INCOHERENT AND UNSAFE

How the NHS's failure to reliably record sex puts patients at risk



A report from Women's Rights Network

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A joint report by Women's Rights Network, SEEN in Health and the Clinical Advisory Network on Sex and Gender

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Note on report scope and terminology

This report is primarily focused on the NHS in England, operating under the oversight of NHS England and the Department of Health and Social Care.

We use the term 'patient' to refer to any person who receives care from NHS physical or mental health services.

Note on screenshots

This report presents a series of screenshots from electronic health record systems used in the NHS. No real patient information is displayed in these screenshots.



Women's Rights Network (WRN) is a grassroots network of women across the UK which focuses on defending the sex-based rights of women. The WRN Health Group consists of doctors, nurses, allied health professionals and healthcare managers working in the NHS and in private care.



SEEN in Health (SiH) is an NHS staff network representing the protected characteristic of sex which is committed to promoting and supporting sex equality and equity in NHS workplaces.



The **Clinical Advisory Network on Sex and Gender** (CAN-SG) is a network of clinicians which aims to enhance professional and public understanding of the nature of sex, gender, gender roles and identity with respect to medicine and healthcare. The Network believes clinicians have a responsibility to examine potential harms associated with healthcare interventions, especially when treating vulnerable populations.

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Glossary

CAN-SG	Clinical Advisory Network on Sex and Gender
DSDs	Differences of Sexual Development
EHR	Electronic Health Record
EPR	Electronic Patient Record
GRC	Gender Recognition Certificate
NHSE	NHS England
PCSE	Primary Care Support England
PRSB	Professional Record Standards Body
SEEN	Sex Equality and Equity Network
WRN	Women's Rights Network

Foreword

Everyone has a sex and is either female or male. Our sex is determined at conception and coded into every cell in our body. It shapes our anatomy, our risk of disease and it impacts our health in myriad ways. Our sex guides diagnosis and what is considered 'normal' on blood tests, our response to medicines and the size and design of many medical devices.

Yet a joint investigation by the Women's Rights Network, SEEN in Health and the Clinical Advisory Network on Sex and Gender (CAN-SG) confirms our worst fears. The conflation of sex and gender in electronic NHS records means that patient data is now so muddled that doctors and other healthcare professionals can no longer trust them to show the correct sex of the person they are treating.

Women's Rights Network founder, Heather Binning warns, "This is the dangerous and entirely unintended consequence of policies and practices which were introduced in the name of inclusion. Yet those most at risk are people who identify as 'trans'."

Imagine the scene in a busy emergency room. A patient presents with abdominal pain. They have a beard, a masculine name and their patient record indicates they are a man.

But despite their appearance and patient record, this is a woman who has undergone a double mastectomy and has been taking testosterone. She is also one of the 11,000 UK women a year to experience an ectopic pregnancy — and if her fallopian tube ruptures and she does not receive emergency surgery she could die.

This lack of clarity, when seconds can mean the difference between life and death, puts frontline NHS staff in an impossible position. A spokeswoman for SEEN in Health explains, "The risks associated with not knowing a patient's sex cannot be overstated. As health professionals, everything we do is based on the principal of 'first do no harm' but this relies on having accurate, comprehensive patient data."

This ill-considered approach undermines the reputation and credibility of the NHS and jeopardises our ability to deliver safe care in both the public and private sector.

CAN-SG co-chair Dr Louise Irvine warns, "Replacing the biological reality of sex with the nebulous concept of gender means the NHS is putting ideology ahead of science.

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"That puts patients at risk and undermines the effectiveness and reputation of our health services. It is imperative the NHS returns to accurate recording of sex in medical records."

All three organisations now call on the Health and Social Care Secretary Wes Streeting to act on the findings of this report — before a patient is killed by dangerous record keeping which has been introduced in the name of kindness.

Heather Binning, Executive Director, Women's Rights Network

Co-chairs, SEEN in Health

Dr Louise Irvine and Dr Stella Kingett, Co-Chairs CAN-SG

Executive summary

Healthcare professionals need to know the sex of a patient to provide safe healthcare. Patient sex influences diagnosis, care, treatment and medication for many health conditions. If healthcare professionals do not know whether a patient is female or male, serious harm can occur (paragraphs 1.13-1.22, and 4.6-4.8).

The NHS acknowledges the importance of sex to safe healthcare (paragraphs 2.3 and 2.7). It also understands the difference between sex and gender identity and the risks inherent in using the ambiguous term 'gender' in medical records (paragraph 2.11 and 2.14). And yet, the NHS no longer requires patient sex to be recorded in electronic health records. Instead, the NHS prioritises the recording of patient 'gender' and gender identity over sex (paragraphs 2.2-2.3).

Muddled and inconsistent

This report evidences the various muddled ways that NHS organisations in England are currently recording sex and gender identity. NHS electronic health records now hold information in a 'gender' data field which the NHS acknowledges is unsafe (paragraph 2.11), alongside self-reported gender identity, and data purporting to be about sex but which, in some instances, actually reflects gender identity (paragraphs 2.9-2.46).

There is no consistent service-wide approach which ensures a safe and reliable record of patient sex, readily accessible by healthcare professionals who need to see it for clinical purposes. The NHS has failed to safeguard data by allowing information about sex and gender identity to become blended; this renders key data sets unreliable and therefore unsafe for patient care, and less valuable for research. This blending has arisen because of the ambiguity of the term 'gender', and data linkages between NHS digital systems which have not been adequately safeguarded to maintain data accuracy (paragraphs 2.15-2.18).

The NHS permits patients of any age to change their 'gender' on their medical record any number of times, on demand. The patient is given a new patient record and permitted to prevent the transfer of some clinically relevant information to their new record if it would reveal their change in gender. No record is kept of who has changed their gender in medical records, and no links are maintained to old

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records. This creates patient safety risk, reduces data quality and is a right not afforded to any other patient group (paragraphs 2.47-2.54 and 4.9-4.15).

Well-intentioned but counter-productive

The NHS's approach to recording sex and gender identity has emerged from a laudable desire to be more inclusive and avoid distress to patients with a trans identity. Whilst knowing someone's gender identity can help healthcare professionals give care that reflects the patient's wishes, the significant implications of this wide-reaching change for all patients, and in particular those with a trans or non-binary identity, have not been properly thought through. In practice, these changes offer minimal benefit to transgender patients and come at the expense of significant and entirely avoidable risks to patient safety, safeguarding and a range of other serious detriments detailed in this report (paragraphs 4.1-4.50).

The risk of harm is greatest for people with a trans identity

We have found no evidence that workable mitigations for these risks were developed, the equality impact of the changes assessed, or the changes appropriately tested for clinical usability before they were rolled out (paragraphs 2.28, 2.39 and 2.64-2.65).

The current NHS approach incorrectly assumes that everyone has a gender identity. It also erroneously implies that it is possible to change sex and adopts highly contested language and ideas about sex and gender (see paragraphs 2.72-2.78).

We call on the Health Secretary and NHS England (NHSE) to take rapid action to address these failings.

Risks of inaction

The NHS's current approach to the recording of sex and gender identity has a number of very serious consequences:

 Risks to patient safety: Inaccurate or unreliable information about sex increases risk of misdiagnosis, incorrect interpretation of laboratory tests, inappropriate prescribing and failure of communication between healthcare staff. The risk of harm is greatest for people with a trans identity because this patient group is more likely than others to have a 'gender' or 'gender identity' or 'legal sex' which does not align with their biological sex. Trans-identifying patients may also miss out on invitations to appropriate sex-based health screenings. This report presents documented examples where patients with a trans identity have suffered serious or potential harm due to confusion about their sex in a healthcare setting (paragraphs 4.2-4.15).

- Undermines safeguarding: The Cass Review identified a range of serious safeguarding risks arising from the issuing of new medical records to patients who change their recorded 'gender' (paragraphs 4.16-4.18).
- Compromises clinicians: New records issued to patients who change their recorded gender exclude some of the patient's previous medical history. Safe clinical judgements rely on access to accurate patient sex data and relevant historical medical information. The absence of this information leaves healthcare professionals and their employers open to claims of clinical negligence (paragraphs 4.19-4.24).

Healthcare professionals and their employers are open to claims of clinical negligence

- **Risks acting unlawfully:** By ascribing a gender identity to people who do not have one, the NHS risks legal challenge for unlawful discrimination on the grounds of belief. Gathering data on sex and mixing it with self-declared gender identity data renders this data inaccurate, which contravenes data protection law. A lack of reliable data also means the NHS is unable to meet its legal obligation to monitor equality of its service provision on the grounds of sex and gender reassignment (paragraphs 4.25-4.31).
- Undermines public trust and confidence: Patients quite reasonably question the NHS's ability to meet their basic expectations of a safe healthcare provider when it is clear that the NHS does not have a reliable record of their sex; for example, when radiographers ask men if they might be pregnant. Concealing the importance of sex in healthcare undermines public faith in the NHS's integrity and reputation as a safe, transparent and science-based healthcare service (paragraphs 4.32-4.39).

