditions or a denial of treatment.

The interaction between these systems and gender-diverse experiences is under-researched and, crucially, missing the lived-experience insights of those most impacted.

The NHS has recognised that understanding people's lived experience is important to improve healthcare services.⁷⁵ In a case study of the North East and North Cumbria Integrated Care System, a patient engagement strategy centring lived experience resulted in clinicians getting valuable and honest feedback on people's experiences of living with multiple health conditions. As noted by a GP partner: 'Because of the valuable insights of the group, we were able to create a service which is highly valued by patients and clinicians alike. This is a great example of how genuine patient engagement can deliver excellent results for everyone involved.'⁷⁶

Similarly, a significant finding from our report *A Knotted Pipeline*, which outlined our research on the complex interplay between data and health and social inequalities, was the need for better engagement with patients in the process of designing and deploying digital healthcare systems.⁷⁷ Our research also highlighted the importance of considering lived experience in the design of digital health services, especially for those already facing barriers to accessing healthcare services.

⁷⁴ Mermaids, 'Census 2021' (n72).

⁷⁵ NHS England, 'Case Study: How People's Lived Experience Is Improving Health and Care Services in the North East and North Cumbria' (6 April 2023) [www.england.nhs.uk/long-read/case-study-how-peoples-lived-experience-is-improving-health-and-care-services-in-the-north-east-and-north-cumbria/#:~:text='Lived%20experience"%20recognises%20the%20personal,health%20service%20such%20as%20maternity](https://www.england.nhs.uk/long-read/case-study-how-peoples-lived-experience-is-improving-health-and-care-services-in-the-north-east-and-north-cumbria/#:~:text='Lived%20experience) accessed 25 July 2024.

⁷⁶ Ibid.

⁷⁷ Machiori, *A Knotted Pipeline* (n 61).

This gap in the research, on transgender and non-binary people's experiences, warrants urgent attention; we have already seen how using unrepresentative data to train AI systems or build complex algorithms can negatively affect health outcomes for marginalised people.

As our health service builds in greater use of AI, it is critical that these systems work for all subgroups of the population.

Findings

As highlighted earlier, we found three key issues regarding data collection for transgender or non-binary people.

1. Clinical information systems do not consistently allow for a range of options when recording gender identity and sex.
2. The NHS number change process disrupts people's continuity of care.
3. Legacy systems in the NHS are difficult to navigate and change.

The failure to ensure that data systems reflect the lived experience of marginalised groups has profound impacts on their experience of care.

Clinical information systems do not allow for a range of options when recording gender and sex

When a person accesses NHS care⁷⁸ in England, Wales or the Isle of Man for the first time – at birth⁷⁹ or through later registration with a GP – a unique NHS number is assigned and a GP record is created for them. The unique 10-digit number links up various records between providers across NHS services and is meant to be valid for life, except in the case of adoption or gender reassignment or to protect an individual's identity.⁸⁰ This NHS number is also present in the Summary Care Record (SCR) and the Personal Demographics Service (PDS), which contain relevant clinical information as well as basic details about each person.

As mentioned previously, two clinical information systems that provide management for electronic patient records effectively hold a duopoly in primary care: EMIS and SystmOne. A representative of EMIS who spoke to us stated that at the time of our research, EMIS was used by 60% of GPs.

78 NHS England, 'The NHS Number' (27 June 2024) www.england.nhs.uk/long-read/the-nhs-number accessed 25 July 2024. Scotland NHS uses a 'CHI number' – a 10-digit number where the 9th digit identifies a person as male or female.

79 Even if a person is born in a non-NHS hospital, a statutory notification of birth is required which prompts the assignment of an NHS number.

80 NHS England, 'The NHS Number' (n 78).

Recording someone's gender identity but treating it as their sex means that important medical decisions may be made using incomplete information

All GPs interviewed for this report had experience of using one of these two systems.

A notable finding in surveys conducted by trans-focused organisations is that the systems used by GPs to manage patient records are often unable to accommodate gender-diverse identities.⁸¹ This finding was also highlighted in a report published by the London Assembly Health Committee in 2022, which noted that NHS IT systems 'do not enable TGD [trans and gender-diverse] status to be recorded in a consistent and inclusive way'.⁸²

Another report, by the TRANSForming Futures partnership, a group of organisations focused on trans equality, highlights the difficulties of navigating NHS patient records, especially when changing gender markers.⁸³ Through community engagement workshops, TRANSForming Futures spoke to participants who stated that IT systems used by the NHS did not contain any option to record non-binary gender identity, and that updating or changing gender information in the systems was a confusing process.

Some GPs we interviewed referred to the health record as the 'Spine record'. The Spine allows information to be shared across various health services: it is essentially a copy of key information held in the GP record and enables other staff involved in a person's care, such as at A&E, to make safe and accurate decisions. However, this is categorised in a binary format. One GP interviewee explained that the EMIS system 'has a blue bar on top and a male/female option for sex. There is no non-binary option'.

The use of 'gender' and 'sex' as interchangeable categories within these systems, and largely within other NHS clinical systems, leads to many challenges. 'Non-binary' as a gender identity category may not be the correct medical term when referring to a person's physiological sex characteristics, but it is an important part of their identity that needs to be captured so that they can receive respectful and inclusive care. Noting sex characteristics is often medically necessary, but this provides a clinician with no information about the person's gender identity, title, pronouns, etc. Conversely, recording someone's gender identity but always treating it as

81 LGBT Foundation, 'LGBTQ+ Patient Experiences in Primary Care' (2023) <https://lgbt.foundation/wp-content/uploads/2023/10/LGBTQ-Patient-Experiences-in-Primary-Care.pdf>.

82 'TGD' is the term used in the report to refer to transgender and gender-diverse people (see Glossary).

83 L Hord and K Medcalf, 'Trans People's Experience of Healthcare in England' (TRANSForming Futures Partnership) www.transformingfuturespartnership.co.uk/healthcare.

denoting their sex means that important medical decisions may be made based on incomplete information.

It is worth noting that, at least within mental health care, the NHS has acknowledged its public sector duty to ensure equality for all patients, including transgender and non-binary patients. The NHS Data Dictionary contains guidance on collecting data about gender identity, to better understand transgender and non-binary people's experiences and provide more personalised care. The Data Dictionary includes codes such as 'gender identity code' and 'gender identity same as birth indicator'.⁸⁴ However, the guidance notes that this data item 'should not be completed by linkage to the NHS Spine' and may not match the gender recorded by other NHS systems. Additionally, the patient's medical record will retain the male/female code, which cannot be overridden.⁸⁵

The NHS page on this links to a resource developed by the LGBT Foundation on 'Monitoring Sexual Orientation and Trans Status', and explains that the purpose is to collect data that the NHS does not currently have on transgender and non-binary people as well as to provide inclusive care. However, these new codes are for use within the Mental Health Services Data Set (MHSDS) and the Improving Access to Psychological Therapies (IAPT) Data Set.⁸⁶ They are not used in general practice, and the NHS Spine record retains binary male/female categories.

Having information recorded accurately is necessary not only for providing good care to patients and making diagnoses but also to avoid system errors that come up when there is a perceived mismatch between a person's stated pronouns and the clinical tests or preventative health screenings that they are eligible for, such as cervical or prostate cancer. For example, an interviewee working at an NHS clinic catering to transgender and non-binary people told us:

'We add "precaution flags" on people's records and manually write in pronouns but still get many errors from the system, such as when prescribing contraception.'

84 NHS England, 'Guidance on Collecting and Submitting Data' (n 35).

85 Ibid.

86 NHS England, 'Gender identity' <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/submit-data/data-quality-of-protected-characteristics-and-other-vulnerable-groups/gender-identity> accessed 25 July 2024.

While providing testimony to the London Assembly Health Committee, Kamilla Kamaruddin noted the issues with some of the old IT systems: 'We use read codes to identify patients who are diabetic, for example, and so we use "diabetes mellitus" as a proper title so that we can identify the people who have diabetes. For trans people there is no read code. There are no read codes to say that you are a trans man, trans woman, trans feminine or trans masculine.'⁸⁷

The use of pejorative language in reference to transgender people was also common, as many IT systems had not been updated in years. This, coupled with exclusively binary language and frameworks, has meant that GPs are unable to rely on appropriate codes for their transgender and non-binary patients.

As one of the GP interviewees stated:

'In the NHS, [the] IT system is very binary. How we talk, how we document something, is by using read codes. Then we can do a survey of the data, but there's not enough read codes for trans people; for example, there's no read code to say sex is female assigned at birth or male assigned at birth.

'I think a few years ago, I mean I'm talking about five to six years ago, there were still some very horrible read codes like "Sexual encounter with a transsexual". But it's all gone now, you know. Thank God for that. Was quite upset when I saw those read codes.'

As understood from interviews and the literature review, the Spine record contains no provision to record information about both physiological sex characteristics and gender. When a person's gender is changed in their electronic record, the system effectively treats it as a change in their sex and, for diagnostic and screening purposes, assumes that their sex characteristics must align.