Weakens research and policy making: Medical records which do not clearly and accurately record patient sex undermine the reliability of official statistics and any research findings based on those records. A lack of reliable data on sex-based differences in disease incidence rates and health outcomes undermines the ability to formulate appropriate policy responses to the distinct health needs of women and men. Also, research into the healthcare of people with a trans identity is weakened because the practice of creating a new medical record makes it difficult to track long-term health outcomes for this group (paragraphs 4.40-4.46).

Creating a new medical record makes it difficult to track long-term health outcomes for trans people

 Impairs policy implementation: The NHS's Same Sex Accommodation policy cannot be implemented properly if the NHS does not know the sex of patients. The NHS also needs to accurately record the sex of its employees to respond to patient requests for same-sex care and to monitor the treatment of employees on the grounds of the protected characteristic of sex (paragraphs 4.47-4.50).

Recommendations

To preserve patient safety, the NHS must urgently develop and implement a clear and coherent policy for the recording of patient sex and gender identity. This policy should:

Recommendation 1

Require a clear, accurate and readily accessible record of patient sex to be held in NHS patient record systems: Completion of this data field should be mandatory and restricted to a clearly defined set of values. Overwriting the record of sex should be limited to instances of scrivener's error, or rare cases where clinical testing is required to determine whether a person is male or female.

Recommendation 2

Include the option of recording patients' gender identity: Ensure that NHS electronic patient record (EPR) systems have the option to record a patient's gender identity which may be altered on patient request. This field should include 'no gender identity' as a possible response. This data field must be kept entirely separate from the field recording sex to avoid confusion between the two.

Recommendation 3

Ensure clear language at all times: Given the serious risks this report lays out, cease using the terms 'gender', 'legal sex', or the pair of data fields about gender identity sometimes used to infer patient sex.

Recommendation 4

Review data linkages between NHS digital systems on sex and gender: Cease making data linkages between NHS digital systems which feed data from a 'gender' or 'gender identity' field into a 'sex' field, and vice versa.

Recommendation 5

Revise the current response to patient requests to change 'gender' (i.e. gender identity) on medical records: It is important that relevant medical information is no longer lost, and an accurate record of patient sex is retained. The NHS should resume responsibility for inviting patients with a trans identity to sex-based population screenings.

Recommendation 6

Amend guidance supporting the Core Information Standard for health records: Update the guidance to provide an accurate account of the law as well as practical advice on the handling and confidential sharing of patient data on sex and gender identity for trans-identifying patients both with and without a Gender Recognition Certificate.

Recommendation 7

Ensure national and international standards on healthcare data prioritise patient safety, by mandating and prioritising the clear recording of sex. Any separate, additional requirement for the recording of 'gender identity' should include an option for patients to record that they have 'no gender identity' so as not to cut across UK legal protections for belief discrimination.

The NHS must also develop and implement a clear and coherent policy for the recording of employee data.

Recommendation 8

On the recording of employee sex and gender identity: NHS organisations should accurately record the sex of their employees to support policy delivery and enable equality monitoring in line with the Equality Act 2010 and the Public Sector Equality Duty.

1. Introduction

1.1 This report identifies a number of serious concerns created by the NHS in England's muddled approach to recording sex and gender identity in patient records. The NHS's failure to maintain reliable records of patient sex threatens safe patient care, undermines public trust and confidence in the Service and exposes healthcare providers to the risk of litigation for failing to meet their obligations under the Equality Act and other legislation.

Purpose of medical records

1.2 According to the NHS England (NHSE) website:

"Delivering safe and efficient patient care depends on having high quality patient records and, therefore, the right information available when clinical decisions are made."¹

- 1.3 High quality patient records, which include a full medical history and all clinically relevant information, are essential for safe and effective care. These records also provide data which informs health service planning and population health management, and they help advance science and healthcare by providing pseudonymised data for research purposes.
- 1.4 To support these objectives effectively, the information held in medical records must be accurate, clear and readily accessible by those who need to see it.
- 1.5 Most NHS medical records are now held within electronic patient records (EPR) systems. A range of different digital systems is used across the NHS to record patient demographic data, and GP practices and NHS Trusts procure and operate their own EPR systems. These systems are under continual development by their developers and can be customised during implementation or beyond, so the same EPR can look slightly different in different NHS organisations. However, NHSE and the Professional Record Standards Body (PRSB) set central standards for the display and input of information to these systems, which developers and NHS organisations must follow.

Definitions

1.6 It is important to be clear about definitions.

¹ (NHS England, 2024a)

- 1.7 **Sex** is a biological category. Humans, like all mammals, have two distinct sexes: females have ovaries and produce large gametes (eggs), while males have testes and produce small gametes (sperm).² It is not possible for humans to change sex.
- 1.8 People with a Difference of Sexual Development (DSD or 'intersex') have conditions that affect the development of their reproductive anatomy. However, their sex can be identified by medical tests. In data terms, sex is a verifiable, objective variable.
- 1.9 The World Health Organisation (WHO) states that Gender refers to norms, behaviours and expectations associated with being a woman, man, girl or boy. WHO notes that: "as a social construct, gender varies from society to society and can change over time."³ The term 'gender' is sometimes used as a synonym for sex, but it is also used as shorthand for 'gender identity'. These distinct meanings make 'gender' an ambiguous term. Ambiguity undermines accuracy in data, so the term 'gender' is best avoided in data collection.
- 1.10 According to the World Health Organisation, **gender identity** refers to a person's "deeply felt, internal and individual experience of gender, which may or may not correspond to the person's physiology or designated sex at birth."⁴ Gender identity is self-declared and is a subjective variable known only to an individual themselves. Some people do not ascribe to this belief in an innate gender essence or gendered 'soul' and reject the idea of gender identity.

Note on the Protected Characteristics and Public Sector Equality Duty

- 1.11 The Equality Act 2010 sets out nine characteristics under which all individuals have legal protection from discrimination. These protected characteristics include 'sex' and 'gender reassignment', but not 'gender' or 'gender identity'. The Act says that someone has the protected characteristic of 'gender reassignment' if that person "is proposing to undergo, is undergoing or has undergone a process...for the purpose of reassigning the person's sex by changing physiological or other attributes of sex".⁵
- 1.12 All public authorities, including the NHS, are subject to the Public Sector Equality Duty which requires them to have due regard to the need to foster good relations between different people, eliminate discrimination and monitor equality. Government guidance unequivocally advises public authorities **not to use concepts such as 'gender' and 'gender identity'** in

² (Bhargava *et al.*, 2021)

³ (World Health Organisation, 2024)

⁴ (World Health Organisation, 2024)

⁵ (Equality Act, 2010)

relation to the protected characteristics as these concepts are not used in the Equality Act and can be understood in different ways.⁶

Why sex matters in healthcare

1.13 To give safe healthcare, it is essential that healthcare professionals know a patient's sex. Sex differences are not confined solely to diseases related to reproductive anatomy such as ovarian or testicular tumours, endometriosis or prostate hypertrophy. Sex differences have been found in every tissue and organ system of the body.⁷ These sex differences influence the diagnosis, medication, care and treatment of very many health conditions.

Sex differences have been found in every tissue and organ system of the body

Diagnosis

- 1.14 Healthcare professionals draw on their clinical experience and use a range of methods to make a differential diagnosis, i.e. a list of potential diagnoses starting from the most likely. A lack of reliable information about a patient's sex undermines this diagnostic method and makes errors more likely.
- 1.15 For example, abdominal pain can have many causes. Some causes, such as appendicitis, constipation, gastro-intestinal infection and hernias affect both sexes. But abdominal pain in women could also be due to ovarian torsion, pelvic inflammatory disease, ectopic pregnancy, pregnancy complications or going into labour. In men it might be caused by testicular torsion or testicular infection.
- 1.16 The prevalence, course and severity of the majority of common diseases differ between men and women⁸ which is why knowing a patient's sex influences clinical decision-making. For example, deaths from Alzheimer's disease are more common in women,⁹ and women account for four out of five people with autoimmune conditions¹⁰ such as multiple sclerosis and rheumatoid arthritis.

⁶ (UK Government, 2023)

⁷ (Marts and Keitt, 2004)

⁸ (Karp *et al.*, 2017)

⁹ (Mauvais-Jarvis *et al.*, 2020)

¹⁰ (Dou *et al.*, 2024)

- 1.17 Women have a higher incidence of depression¹¹ and more frequent and severe adverse reactions to vaccines.¹² The location and severity of stroke differs between the sexes,¹³ as does the progression of Parkinson's disease¹⁴ and the effects of alcohol on the body.¹⁵
- 1.18 The diagnostic range values considered normal for women and men frequently differ; for example, haemoglobin levels¹⁶ and markers of kidney and liver function.^{17,18} Patient sex also influences the safe administration of the contrast dye used in some diagnostic imaging tests.