Some GP surgeries offer patients the option to record their gender as 'unspecified' or 'indeterminate'. However, this does not link back to the Spine record, which, as set out above, has only the binary option of male or female.

87 London Assembly Health Committee, 'Trans Health Matters' (n 33).

Another GP interviewee explained:

'The Spine uses gender. It doesn't use sex, and that has caused apparently lots and lots of problems because gender currently is tended to be used for what you identify as not as your biological sex. You can no longer define a biological sex *and* an identified gender.'

This causes problems for people whose recorded gender does not correspond in the expected manner with their physiological sex characteristics, and consequently they become ineligible for certain cancer screening reminders and other 'flags' that GP systems show for diagnostic decision making.

As another interviewee working on developing more inclusive health tech platforms pointed out, labs use binary coding to calculate the kidney function of patients. Their calculations include 'sex assigned at birth': a binary categorisation of male or female. The interviewee stated that collecting gender identity data as well as sex at birth has allowed them to provide gender-affirmative care while still enabling accurate diagnoses:

'If a patient has maybe been receiving gender affirming hormone therapy for somewhere between 6 to 12 months ... their affirmed gender is probably going to be more appropriate choice for that kidney calculation than their sex assigned at birth. Now, the lab doesn't necessarily have the capacity to do that, and so we almost take that data back and take on that clinical responsibility – when we translate that back out of the system to partners.'

However, GPs are often forced to contend with IT systems that do not contain the necessary system features to record all relevant data about a patient, and so they struggle to provide the quality care that all patients deserve.

The NHS number change process disrupts people's continuity of care

One of the most important findings in this research is around the process of changing gender markers in the electronic health record and getting a new NHS number as a result. According to NHS England,⁸⁸ a patient may be assigned a new NHS number following adoption or gender reassignment or to protect their identity. This newly allocated NHS number is not linked to the patient's previous NHS number.

The NHSX Records Management Code of Practice⁸⁹ states that any patient or service user can request that their gender be changed in a record. The formal legal process (as defined in the Gender Recognition Act 2004) is that a Gender Reassignment Panel issues a Gender Reassignment Certificate (GRC). At this time a new NHS number is issued, and a new record can be created, if this is the wish of the patient or service user. However, it is unclear why the Code of Practice still mandates a GRC; the Equality Act 2010 makes it clear that a GRC is not required for a person to be legally recognised as their gender, and NHS guidance also states this. GP interviewees confirmed that rather than having the existing NHS number and record reflect a change of gender, new NHS numbers are always assigned, although the process may take a long time.

The Primary Care Support England (PCSE) website states that: 'Patients may request to change gender on their patient record at any time and do not need to have undergone any form of gender reassignment treatment in order to do so.'⁹⁰

88 NHS England, 'The NHS number' (n 78).

89 NHS England, 'Records Management Code of Practice' (7 August 2023) <https://transform.england.nhs.uk/information-governance/guidance/records-management-code/records-management-code-of-practice> accessed 25 July 2024.

90 PSCE, 'Adoption and Gender Reassignment Processes' (n 36).

Guidance produced by PCSE lays out the following process for a change in NHS number:

- The National Back Office sends the patient's new NHS number and any other amended details (e.g., name, address) to PCSE.
- PCSE sends the GP practice a deduction notification for the patient and emails the main contact it holds for the practice (if available) the new details for the patient.
- The practice accepts the deduction and registers the patient using the new details provided by PCSE. The practice must not update the patient's original record with their new NHS number. If this happened, they would not be registered and would miss out on continuity of care.
- PCSE sends a new patient medical record envelope with the patient's updated details to the GP practice.
- The GP practice creates a new patient record using the new details and transfers all previous medical information from the original medical record.

The GPs and transgender and non-binary people we spoke to all identified this as a messy and difficult situation to navigate, especially for those with complex medical needs. The EMIS representative confirmed that once test results and other documents are uploaded into a medical record, they cannot be edited by the GP. The only way to edit would be to print them and manually make edits which would then need to be scanned and re-uploaded into the system. The lack of clarity in the guidance is also evident in the fact that different NHS Trusts provide conflicting information on care for transgender and non-binary people. Some are restrictive and require 'proof' of trans status, while others do not.

For example, guidance from the Solent Trust – an NHS Trust that offers primary care and mental health services to Southampton, Portsmouth and other parts of Hampshire – refers to the Equality Act and notes: 'Names and titles on medical records can be changed at the point that the individual changes their gender role permanently (or sooner if this is requested and there is some evidence of the intended permanency) such that the

individual has a protected characteristic of gender reassignment in line with the Equality Act.'