Prescribing

1.19 Patient sex influences prescribing. For instance, Alosetron is used to treat severe chronic irritable bowel syndrome in women but is not approved for use by men.¹⁹ Spironolactone, an acne treatment, is less commonly prescribed to men because of the sex-based side effects.²⁰

Treatment and care

- 1.20 Patient sex influences medical treatment. For example, women taking oral retinoids for acne are put on a pregnancy prevention programme during treatment because the drug can cause serious birth defects.²¹
- 1.21 Several academic studies have identified worse outcomes for organ donation if the donor and recipient are different sexes.²² Sex also matters in blood transfusions: Rhesus positive blood must not be given to women with Rhesus negative blood type because of a danger to the foetus if the woman becomes pregnant in future.^{23, 24}
- 1.22 For these reasons, it is vital that we record everyone's sex accurately in medical records, without exception. Absence of this information prevents clinicians from providing safe, high-quality care.

²³ (The Stationery Office, 2005)

¹¹ (Eid, Gobinath and Galea, 2019)

¹² (Chiang *et al.*, 2023)

¹³ (Acciarresi et al., 2014)

¹⁴ (Cerri, Mus and Blandini, 2019)

¹⁵ (U.S. Centers for Disease Control and Prevention, 2025)

¹⁶ (Gloucestershire Hospitals NHS Foundation Trust, 2024b)

¹⁷ (South Tees Hospitals NHS Foundation Trust, 2024)

¹⁸ (Gloucestershire Hospitals NHS Foundation Trust, 2024a)

¹⁹ (Drugs.com, 2024)

²⁰ (Santer and Layton, 2023)

²¹ (UK Government, 2014)

²² (Puoti *et al.*, 2016)

²⁴ (Jackson and Baker, 2021)

Gender identity information

- 1.23 The last Census in England and Wales suggested that in 2021, 262,000 people (0.54% of the overall population) identified as trans.^{25, 26} Subsequent evidence indicated that some people may have found the Census question about gender identity confusing (particularly if English is not their first language) and therefore they may have given a response that did not reflect their gender identity.²⁷ This doubt about the accuracy of Census responses resulted in the statistics on gender identity being downgraded to "in development".²⁸ Nonetheless, this figure remains the best available estimate.
- 1.24 Knowledge of a patient's gender identity, if the patient has one, can help clinicians give patient-centred care. For patients taking cross-sex hormones or those who have had gender-related surgeries this information may be material to them receiving safe, high-quality care.²⁹ For example, knowing that an individual is taking cross-sex hormones will affect the interpretation of some diagnostic test results.³⁰
- 1.25 People with a trans identity are at higher risk of medical problems caused by taking cross-sex hormones or gender-related surgeries. For example, females taking testosterone at a typical male level are at increased risk of vaginal atrophy.³¹ Transgender individuals of either sex who take cross-sex hormones are at an increased risk of adverse cardiovascular outcomes.³² Knowledge that a patient has a trans identity thus aids accurate diagnosis and treatment.

²⁵ (Office for National Statistics, 2023)

²⁶ In 2022, 19,970 people or 0.44% of the population of Scotland identified as trans (Scotland's Census, 2024). The figure for Northern Ireland is unknown as the census did not include a question about gender identity.

²⁷ (Office for Statistics Regulation, 2024b)

²⁸ (Office for Statistics Regulation, 2024a)

²⁹ Cross-sex hormones and/or gender identity-related surgeries can alter a person's appearance, but they do not change their sex, which is coded in every cell in the body.

³⁰ (Cheung *et al.*, 2022)

³¹ (Krakowsky *et al.*, 2022)

³² (Spanos *et al.*, 2020)

2. NHS approach to recording data on sex and gender identity

- 2.1 Before we look at how the NHS in England records sex and gender identity in medical records it is important to know that:
 - 'Sex' data has been de-prioritised. The NHS recognises the critical importance of sex to safe healthcare. However, it has chosen to de-prioritise the 'sex' data field and make it non-mandatory in patient records. Meanwhile, it has prioritised data on 'gender' and 'gender identity' (paragraphs 2.2-2.3).
 - Data in the 'gender' and 'sex' fields is now unreliable. The NHS acknowledges that the 'gender' data field in NHS systems now contains a mix of sex and gender identity information owing to the ambiguity of the term 'gender'. Furthermore, multiple linkages exist between NHS systems, and in some cases data on patient 'gender' in one system feeds into a 'sex' data field in another system, and vice versa. This creates a patient safety risk (paragraphs 2.5-2.8 and 2.15-2.18).
 - A range of approaches is in use. A range of different data fields is used to record sex and gender identity in NHS medical records, with no consistent approach in operation across the Service (paragraphs 2.9-2.46).
 - Exceptions are made for trans-identifying patients about changes they can make to their medical record. Normal rules about what patients can change on their medical record do not apply in relation to this topic. Patients who want to change their 'gender' receive a new medical record and are able to influence what information is carried forward into their new record. This creates a patient safety risk if important information is omitted; it also undermines safeguarding (paragraphs 2.47-2.54 and 4.9-4.18).

We consider each issue in turn below.

De-prioritisation of sex data

2.2 The PRSB is responsible for developing standards for digital health and social care records in the UK, and its work includes setting out what data must be held in medical records and what information is optional.

2.3 The PRSB, in conjunction with NHSE, develops the Core Information Standard (the Standard) for medical records in England³³ and the wording of this Standard acknowledges that sex informs "how the person will be treated clinically".³⁴ However, despite acknowledging the importance of sex to clinical care, the Standard declines to classify the 'phenotypic sex' data item (i.e. biological sex) as either Mandatory, Required, or Optional in medical records. As a result, it is no longer necessary - according to the Standard - for a patient's sex to be recorded in their health record, (see **Figure 1**). This de-prioritisation of the recording of sex implies that sex has little significance for safe healthcare – this could not be further from the truth.

Figure 1: Core Information Standard for medical records in England

Note: some columns have been removed for presentational purposes.

Core information standard V2.0

N.B. Conformance key: Mandatory: the information must be included. Required: if it exists, the information must be included. Optional: a local decision is made as to whether the information is included.

Name	Conformance	Description
Person demographics	М	The person's details and contact information.
Person name	М	Details of the person's name
Person first name	M	The first name(s) of the person. This includes middle names.
Person family name	M	The family name or surname of the person
Person preferred name	R	The name by which a person wishes to be addressed. The preferred name
		volunteered by the person or a preferred name given by PDS that the person has
		asked to be called by.
Title	R	Person's title
Person name suffix	R	A textual suffix that may be added to the end of a PERSON's name, for example,
		OBE, MBE, BSc, JP, GM
Person full name	R	The full name of the person in text representation.
Date of birth	M	The date of birth of the person.
<u> </u>		····
$\langle \rangle$	~	
Gender	(_R)	The person's stated gender.
Ethnicity	R	The ethnicity of the person as specified by the person.
Religion	R	The religious affiliation as specified by the person.
Sex	Ö	The person's phenotypic sex. Determines how the person will be treated clinically \sim
NHS number	Ŷ	The unique identifier for a person within the NHS in England and Wates
	IX IX	The anique identifier for a person within the WHS III Eligiand and Wales.

Source: (Professional Record Standards Body, 2021b)

Data in 'gender' and 'sex' fields is now unreliable

- 2.4 NHS medical records use a range of different terms to record information about patients' sex and gender identity. Historically, the NHS used two data items:
 - a) 'Person Phenotypic Sex' (i.e. biological sex) this is now de-prioritised.
 - b) 'Person Stated Gender' (self-declared gender of the person).

³³ The NHS in Scotland has its own records management code of practice (Digital Health and Care Scotland, 2024), as does the NHS in Wales (Welsh government, 2022) and the Department of Health in Northern Ireland (Public Health Agency, 2023).

³⁴ (Professional Record Standards Body, 2021b)

Definitions for these data fields are set down in the NHS Data Dictionary, which is the reference source for data in the NHS in England. The possible responses that can be entered into these data fields according to the NHS Data Dictionary are shown in **Annex 4**.

- 2.5 In 2022, NHSE split the 'Person Stated Gender' item into three items:
 - a. Gender identity code ("gender identity of a person as stated by the person") this is now a priority data item
 - Gender identity same at birth indicator ("whether the patient's gender identity is the same as their gender assigned at birth") – this is now a priority data item
 - c. Person Stated Gender Code ("the self-declared gender of a person") this is now a low priority item because of concerns about the accuracy of the data.³⁵
- 2.6 NHSE said it made this change to:

"remove the **mixing of gender and sex registered at birth that exists in data** held within Person Stated Gender".³⁶ [Emphasis added]

2.7 In a similar vein, the NHS notes that:

"[in relation to] **Delivering clinically safe care to patients where sex-based characteristics are relevant**: All services should be asking all patients inclusive questions to identify relevant *care information. It is not safe to make assumptions about an individual using the Person Stated Gender code."³⁷ [Emphasis added]*

2.8 These statements acknowledge that information held in patient records (within the Person Stated Gender code) has, for some time, mixed up information about sex and gender identity and that this poses a safety risk.