Leicestershire Partnership NHS Trust, however, simply states 'The new record may or may not make reference to the patient's trans status: this is the patient's decision. Where it is clinically relevant for a clinician to know if a patient is Transgender or not, this information should be sought through sensitive discussion with the patient.'

This process is made more complicated by how much of the responsibility for deleting old records and maintaining new ones is placed on GPs, and how time consuming the process can be. Our findings indicate that this process is onerous, and many GPs do not have the capacity or resources to adequately complete it.

As one of our GP interviewees put it:

'Only the GP practice can change the gender because it's part of the NHS Spine. So even the hospitals cannot change the patient's details. All patient details can only be changed by or in general practice. Yes, they give us some guidelines, but the guidelines are just ... copy or scan the documents [into the record linked to the new NHS number] and then you need to redact all the references to previous gender, it's almost impossible to do that.'

The interviewee also noted that this would mean important information, such as lab tests or notes about diabetes and other health conditions, would not be reflected accurately in the new record.

Adopted children face similar challenges when they are assigned a new NHS number and record once they are legally adopted. Another GP interviewee who has worked closely on issues that adopted and looked-after children face spoke about the process from the perspective of safeguards:

'We're actually giving GPs permission from here on in to just copy [from the old record] straight over. The one thing that we are asking for though is that there would have to be a high priority flag on the record to say this is an adoption record and also to say that there is third party information on this record because there will be all the pre-adoption safeguarding information around the birth parents that we don't want to be released by accident.'

'It's a work around and I'm not totally happy that we're having to do a work around because there should be a digital solution out there for this. It should be possible to keep your NHS number.'

The difficult nature of this process cannot be understated. However, as one of the participants in our workshop with transgender and non-binary people noted, this is also a question of prioritisation: which issues the NHS chooses to dedicate resources to and which are ignored.

Legacy systems in the NHS are difficult to navigate and change

The challenges of using a system designed with a binary approach are compounded by the fact that clinical information systems within the NHS are outdated and reliant on decades-old infrastructure. The variance in systems between GP surgeries, A&E, pharmacies, etc. also means that interoperability is a significant issue. Although digital transformation has brought important innovations to healthcare, the digitisation of all data has at times complicated delivery of care.

As one interviewee explained:

'Basically, everything in the NHS is an algorithm of a chart. And what's the difference? Well, one's a computer, one's on paper. Everything in the NHS is – "This happens. Therefore, you do X. Therefore, you do Y." That's basically what all of medicine is. We're just making that flow chart incredibly more complicated.'

The digitisation of the NHS and the deployment of data-driven systems has added a layer of complexity to this flow chart. This finding is echoed in the Ada Lovelace Institute report *A Knotted Pipeline*, which highlights the pitfalls of data curation done in a top-down way that flattens important nuance, poor coding and categorisation of data, lack of historical or situational knowledge in data analysis, and poor-quality data, all of which can cause unequal outcomes.⁹¹

91 Machiori, *A Knotted Pipeline* (n 61).

The National Audit Office's examination of digital transformation in the NHS explains that it is complicated due to 'legacy' (aged) IT systems, as well as 'the nature of healthcare information, the large number of organisations and stakeholders, complex governance arrangements, and existing commercial arrangements with technology suppliers'.⁹² Previous attempts to digitise have been unsuccessful, and the NHS has not yet met its target of becoming 'paperless', which was supposed to happen by 2018. The National Audit Office report adds that interoperability of data and IT systems is essential for digital transformation but has proven to be extremely challenging – especially because the NHS may not have applied all of the lessons learned from previous attempts at transformation.

Interviewees working on health tech platforms noted the difficulty in making large-scale changes due to the number of people and systems involved:

'Making even small changes is quite complex. [Let's say] you come into the system and then just update all the sex and gender coding. This system has been running with this NHS Trust for 10, 20, 30, 40 years. What do you then do with all of that data? What if there's an issue? How do you control for ramifications of people that may have specific requirements around not disclosing their gender identity? There are a multitude of considerations and risks once you're working at that scale, and I think that's really part of the issue is that there's so much work that has gone into the way that these systems work.'

Another interviewee, a GP, similarly stated:

'The digital processes around that are just too complicated. There are so many different stakeholders involved, each one has a process, a little bit of work to do around a record and then move it on to the next stakeholder. And there didn't appear to be any easy way to join each of those different stakeholders digitally. It was going to need some investment, basically ... as you start to unpick the systems, you realise how many different stakeholders you're going to have to influence in order to make that change.'

In addition, GP surgeries thus far have so far mostly been using off-the-shelf systems for the management of patient records. One of our health policy expert interviewees explained that because these systems are not designed or built by the NHS, GPs must 'buy them as they are' and have no say in the data models or frameworks used. While the NHS can specify what it wants

92 DHSC, NHS England and NHS Improvement, NHS Digital, 'Digital Transformation in the NHS' (National Audit Office, 2020) www.nao.org.uk/wp-content/uploads/2019/05/Digital-transformation-in-the-NHS.pdf.

GP surgeries have little input into the features of the systems they use for patient record management

out of the system, there is little opportunity to have bespoke systems and thus little say in the features or updates that can be made.

Changes to the legacy environment can also be met with resistance on the ground, as clinicians push back against what they see as a top-down, time-consuming imposition when they have more immediate problems to attend to. The National Audit Office report also identifies one of the causes of the failure of the 'National Programme for IT' (the attempt between 2001 and 2011 to digitally transform the NHS) as a lack of engagement with clinical staff; the emphasis was too heavily placed on the technology rather than the adaptive changes required in the workforce.

Impact on transgender and non-binary people

Clinical information systems and the policies around recording gender information are outdated and difficult to navigate. The impact of this is that many transgender and non-binary people disengage entirely from NHS care – pursuing private options if they can afford it, or simply putting off medical needs unless they are urgent.

GPs and transgender and non-binary people highlighted the challenges in delivering and receiving continuity of care due to the inability of clinical information systems to record gender identity or 'trans status' in a consistent manner. This chapter draws on the lived experiences of transgender and non-binary people to highlight their exclusion within the NHS. These insights were gathered in workshops as well as one-to-one interviews. Pseudonyms have been used to maintain anonymity.

A constant theme in these conversations was the fact that the various systems used by NHS organisations all have different ways of recording gender information and there is poor interoperability. What this means in practice is that someone may receive care that affirms their gender identity in one place, such as from their GP or through mental health services, but might face misgendering at another place, such as A&E, that relies on data from the Spine.

One of the participants in the workshop, Sam, a transgender man, told us about their experiences of being treated for an injury and collecting medication. Sam clarified that their GP had been supportive and had brought up the option to change their name in the electronic record (without changing their gender). But this had had unintended consequences, as neither Sam nor the GP realised that the name change would not be reflected in other systems. Sam had then had a distressing experience at hospital when they were deadnamed⁹³ and incorrectly referred to as a transgender woman, as the hospital's IT system did not have accurate

⁹³ The UK Deed Poll Office defines deadnaming as 'calling a transgender person by the original or birth name that they went by before making a transition and changing their name'. Deadnaming can be hurtful and often traumatic for a person, even if done unintentionally. UK Deed Poll Office, 'Deadnaming in the UK (19 September 2022)' www.ukdeedpolloffice.org/deadnaming-in-the-uk accessed 16 August 2024.

information. In the middle of a medical trauma, this mistake escalated to Sam being sent to a 'female bed'.

Another participant, Jamie, a transgender man, had a similar experience and felt that the clinician and the receptionist at the reproductive clinic were seeing different information to each other on their records, leading to different treatment. Jamie told us that because the clinic was gender-segregated (i.e. with separate sections for men and women only), the receptionist had asked him to sit in the women's section while his doctor was looking for him in the men's section.

The effects on continuity of care were also raised by GPs we interviewed. Many GPs accept that the situation is not ideal and use workarounds to navigate the system. One of them said:

'Sometimes I ask for patience, and this is more for like ... the non-binary patients. I tell them about the risk of changing the gender [in the record] or the risk of continuity of care. And then I say that if you prefer to keep the same NHS number, you might want to consider changing gender to unspecified or indeterminate.'

Where private, trans-inclusive options are available and affordable, many transgender and non-binary people opt for these due to their negative experiences in the NHS. As an interviewee from a health tech platform stated:

'A struggle that I've recognised for a lot of our trans patients is that they have this transient experience between different services, probably why they love coming to [us] because all the stuff that they would usually worry about is thought through.'

Another workshop participant, Alex, a transgender woman, pointed out that the NHS systems appeared to be deliberately designed to exclude certain options. For example, when she changed her name, she could not have 'Ms' as the title but had to pick 'Mx'. Alex noted:

'Someone had to write some code to exclude that as an option.'

Alex spoke about the coding that resulted in titles being strictly linked with the recorded gender; as Alex is a trans woman, she felt that she had been deliberately prevented from using a different title unless she also chose to change her gender in the record, thus getting a new NHS number.