Range of approaches to recording sex and gender identity

- 2.9 We have identified a range of different ways that NHS electronic patient record systems record sex and gender identity. These include:
 - a) a single 'gender' field (paragraphs 2.10-2.12)
 - b) both 'sex' and 'gender' data fields (paragraphs 2.13-2.18)

³⁵ Although it was de-prioritised, the Person Stated Gender data field was retained because it serves to match data held on the NHS Spine, and its retention helps avoid any potential issues with data linkages and matching.

³⁶ (NHS England (Digital), 2024)

³⁷ (NHS England (Digital), 2024)

- c) a single 'sex' field, which nonetheless may display 'gender' data drawn from another system (paragraphs 2.19-2.20)
- d) a pair of data items about gender identity which supposedly enable a patient's sex to be inferred (paragraphs 2.21-2.39)
- e) 'legal sex': one commonly used electronic system uses this term even though it does not appear in the NHS Data Dictionary and so should not be used (paragraphs 2.40-2.46).

We examine each of these ways of recording sex and gender identity below.

A single 'gender' field

2.10 Systems which use this approach have no data field for sex, and instead have a single data field using the ambiguous term 'gender'. According to the NHS data dictionary, information in a 'gender' field is self-declared (Annex 4). A single 'gender' field is the most common approach in operation. It is used by the National Care Record and the two largest records systems used by GPs in England (*EMIS* and *SystmOne*³⁸), see Figures 2, 3 and 4. A range of other NHS electronic systems also uses a single 'gender' field, including *Trakcare, Careflow, Nervecentre, PCMIS*, some versions of *Rio*, and local shared care records (see Annex 1).

Figure 2: National Care Record



Source: SEEN in Health/ Women's Rights Network member

³⁸ SystmOne is also used by some Community and Mental Health trusts.

Figure 3: EMIS (GP records)

ems	Carl Con	Notice Nector	tion Problems Investin	ations Care Histo	or Dian	Docu	EMIS Wel	Health Care System	n - THORPE	HESLEY SURGERY
C Add	Edit Consultatio	n stion Trend Co	B Show Time My reultations	Filters Search View	Print	CR Config	Search			
Mail Ink	AddEdit	art Management	View - 7 <u>SCR</u> - 3 <u>Test Rec</u>	Filter	Print	Config (9) Rec	Knowled	83 (22) <u>Tasks</u>	50 (22)	
•	New priority Work	flow Items receiv	ed - Tasks, Registration, GP	P2GP			(
2.	Active ¥ MC	IUSE, Mickey (N	*)		Born 2	9 May 1	989 (27y)	Gender Male	NHS NO.	999 999 9999

Source: (NHS, 2019)

Figure 4: SystmOne

Demographics	Practice Search Patient Details	Registration	
Changing patie SystmOne use	nt demographics using this screen will change them for all rs and may update Spine.	Registered practice	G X Barlby Surgery
NHS number	9990026122	Currently in arme	d forces Prisoner
Hospital number	S2861771	Other details	
Title	Ms	Marital status	
First name	Ebs-Donotuse	Ethnicity	British or mixed British - ethnic categor 🗣 💌
Middle name(s)	Donotuse	Occupation	Clinical Term C Free-text
Surname	Xxtestpatientaatb		
Gender	Female	Language	
Known as		English speaker	Unknown
Date of birth	04 Aug 1978 🔽 00:00 🔽 Approximate	Religion	

Source: (Leicestershire Health Informatics Service, 2020)

Problems with a single 'gender' field

2.11 In 2009, a report by an NHS working group on the digital recording of patient sex and gender identity warned:

"The term 'Gender' is now considered too ambiguous to be desirable or safe because different locations and systems use it to mean different things".³⁹ [Emphasis added].

2.12 Despite these concerns, we saw in Figure 1 that the Core Information Standard v.2.0 instructs that 'gender' is a 'Required' field in medical records, while the 'sex' data field is given no classification and is neither Mandatory, Required nor Optional. This implies 'sex' is not important, despite the Standard acknowledging that a patient's sex is used to guide the care they receive.

³⁹ (NHS Clinical User Interface Programme Team, 2009)

Both 'sex' and 'gender' fields

2.13 Some systems, such as Oracle, have 'sex' and 'gender' fields within the patient record (see Figure 5).

Figure 5: Oracle Cerner (as used by Royal United Hospitals Bath NHS Foundation Trust)

Allergies: Br.	CP-IS: Not Performed Weight:80 kg	Age:21 rs DOB: Phone:	Sex:Female MRN: NHS:
	1	· · · · · · · · · · · · · · · · · · ·	
Surname:			
Forename:			
Gender:			
Female Male			
Not Known Unspecified Age:			

Source: SEEN in Health/ Women's Rights Network member

Problems with both 'sex' and 'gender' fields

2.14 The 2009 NHS working group on digital recording of patient sex and gender identity warned of the risk of conflating sex and gender:

"Users may confuse the terms current gender and sex, or assume that they are synonymous. Therefore, it is essential that all NHS applications display and explain current gender and sex terminology and values in a clear and consistent manner."⁴⁰ [Emphasis added].

2.15 As noted above, the NHS acknowledges that data in the 'gender' data field already contains a blend of sex and gender identity information, (paragraphs 2.5-2.8). This data mixing arises in part because of ambiguity about the term 'gender', (paragraph 2.11). It also arises because patients can change the 'gender' shown on their medical record if they wish simply by asking their GP to make the change (paragraphs 2.47-2.54).

Patients can change the 'gender' shown on their medical record simply by asking their GP

⁴⁰ (NHS Clinical User Interface Programme Team, 2009)

- 2.16 In addition, data linkages exist between NHS systems whereby patient 'gender' data held in GP records is pulled through to populate data fields in hospital records systems which are sometimes marked 'sex'. This means a female who has changed the 'gender' in their GP record to male may incorrectly show as male on a hospital system which draws that data into a 'sex' field. This creates a patient safety risk for people with a trans identity, because their gender identity will be incorrectly displayed as their 'sex'.
- 2.17 The fact that a digital system has separate data fields for 'sex' and 'gender' cannot therefore be assumed to indicate those fields provide reliable information about the distinct attributes of sex and gender identity. Indeed, situations where a data field labelled 'sex' has been populated with 'gender' data may give false assurance to healthcare professionals about a patient's sex. In many cases, data linkages between IT systems mean the two fields ('sex' and 'gender') will simply reflect the same attribute, most commonly the patient's 'gender' as recorded in their GP record which, as we have noted, can be changed at patient request.
- 2.18 Some other data linkages cause data about sex to feed into a 'gender' data field. While data linkages which feed sex information into a 'gender' data field do not create a safety risk, such linkages ascribe a gender identity to patients who may not believe in gender identities or say they have one.

Single 'sex' field

2.19 Some versions of systems such as *Maxims* and *Expanse* have a single 'sex' field, see Figure 6.



Figure 6: Meditech Expanse (extract from ambulatory care user manual)

Source: (CARE 4, 2021)

Problems with single 'sex' field

2.20 As noted above, for some patients the sex data field is populated with information taken from a 'gender' field in another digital system, most often GP records (paragraphs 2.16-2.18). This data field does not therefore necessarily provide a reliable record of patient sex.

Gender identity data pair

2.21 In an attempt to preserve the privacy of trans-identifying patients who do not want their sex known, two data fields about gender identity were introduced in 2022: the 'gender identity code' and 'gender identity same at birth indicator'. This approach is used across a range of NHS data systems, including some versions of *Rio*, see Figure 7. Further instances of this approach are shown in Annex 2.

Figure 7: Rio (as used by East London NHS Foundation Trust)

How do you describe your gender?	Non-binary
Does your gender align with the sex you were assigned at birth?	Please Select Male (including trans man) Female (including trans woman)
What pronouns do you use?	Non-binary Gender fluid Self-described
Further information	Do not wish to share Not known (not recorded)

Source: (East London NHS Foundation Trust, 2023)

Problems with the gender identity data pair

2.22 This approach has three problems:

- There is no single data field which clearly and reliably shows patient sex. This increases the risk of confusion and creates avoidable clinical risk.
- ii. The sex of some patients cannot be inferred from the two gender identity data fields, leaving the sex of those people unknown. This creates avoidable clinical risk.
- iii. The purported benefits of using two gender identity fields are not delivered.

Further detail about these problems is set out below.