The issue with changing titles seemed to happen with several GPs. Cameron, a trans man who spoke with us about his experiences in an interview, said he had no problem changing his name in the record but continued to get letters addressed to 'Ms'. This was particularly distressing as he lived in shared accommodation and did not want anyone to know that he was transgender. Cameron raised this with his GP and was told 'the computer won't do that'. He ended up getting a new NHS number to resolve this and is now referred to as 'Mr', but as a result all records of his childhood vaccinations and other medical information were lost.

Lived-experience insights also revealed that not all GPs or transgender and non-binary people are aware of the actual process for changing gender in the NHS record.

Jamie told us that they had changed their name with their GP but were asked for a Gender Reassignment Certificate to change gender and were unaware that this was not required by law. Cameron similarly decided to undergo the process after finding out about it from online support groups, but did not realise he would lose all of his previous medical history.

There is clearly a technical problem that requires a solution here. The data-driven systems appear to link pronouns quite rigidly with the official gender on the record, but this is often counter-intuitive to providing gender-affirmative care. It is possible for a person to request that they be referred to with a different name and pronoun while still keeping their gender marker as it is in the record. Transgender and non-binary people may have many reasons for not wanting to officially change their gender, and this should not preclude them from getting the care they need.

Alex, who had worked as an IT consultant in hospitals during the 1990s, argued that while it is easy for people to blame the system, the problem is more that there is not enough willingness in the NHS to change it. She noted:

'In a small GP office, you don't have money to be able to have a proper iterative design process. In larger [NHS] Trusts, it's about management not being onboard.'

This was echoed by an interviewee who had been working on developing more gender-inclusive technology. As they said:

'When you're thinking about big systems as well, the other huge piece of the puzzle is behaviour change and it's actually the behaviour of the people that use the systems. There are already options in place to provide information around gender and sexuality, and quite a few large NHS systems have it, but actually what they find is that staff don't feel comfortable asking these questions. So, because it doesn't seem mandatory, it doesn't get added and that data is missed.

'We have a core belief as an organisation that data fully informs your entire journey with us, and it's a really important piece of the puzzle that is not often reflected in the current systems, which is why we often have people that disengage from care in the NHS.'

Clinical information systems that store important demographic and medical data about patients are designed in such a way that a person is only legible to the system if they conform to certain societal norms, and if their bodies conform to the 'standard'. As discussed previously, our healthcare institutions and systems have been designed for a cisgender male standard (which is also usually white), embedding stereotypes and outdated assumptions about gender. Furthermore, many of the underlying processes have not been updated to reflect changes in law and policy or in society, such as a higher average age of adoptees or an increase in patients who are open about their gender-diverse experiences.

Having a rigid binary framework for these systems has resulted in incomplete data about people being recorded, which is likely to have a lasting impact on their wellbeing and access to care.

As our interviewees and workshop participants explained, the inability of current data-driven systems to accommodate gender-diverse experiences results in their receiving poorer-quality or delayed care.

In the context of healthcare, it may be necessary to collect data about people's sex characteristics – but this need not prevent a widening of the range of pronouns and titles that can be included in a health record.

People can have complex medical needs and systems should be designed to handle all of these needs

During the workshop, Sam, who is partially sighted, drew an interesting parallel between being transgender and being disabled. They told us about getting involved in their NHS Trust in trying to make services more accessible for disabled and homeless people. Sam was assessing the digital system for accessibility and was surprised that accessibility consultants didn't seem to know much at all about the process of making services accessible and were just 'taking advice from one random guy'. Sam observed that their experience of being disabled made it easier to deal with being 'officially trans', as they were used to having to work through these difficult systems.

Sam's experience is significant because it highlights the complex medical needs that people can have and the necessity to design systems that are able to handle all of these needs. Sam had so far not changed their gender marker in their official record, as they would have 'too much to lose' if their old record did not link with their new one. For some people, this is an easier decision – Alex, for example, told us that she did not have a complex medical history and therefore did not mind having her old record essentially wiped clean.

Overall implications

The inability of clinical information systems, and of NHS systems generally, to offer a range of options for recording legal sex and gender identity data can result in serious harms to people on three main levels.

First, it results in a mismatch between people's understanding or experience of their gender identity and their body, and the assumptions that NHS systems place on them due to their operating within a gender binary.

As one participant noted, simply knowing if someone is a woman (or if their recorded gender is female) tells us nothing about their body configuration. In the workshops and interviews, transgender and non-binary participants emphasised the flaws in clinical information systems in healthcare that are unable to account for different configurations of body types, anatomy and other visible characteristics, and gender identity.

| What we need are inclusive health systems that can enable clinicians to provide care to *everyone*.

Second, it leads to issues with diagnostic methods and disruption to the continuity of care. This happens when clinical information systems do not allow for the recording of gender identity as separate from legal sex and instead assume that a person's gender identity aligns perfectly with the expected physiological sex characteristics within a binary framework.

People whose health record has their gender marker as 'male' are not invited to cervical cancer screenings unless they make an appointment themselves or their GP proactively maintains a separate register to remind patients who are not automatically invited. They are similarly not invited to breast screenings. People whose health record has their gender marker as 'female' are automatically invited for breast cancer screenings – but as Cancer Research UK notes, those who take feminising hormones do have some risk of breast cancer and so should be offered the opportunity to consider if they want to take part in screenings.⁹⁴

94 Cancer Research UK, 'I'm Trans or Non-Binary, Does This Affect My Cancer Screening?' www.cancerresearchuk.org/about-cancer/cancer-symptoms/spot-cancer-early/screening/trans-and-non-binary-cancer-screening accessed 25 July 2024.

The onus of care is largely on patients, who have to identify and ask for the preventative screenings and care that they might need

All of this largely leaves the onus of care on the patients, who not only are expected to be aware of all the tests and screenings that the NHS offers but have to remember to identify and ask for the preventative screenings and care that they might need.

Third, people get lost in overall health data when important information about them is not collected or is misrepresented. This inevitably frustrates the vision of data-driven and AI systems as revolutionising healthcare and improving health outcomes, as certain groups of people will not receive the benefits of technological advancements.

Finally, harm also results from the additional pressures these shortcomings create for a healthcare system which is already overstretched. Requiring the assignment of a new NHS number and tasking GPs with ensuring that all data gets transferred over to the new record associated with this number, while working within the confines of outdated clinical information systems, significantly adds to GPs' responsibilities and impacts their ability to provide good care to all patients.

Conclusion and next steps: Can better data save lives?

Clinical information systems that are inclusive and designed to accommodate a wide range of care needs are crucial for all people and for a well-functioning health system overall. The healthcare access challenges that transgender and non-binary patients face, while unique with respect to their gendered experiences, are not dissimilar to the challenges that other marginalised groups encounter. As one of our interviewees put it:

‘The real concern for the NHS today should be how to provide care no matter who shows up.’

The implications of a health system in which records do not reflect key information on patients affect everyone, while raising particular concerns for groups who may be additionally vulnerable, such as transgender and non-binary people and adopted children who may have to apply for a new NHS number.

This was a small-scale study, and more research is clearly needed in this area. In particular, the risk of losing safeguarding information for a legally adopted child merits an immediate review of this process and the guidance around it.

The experiences documented in this report build on our previous research highlighting the gaps between those who develop and deploy health services and those who are expected to benefit from them. With this project, we offer insights into a complex situation that is limiting for clinicians and patients and lay out the potential for harm if measures are not taken to improve inclusivity in the design process of clinical information systems, as well as more advanced data-driven systems.

We acknowledge that there are changes happening within the NHS and efforts are already underway to include transgender and non-binary people's experiences in research into and design of systems. Some NHS

Trusts have begun using Epic⁹⁵ – an electronic health records system for hospitals that allows for the recording of legal sex, sex assigned at birth and gender identity as distinct categories.⁹⁶ Although this does not override the Spine record and is not used by GPs, it is a more inclusive model that is being trialled in some places, such as hospitals.

Work is also being done internationally to develop recommendations for standards on gender and sex-related data collection. ISO – the International Organization for Standardization – has started work on representing sex and gender in electronic health records, stating that it is difficult to describe health outcomes for transgender and non-binary people because often they are not represented at all in the records.⁹⁷ The latest Snomed CT International release – clinical vocabulary for recording information in patient records – includes the terms 'identifies as transgender male' and 'identifies as transgender female', which can now be used in general practice.⁹⁸ While this too does not address the issue of male/female as the only options in the Spine record, it is likely to help clinicians provide gender-affirmative care to their patients.

There is need for system-wide review. However, there are some more immediate changes that could lead to significant improvement in the quality of care that people receive and the impact this has on their wellbeing. We recommend:

- that as NHS Digital advances its Spine Futures programme and makes use of more modern technologies and open standards, it considers the ongoing work and best practices being used internationally to ensure that transgender and non-binary people are represented in data and data-driven systems
- that developers of data-driven health systems consider the importance of including transgender and non-binary people in the process of creating or modifying their systems

95 NHS Manchester University, 'MFT Signs Contract with Epic for Ambitious New EPR Solution' (26 May 2020) <https://mft.nhs.uk/2020/05/26/for-immediate-use-26th-may-mft-signs-contract-with-epic-for-ambitious-new-epr-solution> accessed 25 July 2024.