The sex of some patients cannot be inferred from the two gender identity data fields, leaving the sex of those people unknown

i) No single indicator of patient sex

- 2.23 The use of two data fields relating to gender identity means key information about patient sex is obscured. Healthcare professionals are forced to combine the information in the two gender identity fields to infer a patient's sex.
- 2.24 This use of two variables (gender identity, and gender identity same at birth) to determine a third variable (sex) is illogical, unwieldy and relies on accurate interpretation by individual clinicians.
- 2.25 Usability is a measure of the quality of a user's experience when interacting with a system. Academic research has found that:

"Poor usability is a primary cause of unintended consequences related to the use of electronic health record (EHR) systems, which negatively impacts patient safety".⁴¹

2.26 The same researchers went on to say that:

"Recent evidence suggests that poor usability in EHRs is associated with an increase in clinicians' cognitive workload, EHR-related fatigue, burnout, work inefficiency...To optimize the benefits of EHRs for clinicians and avoid any unintended consequences that adversely impact patient safety, it is **imperative to establish a system's usability before its widespread implementation in real-world practice**."⁴² [Emphasis added].

2.27 In 2019, the lead designer for the NHS website acknowledged this concern when he said that: "Usability is a clinical safety issue".⁴³

Usability is a clinical safety issue

2.28 The use of two gender identity variables to indicate a patient's sex increases cognitive workload for clinical staff who may already be struggling with heavy workloads and long hours - this in turn increases the risk of error in clinical decision-making. And while the NHS clearly recognises the importance of usability, it is unclear how much, if any, usability testing was performed before the decision was made to introduce this significant change. It is important that any future changes the NHS makes to the recording of sex and gender identity, as recommended in this report, are subject to appropriate testing.

⁴¹ (Cho *et al.,* 2022)

⁴² (Cho *et al.*, 2022)

⁴³ (NHS England, 2019b)

ii) Sex of some patients cannot be inferred from the two gender identity data fields

- 2.29 It is not possible to infer the sex of all patients from the two gender identity data fields. Some people, including politicians, believe there are a large number of possible gender identities.^{44,45} Clinicians will be unable to infer sex from this data pair if the patient claims an identity not listed, or if they have a non-binary identity. And if, as some people claim, gender identity is fluid, medical records may not reflect a patient's current identity. **Figure 8** shows that the gender identity data pair is insufficient to infer a patient's sex if any of the following apply:
 - Patient does not have a gender identity
 - Patient's gender identity is non-binary
 - Patient's gender identity is not listed i.e. identity is not 'male including trans man' or 'female including trans woman', or
 - Patient's gender identity is not recorded for any other reason.
- 2.30 The guidance is also silent on how this approach indicates the sex of someone with a difference of sexual development (DSD) whose sex may differ from that recorded on their birth certificate.
- 2.31 The guidance advises 'patient assessment' in instances where a patient's sex cannot be inferred from the gender identity data pair. However, the guidance is silent about how healthcare professionals should go about this assessment, and it acknowledges that asking patients directly about their sex may be difficult:

"non-binary individuals actively do not wish to be considered within the binary protected characteristic of sex and may decide not to answer any questions that cover this area. It was through engagement that it was established that non-binary people were likely to reject a direct sex question and including one could mean that cohort disengaging and rejecting to answer any of the questions on gender."⁴⁶

- 2.32 It may be difficult to determine a patient's sex through clinical observation while also maintaining patient dignity and showing sensitivity and respect to the patient. This is particularly true for some patients who present as non-binary or who have had gender surgery and who do not want to talk about their sex.
- 2.33 Furthermore, in some situations, such as a patient being unconscious, rendered incoherent by dementia, alcohol or drugs, or unable to speak English, asking a patient may not be a feasible

⁴⁴ (Sanderson, 2022)

⁴⁵ (Sanderson, 2024)

⁴⁶ (NHS England (Digital), 2024)

or reliable way to confirm their sex. In an emergency, where seconds can make the difference between life or death, clinicians should not be forced to make clinically important assumptions about a patient's sex based on their appearance. If a patient's sex is ambiguous or their sex is wrongly recorded or not recorded in medical records, there could be misdiagnosis and the patient may not get the correct emergency treatment, with potentially life-threatening consequences.

Gender identity code (as per NHS data dictionary)	Gender identity same at birth indicator (as per NHS data dictionary)	Conclusion which may be drawn about a patient's sex (authors' analysis)
Male (including trans man)	Yes – the person's gender identity is the same as their gender assigned at birth	Male
	No – the person's gender identity is not the same as their gender assigned at birth	Female
Female (including trans woman)	Yes – the person's gender identity is the same as their gender assigned at birth	Female
	No – the person's gender identity is not the same as their gender assigned at birth	Male
Non-binary	Yes – the person's gender identity is the same as their gender assigned at birth	Data gives no indication about sex
	No – the person's gender identity is not the same as their gender assigned at birth	Data gives no indication about sex
Other (not listed)	Yes – the person's gender identity is the same as their gender assigned at birth	Data gives no indication about sex
	No – the person's gender identity is not the same as their gender assigned at birth	Data gives no indication about sex
X - Not known (not recorded)	Yes – the person's gender identity is the same as their gender assigned at birth	Data gives no indication about sex
	No – the person's gender identity is not the same as their gender assigned at birth	Data gives no indication about sex
Z - Not stated (person asked but	Yes – the person's gender identity is the same as their gender assigned at birth	Data gives no indication about sex
a response)	No – the person's gender identity is not the same as their gender assigned at birth	Data gives no indication about sex

Figure 8: Conclusions to be drawn about patient sex from gender identity data pair

Source: Authors' analysis

iii) Purported benefits of the two gender identity fields are not delivered

2.34 NHSE claims that gathering data about the pair of gender identity items (Gender Identity Code, and Gender Identity Same at Birth Indicator) has the following benefits:

"The new data items to record Gender Identity Code and Gender Identity Same at Birth Indicator enable more inclusive recording of gender identity while also more clearly identifying gender at birth for cisgender and transgender patients."⁴⁷ [Emphasis added].

"Gathering information on gender identity and trans identity is important to allow us to better understand health inequalities. By collecting this data, services can provide more personalised care to patients, as well as better understand trans and non-binary people's experiences, outcomes, and inequalities at a local system level."⁴⁸ [Emphasis added].

2.35 Most importantly, NHSE claims this approach meets patients' wishes and enables better patient care:

"[the] two new data items, which relate to gender identify [sic] and gender at birth... together aim to better capture how patients would like their gender and sex to be recorded. They will also support services on how to better care for their patient."⁴⁹ [Emphasis added].

2.36 Figure 9 shows that none of these claimed benefits is being fully realised, and in many instances the use of the two gender identity data fields is causing harm or disadvantage.

⁴⁷ (NHS England (Digital), 2024)

⁴⁸ (NHS England (Digital), 2024)

⁴⁹ (NHS England (Digital), 2024)

Figure 9: Assessment of benefits claimed for new gender identity data fields

Benefit claimed by NHSE	Is the claimed benefit being delivered?				
"support services on how to better care for their patient."	No Creates avoidable patient safety risk for those patients whose sex remains unknown under this approach (see Figure 8). This situation is worse not better than if a clear record of sex were maintained. 				
"more clearly identifying gender at birth for cisgender and transgender patients" In the context of the wider quote (see paragraph 2.34), 'gender at birth' appears to mean sex.	 No Fails to clearly identify patient sex: No single, clear 'sex' data field. For some patients their sex cannot be inferred from the information gathered (see Figure 8). 				
"more inclusive recording of gender identity"	 Partially Improved recording of gender identity for people who have a gender identity, but Presumes everyone shares the belief in gender identity which is not the case. It is not inclusive to ascribe to individuals an identity that they do not have. 				
"better capture how patients would like their gender and sex to be recorded"	 No Sex is not recorded. Some patients are ascribed a gender identity they do not have. There is no evidence presented that this approach captures how all patients would like their gender identity (if they have one) and their sex recorded. 				
allows us "to better understand health inequalities"	No • Understanding health inequalities relies on good data. This approach undermines the quality of data on the protected characteristics of 'sex' and 'gender reassignment', thereby weakening the insight into health inequalities (because there is no sex data field, and sex can't be inferred for some patients).				
"more personalised care to patients"	 Partially Clear information about a person's gender identity, if they have one, can help clinicians engage with the patient in a way they prefer. However The ability to give personalised care is undermined because medically relevant information about sex is not clearly recorded and historical medical records may no longer be accessible for trans identifying patients (see paragraphs 2.46-2.53). Using clinical assessment to determine sex may be experienced as intrusive by patients. 				
"better understand trans and non-binary people's experiences, outcomes, and inequalities at a local system level"	 No For some patients their 'sex' cannot be inferred from the information gathered (see Figure 8). This undermines the NHS's ability to draw meaningful conclusions about patient outcomes and inequalities at a local system level. When new patient records are created without links to previous records (see paragraphs 2.46-2.50), information relevant to patient outcomes is lost. 				

Source: Authors' analysis

- 2.37 We have seen that the use of two gender identity data items to infer a patient's sex decreases clinical usability, increases patient safety risk (since sex cannot be deduced for all patients), and does not deliver its purported benefits.
- 2.38 We are also concerned about public comprehension of these gender identity questions, particularly when under pressure e.g. during an emergency. The issues around public comprehension of the question on gender identity in the 2021 Census are noted above (paragraph 1.23), and we are concerned that a similar risk may exist with this pair of questions which are now widely used in the NHS.
- 2.39 We are not aware of any work NHSE carried out to test how easy these questions are for patients to comprehend and therefore answer accurately. We asked NHSE for the equality impact assessment relating to the introduction of the questions about gender identity, but it said it did not hold this information. In its response to our Freedom of Information request, NHSE noted it had engaged with its LGBT health team about the questions, and it reiterated the purported benefits set out in Figure 9 which we have shown have not been delivered.⁵⁰

Legal sex

2.40 The EPIC digital system is used by many acute hospital trusts. EPIC gives priority to what it calls 'legal sex', see **Figure 10**. EPIC defines 'legal sex' as a patient's sex as listed on official documents.

Problems with 'legal sex'

- 2.41 The sex marker on UK passports and drivers' licences can be changed without a Gender Recognition Certificate. ^{51, 52} This means therefore that within EPIC records, 'legal sex' for trans-identifying patients who have changed their official documents actually represents self-declared gender identity.
- 2.42 'Legal sex' is not a term used in the NHS Data Dictionary so it should not be used in NHS medical records. Legal sex may or may not reflect the patient's biological sex – it therefore has little utility for healthcare purposes.

'Legal sex' is not used in the NHS data dictionary so should not be used in NHS medical records

⁵⁰ (NHS England, 2025)

⁵¹ (UK Government, 2024a)

⁵² (UK Government, 2024b)







Source: SEEN in Health/ Women's Rights Network member

2.43 Clinician-facing (rather than patient-facing) versions of EPIC contain a data field for 'sex assigned at birth', see Figure 10. Although the terminology 'assigned at birth' is factually inaccurate, this field should be the most clinically valuable information since it ought to be an accurate record of biological sex. However, this will only be the case if this field is not populated by 'gender' data from another digital system (see paragraphs 2.16-2.18).

2.44 **Figure 11** shows that a male with a trans identity will show as 'female' on the face of their EPIC record. It is only by hovering over the small 'i' symbol next to the word 'female' that a healthcare professional can access further detail showing that the patient is in fact male. It is dangerous to show male patients as 'female' on patient records.

It is dangerous to show male patients as 'female' on patient records

Figure 11: extract from EPIC test environment showing sample record for trans identifying male (as used by Cambridge University Hospitals NHS Foundation Trust)

 'Female' with the 'i' following, means the person with the legal name David Apricot identifies as female, and in this case, that their preferred name is Davina Peach.



 Hover over the 'i' for more details, e.g. David Apricot was assigned male at birth but now identifies as female, and goes by the name of Davina Peach.



Source: SEEN in Health/ Women's Rights Network member

N.B. This graphic does not contain real patient data.

2.45 Figure 12 shows that a healthcare professional needs to hover over the small 'i' symbol to bring up information showing that a patient with a trans identity recorded as 'Other', is in fact female; the patient's sex is not clearly shown on the face of the record. Clinicians need ready access to information about a patient's sex - they should not have to go hunting for it.

Clinicians need ready access to information about a patient's sex they should not have to go hunting for it

Figure 12: extract from EPIC test environment showing sample record for female with a gender identity listed as 'other' (as used by Cambridge NHS Foundation Trust)



Source: SEEN in Health/ Women's Rights Network member

N.B. This graphic does not contain real patient data.

2.46 **Annex 3** shows other examples of EPIC in use in the NHS, including a version which uses terms like 'transgender female' which are very unclear: is a transgender female a female with a trans identity, or a male with a trans identity? These confusing terms create a patient safety risk.

Confusing terms create a patient safety risk

Case study

A paramedic told us, "An update to our electronic patient care records system means it now describes patients as male (including transgender male) or female (including transgender female) and I have personally had several instances where this has been confusing.

"Our first job is to correctly identify our patient and although this seems minor, it can cause confusion and uncertainty in emergency situations where every second counts.

"More importantly, there are medical conditions that will be present or more likely, in one sex than the other. For example, symptoms of a myocardial infarction [heart attack] often differ in men and women — and as first responders, we look for signs and symptoms to help identify a likely cause and therefore an appropriate treatment plan.

"If we are treating a patient with sudden onset abdominal pain, if the patient presents as male and our paperwork states "male (including transgender male)", would we suspect pregnancy-related issues and, crucially, would we ever ask these necessary questions to allow the patient to receive the correct treatment? This is particularly an issue if the patient isn't forthcoming about their transgender status."

Patient ability to change what is recorded

- 2.47 At birth, babies born in England are given a 10-digit NHS number which is used throughout life to match individuals to their unique NHS medical record. However, any NHS patient of any age, including children, can change their 'gender' on their patient record simply by asking their GP surgery to do so – and this will generate a new NHS number.⁵³
- 2.48 Patients are not required to have undergone any gender-related surgery or hormone treatment to change their medical record in this way, and there is no legal requirement for GP practices to request evidence for a name change.⁵⁴ There is no limit to the number of times a patient can

⁵³ Patients in Scotland are also able to change the gender shown on their medical record (NHS National Services Scotland, 2021) as are patients in Wales (Public Health Wales, 2024) and Northern Ireland (Public Health Agency, 2023).

⁵⁴ (Primary Care Support England, 2024a)
change the gender shown on their health record, and each change of gender results in the issuing of a new NHS number, unless the patient opts to keep their existing NHS number.

- 2.49 According to the process set out by Primary Care Support England (PCSE), the GP practice should register the patient making this request as a new patient, issue them with a new NHS number and transfer the patient's previous medical information to a new medical record with the exception of any information relating to the patient's previous identity and any gender-specific terms.⁵⁵ The PCSE's guidance states "Any information relating to the patient's previous identity should not be included in the new record."⁵⁶
- 2.50 NHSE's Records Management Code of Practice takes a slightly different approach and places more weight on discussing with the patient what medical information is transferred, although the patient's wishes about what is contained on their new record are still paramount. It states:

"Discussions will take place between the GP and the patient regarding clinical care, what information in their current record can be moved to their new record and any implications this decision may have (for example, they may not be called for a gender specific screening programme). Patients should be offered ways to maintain their historical records. This could include editing previous entries and removing references containing previous names and gendered language. Any decisions made regarding their record must be respected and the records actioned accordingly".⁵⁷

- 2.51 Newly allocated NHS numbers are not linked to a patient's previous NHS number⁵⁸ and changes made from the old record are not tracked. This means there is no record of what information has changed or how it has changed. This process contrasts with the approach used when an adopted child is given a new NHS number; in these cases, NHSE guidance requires that the child's pre- and post-adoption medical records are merged to provide a continuous health record for the purpose of "protecting their health and wellbeing".⁵⁹
- 2.52 The new GP record contains the new gender marker. PCSE advises GP practices to: "select either 'M' for Male or 'F' for Female."⁶⁰ Elsewhere, PCSE guidance also indicates that patients may ask for their gender to be recorded as 'indeterminate'.

⁵⁵ (Primary Care Support England, 2024b)

⁵⁶ (Primary Care Support England, 2024b)

⁵⁷ (NHS England, 2023)

⁵⁸ (Primary Care Support England, 2024b)

⁵⁹ (NHS England, 2024b)

⁶⁰ (Primary Care Support England, 2024a)

- 2.53 An investigation by The Sun newspaper found that at least 482 males were admitted to hospital in the year to March 2024 for health conditions experienced only by men whilst their medical records recorded them as female.⁶¹
- 2.54 In other contexts, patient requests for factually accurate and clinically relevant information to be removed from medical records are denied, in order to preserve the integrity of the record. The arrangements described above are unique to people seeking to change their recorded 'gender'. No other patient group can request changes to their medical records unless there is an inaccuracy or omission.^{62,63}

How did we get here?

- 2.55 None of the five ways we have found that the NHS uses to record sex and/or gender identity (see paragraphs 2.9-2.46) provides a clear, reliable and readily accessible record of patient sex. The recording of gender identity if a patient has one is justifiable and has utility in healthcare provision. However, the NHS's decision not to operate systems which maintain an accurate and reliable record of sex alongside gender identity is puzzling given the salience of sex to patient safety.
- 2.56 The explanation for this position may lie in guidance from the PRSB which suggests that collecting data on both sex and gender identity could lead to accidental disclosure of a patient's gender reassignment:

"Sex and gender data items may cause accidental disclosure of gender reassignment without consent...Having both may show a difference and therefore disclose gender reassignment without consent. It is **unlawful to disclose, without consent, a person's gender reassignment** with or **without** a gender reassignment [sic] certificate. Section 22 of the Gender Reassignment [sic] Act 2004 makes it **an offence to disclose the history of a transgender patient** who has had formal gender reassignment under the Act, unless consent has been sought."⁶⁴ [Emphasis added].