96 Epic, 'More Inclusive Care for Transgender Patients Using Epic' (12 December 2017) www.epic.com/epic/post/inclusive-care-transgender-patients-using-epic accessed 25 July 2024.

97 ISO, 'ISO/TR 9143:2023(en): Health Informatics – Sex and Gender in Electronic Health Records' www.iso.org/obp/ui/en/#iso:std:iso:tr:9143:ed-1:v1:en accessed 25 July 2024.

98 The codes can be found by searching in the SNOMED CT Browser, <https://browser.ihtsdo.org/?perspective=full&conceptId1=1332082008&edition=MAIN/2024-07-01&release=&languages=en>.

- that the NHS updates guidance and makes clear the impact of changing gender marker in the health record (similarly to NHS Scotland's *Screening Information for the Transgender Community*, which explains in detail who will be automatically invited for screenings and who should contact their GP to ensure they are invited)
- that as the NHS becomes more reliant on AI tools to provide better care, it considers the implications of using data-driven systems built on unrepresentative data and factors in how the benefits or harms of these systems may be inequitably distributed.

There is a growing body of evidence that indicates the need for a change to NHS systems, in particular to resolve the problems of changing NHS number and the impact this has on clinical and research implications that need to be addressed.⁹⁹

One argument underlying the policy of assigning a new NHS number and delinking the records is related to privacy and keeping a patient's medical history, especially any records of medical transition, confidential. As one GP interviewee said:

'I think the initial idea of doing that was because they want to protect the privacy of the patients [...] but we still know the patient's trans status because you still get letters from the gender clinic. You know they're still requesting hormone therapy. And also blood test results. So, the privacy is a bit of a moot point here.'

It is important to note that some transgender and non-binary people may want the option of a new NHS number and a record that is completely delinked from their old one, for various reasons – sometimes including privacy.

In our interviewees we heard of instances where older transgender people, who had not medically transitioned and were not yet open about their gender identity to their family members, wanted to receive letters from GPs and other services still addressed as per their sex assigned at birth. When visiting the GP by themselves, however, they wanted the option of being referred to in a way that matched their gender identity. Transgender and

99 London Assembly Health Committee, 'Trans Health Matters' (n 34); The Cass Review, 'Independent Review of Gender Identity Services for Children and Young People: Final Report' (2024) <https://cass.independent-review.uk/home/publications/final-report> accessed 25 July 2024. The recently published Cass Review has been subject to critique, and we refer to it in this report only to flag that the Review has noted the challenges in requiring a change to NHS number when a person wants to change their gender in the record.

It is important to make sure each person is able to receive care that is compassionate and respects their wishes

non-binary people at different stages in the process of transition will have different views on how they want to be referred to or addressed; it is therefore important to make sure each person is able to receive care that is compassionate and respects their wishes.

We are not suggesting that the way forward is to stop assigning new numbers for anyone, or that patients should be compelled to disclose any information about themselves that they do not want to disclose. Transgender and non-binary people are not a monolith, and it is crucial that we consider differing opinions and experiences in our work.

When some groups of people are not accounted for in the design and deployment of systems, they invariably lose out on its benefits.

As previously shown, medical institutions and the data-driven systems they use have been set up based on a male standard. All of those who are considered to deviate from this have poorer health outcomes due to systemic biases. Moreover, because health systems have not kept pace with changes in society, they currently underserve people and society.

This paper evidences that research in this area has a long way to go in investigating many of these experiences, particularly for transgender and non-binary people. We hope that it makes clear the need for more research on how clinical information systems lead to disproportionately negative impacts for transgender and non-binary people. These findings should be workshopped more broadly, and further engagement would be valuable with other intersectional lived-experience research that explores the perspectives of a range of communities.

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About the Ada Lovelace Institute

The Ada Lovelace Institute was established by the Nuffield Foundation in early 2018, in collaboration with The Alan Turing Institute, the Royal Society, the British Academy, the Royal Statistical Society, the Wellcome Trust, Luminate, techUK and the Nuffield Council on Bioethics.

The mission of the Ada Lovelace Institute is to ensure that data and AI work for people and society. We believe that a world where data and AI work for people and society is a world in which the opportunities, benefits and privileges generated by data and AI are justly and equitably distributed and experienced.

We recognise the power asymmetries that exist in ethical and legal debates around the development of data-driven technologies, and will represent people in those conversations. We focus not on the types of technologies we want to build, but on the types of societies we want to build. Through research, policy and practice, we aim to ensure that the transformative power of data and AI is used and harnessed in ways that maximise social wellbeing and put technology at the service of humanity.

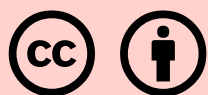
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