2.57 It is not clear what the PRSB means by "formal gender reassignment under the Act": this wording appears to confuse protections offered by the Equality Act 2010 with protections under the Gender Recognition Act 2004. It is possible for an individual to have the protected

⁶¹ (Godfrey, 2024)

⁶² (Medical Defence Union, 2021)

⁶³ (Medical Protection, 2020)

⁶⁴ (Professional Record Standards Body, 2021a)

characteristic of gender reassignment (as defined in the Equality Act 2010, see paragraph 1.11) without that individual holding a Gender Recognition Certificate (GRC). The formal protections under the Gender Recognition Act 2004 apply only to the approximately 9,000 people with a GRC,⁶⁵ not those without such a certificate.

- 2.58 The PRSB's claim that it is unlawful to disclose without consent a person's gender reassignment status if that individual does not have a GRC is incorrect. There is no blanket prohibition on disclosure without consent of a person's gender reassignment status if the individual does not have a GRC. For example, case law relating to private information suggests that in the absence of a GRC, there may be situations where it is proportionate and justified to disclose someone's trans status, such as when the rights of others might depend on disclosure.⁶⁶
- 2.59 It is concerning that a health standards-setting body is making inaccurate claims about the law. A new iteration of the PRSB guidance is now overdue, and the next version of the guidance provides an opportunity for the PRSB to address this error.

It is concerning that a health standards-setting body is making inaccurate claims about the law

- 2.60 The PRSB notes that a legal exemption exists permitting healthcare professionals to disclose protected information⁶⁷ for medical purposes if the patient consents or if they are unable to consent (for example, if they are unconscious).⁶⁸ Unfortunately, this legal exemption does not extend to NHS administrative staff such as triage staff and those who work in digital teams who also routinely need to handle patient data.
- 2.61 Some people with a trans identity appreciate the importance of their healthcare provider knowing their sex and consent to the sharing of this information between the professionals delivering their care. The protection against disclosure offered by the Gender Recognition Act therefore only serves the small group of trans-identifying people who hold a GRC, have capacity, and who do not consent to their healthcare providers knowing their sex. This group amounts to fewer than 9,000 people.⁶⁹ It is astonishing that the NHS has undermined patient safety by changing the way medical records are kept for all patients in England so as to avoid

⁶⁵ (Ministry of Justice, 2024)

⁶⁶ Such instances might include the provision of same sex hospital accommodation or responding to requests for same-sex care.

⁶⁷ Protected information in this case is information about the person's sex and the fact that they hold a GRC.

⁶⁸ (The Gender Recognition (Disclosure of Information) (England, Wales and Northern Ireland) (No. 2) Order, 2005)

⁶⁹ The number of people with a GRC as at September 2024 was 9,055 (source: see footnote 65). Excluding those who consent to their healthcare providers knowing their sex, and also excluding those without capacity (for whom there is a legal exemption) it is reasonable to assume the figure is less than 9,000 people.

disclosing the gender reassignment status of a few thousand people in confidence to their healthcare provider.

2.62 The PRSB proposes solutions to the problem of accidental disclosure about a person's gender reassignment which include the following:

"One option is to leave out the 'Sex' field but **the implications and potential risks of that will need to be considered**."⁷⁰ [Emphasis added]

- 2.63 In practice, this is indeed what has happened the sex field has been left out of many NHS data systems but without appropriate consideration of the risks.
- 2.64 Although the PRSB acknowledges the general risk of omitting the 'sex' data field, the accompanying Clinical Safety Case Report fails to explore this risk in any detail. Indeed, the PRSB passes responsibility for addressing the very serious risks arising from this decision to other un-named organisations responsible for setting national policy. The PRSB simply states the need for:

"Clarity in national policy regarding the recording of 'sex' and 'gender' in [electronic health records] with due regard for the practical risks posed in clinical practice to patients, practitioners and healthcare providers."⁷¹

- 2.65 Despite the critical importance of 'sex' data to the provision of safe healthcare, we have been unable to locate any current national policy on the recording of sex and gender identity which addresses these risks and/or proposes clear measures to safeguard patient safety. For example, neither the NHSE Records management code of practice⁷² nor the NHSE webpage setting out the approach to the recording of gender identity, where one might reasonably expect to find such information, addresses this clear risk to patient safety.
- 2.66 NHS staff are extremely uncertain about the law in this area, and professional caution borne from fear of breaking the law is hampering safe and efficient care of patients. NHS staff and their employers urgently need a clear and accurate exposition of the law as well as practical guidance on the handling and confidential sharing of patient data on sex and gender identity for trans-identifying patients both with and without a GRC.

⁷⁰ (Professional Record Standards Body, 2021a)

⁷¹ (Professional Record Standards Body, 2019)

⁷² (NHS England, 2023)

Summary of NHS approach to recording sex and gender identity

- 2.67 As we have seen, the NHS recognises the importance to healthcare of knowing a patient's sex (paragraphs 2.3 and 2.7), and the important difference between 'sex' and 'gender identity' (paragraphs 2.6 and 2.14). The NHS acknowledges the ambiguity of the term 'gender' and therefore the risk of using it in patient records (paragraph 2.11). The NHS also understands that the usability of electronic medical records contributes to safe care (paragraphs 2.25-2.28).
- 2.68 And yet, despite this knowledge, the NHS has nonetheless prioritised data about 'gender' and self-reported 'gender identity' over information about patient sex. Furthermore, the NHS has allowed patient data to become corrupted through:
 - the blending of information about sex and gender identity within the 'gender' data set (due to the ambiguity of the term 'gender')
 - the feeding of 'gender' data into 'sex' data fields (and vice versa) as data is transferred between IT systems, and by
 - allowing patients to change their recorded 'gender' in medical records (see paragraphs 2.47-2.54).
- 2.69 A range of different approaches are in operation. These include the recording of 'legal sex' a term which should not be used as it does not appear in the NHS data dictionary. Perhaps even more concerning is the introduction of the pair of questions about gender identity from which patient sex can sometimes but not always be inferred. We have grave concerns about the safety of this approach, and the lack of an equality impact assessment (paragraph 2.39) suggests the widespread and significant implications of this change for all patients were not considered. We are also concerned about the reliability of national NHS data sets created from the aggregation of data gathered using these different approaches.
- 2.70 The current position is incoherent and unsafe. A variable as clinically important as sex should never have been de-prioritised. The blending of data on sex and gender identity is a clear failure of data safeguarding and it should never have been allowed to happen.

A variable as clinically important as sex should never have been de-prioritised

2.71 There are further aspects of the NHS's approach to sex and gender identity which are concerning. The current approach:

- incorrectly presumes that everyone shares a belief in gender identity (paragraphs 2.72-2.75)
- uses sex terms for gender identity, erroneously implying it is possible to change sex (paragraph 2.76)
- uses medically inaccurate terminology (paragraphs 2.77-2.78).

These are considered in turn below.

Presumption that everyone shares the belief in gender identity

2.72 The NHSE webpage on gender identity states:⁷³

"Gender identity is a way to describe a person's innate sense of their own gender, whether male, female, or non-binary, which may not correspond to the sex registered at birth. Gender identity should not be confused with registered sex at birth, or with sexuality or who someone is attracted to...For many, but not all people, the sex they were registered at birth is the same as their current gender...It is also important to distinguish between gender identity (which everyone has as per definitions above) and being trans..." [Emphasis added].

2.73 Contrary to NHSE's assertion (see paragraph above), there is no evidence that everyone has a gender identity, and indeed many people say they do not have one. A recent public consultation run by the Department for Education recognised this when it said:

"the belief that a person can have a 'gender', whether male (or 'man'), female (or 'woman'), or 'other', that is different to their biological sex...is a contested belief. Many people believe this concept is one that reinforces stereotypes and social norms relating to sex."⁷⁴

- 2.74 Guidance from the Office for Statistics Regulation advises producers of statistics (which includes the NHS) to consider whether their data collection on gender identity should include a response option for individuals who do not consider themselves to have a gender identity.⁷⁵
- 2.75 In an attempt to accommodate the wishes of patients who claim a gender identity, the NHS has ignored the wishes of those who do not have a gender identity. There is also a risk that by ascribing a gender identity to people who do not believe in gender identities the NHS may be discriminating on the grounds of belief under the Equality Act 2010.

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The current approach incorrectly presumes that everyone shares a belief in gender identity

⁷³ (NHS England (Digital), 2024)

⁷⁴ (Department for Education, 2023)

⁷⁵ (Office for Statistics Regulation, 2024a)

Use of sex terms for gender identity

2.76 According to the NHS data dictionary, the information that can be entered into the 'Gender Identity Code' field includes the terms 'male' and 'female' (see **Annex 4**). The terms 'male' and 'female' refer to sex, not gender identity. It is a matter of fact that humans cannot change sex. Using these terms to denote gender identity could be interpreted as the NHS endorsing the erroneous notion that it is possible to change sex.

This could be interpreted as the NHS endorsing the erroneous notion that it is possible to change sex

Medically inaccurate terminology

- 2.77 Some NHS data systems use the phrase: "sex assigned at birth" (see Figure 7, *Rio* and Figure 10, *EPIC*) as does NHS Blood and Transplant.⁷⁶ This is inaccurate. Clinicians do not 'assign' a sex to babies sex is observed at birth, and indeed it is often observed in utero, well before birth.
- 2.78 The NHS Data Dictionary uses the phrase "gender assigned at birth" (see Figure 25), and the NHS website talks about "gender at birth" (see paragraph 2.34). Under the NHS's own definition gender identity is something individuals self-declare (see Annex 4). Therefore 'gender assigned at birth' is meaningless since clinicians should not (and do not) assign something that can only be self-declared.

⁷⁶ (NHS Blood and Transplant, 2024)

3. Developments in national and international standards on healthcare data

- 3.1 The Data (Use and Access) Bill is currently going through Parliament.⁷⁷ Among other things, this bill will enable the Secretary of State for Health and Social Care to set minimum standards for providers of IT systems used in the NHS, to improve interoperability. It is essential that this legislation and the associated standards mandate the clear and accurate recording of patient sex, and that any separate requirement for the recording of gender identity includes the option for patients to record that they have 'no gender identity'.
- 3.2 Health Level Seven (HL7) is a range of global standards for the transfer of clinical and administrative health data between digital systems. The aim is to ensure digital systems can communicate with each other and ensure healthcare data is processed consistently.⁷⁸
- 3.3 HL7 International, the body which develops these standards, is currently running a project on gender harmony.⁷⁹ It is important that the UK participates actively in this project to ensure patient safety is prioritised specifically through the clear recording of sex. It is also important that this international standard is informed by UK law around the protected characteristic of belief and includes the option for patients to ask for 'no gender identity' to be recorded.

⁷⁷ (Data (Use and Access) Bill, 2024)

⁷⁸ (Wikipedia, 2024)

⁷⁹ (HL7 International, 2023)

4. Impacts of current NHS approach

4.1 The most significant and worrying impacts of the NHS's muddled approach to recording sex and gender identity are the serious risks it poses to patient safety and safeguarding. However, the current approach also undermines public trust and confidence and is neglectful of front-line staff delivering care. There are further negative impacts on research, policy making and implementation. It may also be unlawful.

Risks patient safety

Risks arising from confusion about a patient's sex

4.2 Very serious patient safety risks can arise in situations when information about a patient's gender identity is mistaken for information about their sex.

Systems which use 'gender' or 'legal sex'

4.3 Where digital systems use 'gender' or 'legal sex' the risk that a clinician misunderstands a patient's sex is greatest for those patients with a gender identity that does not align with their sex, for example, someone who is female but identifies as a man and whose medical record shows their 'gender' as male. For these patients, what is labelled as 'sex' or 'gender' in their medical record may be their gender identity, and their sex may not be recorded at all.

Case study

A GP told us, "A patient presented with one-sided back pain. They had a beard, a deep voice and there was nothing in their notes to indicate they were female or using testosterone. Nor did they provide this information when I asked about their medical history.

"As they reported a past history of kidney stones I referred them for a renal ultrasound scan — and was surprised when the results reported the presence of a uterus and ovaries.

"In this case, the lack of accurate information on the patient's sex caused no harm, but it did make me concerned about what would have happened if the patient had presented with abdominal pain because I would not have considered female disorders such as ectopic pregnancy or ovarian cancer and would not have done the correct tests to rule them out."

Systems which use the gender identity pair

- 4.4 For digital systems which use the gender identity data pair, clinical risks can arise for people who have a gender identity other than "male including trans man" or "female including trans woman", or for people who have no gender identity. This is because their sex cannot be inferred from the available information (see Figure 8).
- 4.5 Incorrect or missing information about a patient's sex can result in the patient being given the wrong diagnosis, treatment or medication.⁸⁰ Misunderstanding someone's sex can make it harder to match a patient with their samples, letters and diagnostic images and other information. It also risks failure in communication between healthcare staff during a patient referral, clinical handover or multi-disciplinary team discussion. These risks are acknowledged but have not been addressed in current NHS guidance.⁸¹

Case study

A GP told us, "A 72-year-old male who identified as a transgender woman, but had not undergone any genital surgery, needed investigation for lower urinary tract symptoms.

I requested tests which included testing for Prostate Specific Antigen, a male-only test. The laboratory repeatedly discarded the patient's blood sample as the patient's NHS notes stated they were female. This happened despite the clinical section of the form clearly stating, with the patient's consent, that the patient was male and identified as a transgender women."

- 4.6 Attempts to introduce a supposedly 'trans inclusive' approach to medical records is putting trans-identifying patients at risk of serious harm. It is not clear what measures, if any, are in place across the NHS to monitor these risks, but there are already documented examples of patient harm occurring in the UK and globally as a result of confusion about the sex of patients with a trans identity:
 - A 32-year-old trans-identifying female attended an emergency department with severe abdominal pain. The patient's electronic medical record said the patient was male. As a result, diagnosis and care for cord prolapse was significantly delayed and the patient later gave birth to a baby who was stillborn.⁸²

⁸⁰ (NHS Clinical User Interface Programme Team, 2009)

⁸¹ (NHS Clinical User Interface Programme Team, 2009)

^{82 (}Stroumsa et al., 2019)

- A 33-year-old trans-identifying female experienced a delay of many months in being listed for a kidney transplant when their kidney function was assessed using the diagnostic range for their self-declared gender identity rather than their sex.⁸³
- A number of radiation incidents have been reported in the UK involving patients with a trans identity. These include a trans-identifying female who presented as male and whose NHS medical record indicated they were male. The patient was pregnant and the foetus was exposed to potentially harmful ionising radiation in error.⁸⁴
- 4.7 In addition, there are documented examples of patient harm 'near misses':
 - A 40-year-old trans-identifying female presenting with severe vaginal haemorrhage was nearly given the wrong blood transfusion (un-crossmatched type O, Rhesus D positive Red Blood cells) because their records showed them as male.⁸⁵ The incongruence between the patient's sex and gender identity was spotted when the blood service queried the order for a male patient on a gynaecology ward. The blood units were then switched for Rhesus D negative.⁸⁶
 - A trans-identifying female preparing to have a hysterectomy as part of gender-related surgery was found to be five-months pregnant.⁸⁷
- 4.8 These are publicly documented examples. In addition, we are aware of many other examples where front-line NHS clinicians have witnessed similar situations of harm, near misses of harm, or sub-optimal care and experience for patients with a trans identity which arise directly from the lack of accurate sex markers in patient records. Some of these examples are presented as case studies in this report.

Risks arising from new NHS medical record

- 4.9 We have described the process whereby an entirely new medical record is issued when a patient asks to change their 'gender' on their record (see paragraphs 2.47-2.54). Creating a new medical record directly undermines patient safety in three ways:
 - Loss of medically relevant information
 - Incorrect laboratory reference ranges used to interpret test results

⁸³ (Whitley and Greene, 2017)

⁸⁴ (NHS Ayrshire & Arran, 2018)

⁸⁵ Giving Rhesus D positive blood to a woman with Rhesus D negative blood type can cause serious harm to a foetus if in future that woman becomes pregnant.

⁸⁶ (Mays *et al.*, 2018)

⁸⁷ (Squires, 2024)

• Loss of invitations to sex-based health screenings.

Loss of relevant medical information

4.10 Unless the patient making a request to change their gender gives their explicit consent, information relating to their previous identity and any gender-specific terms are excluded from their new medical record (see paragraphs 2.47-2.51). This means important information about any gender dysphoria, cross-sex hormone treatment, gender-related surgeries and any associated health conditions may be lost. Details of any conditions relating to the sex organs or sex-specific cancers may also be lost. This creates a patient safety risk by impairing future clinical decision-making. It may also undermine continuity of care for trans-identifying patients.

Case study

A GP told us, "A 43-year-old patient presented with what they described as a thick, white and sometimes offensive vaginal discharge. This had previously been diagnosed as thrush via a phone consultation, but despite treatment symptoms had persisted for several weeks

"On examination there was visible scarring in the perineal area and the patient confirmed they had undergone a vaginoplasty — a procedure which inverts penile tissue to create a faux vagina. This had been done privately, was not mentioned in their record, and the patient declined to provide any details.

"The area was too painful to allow any further investigation, but there was visible faecal matter, which indicated a fistula between the anus and neo 'vagina' and the patient was prescribed antibiotics.

"The lack of information about their procedure, and NHS notes which did not show the patient's correct sex, led to a delay in making a correct diagnosis and referral to a urological surgeon."

Incorrect laboratory reference ranges and risk algorithms

- 4.11 The 'gender' data field in primary care records informs the laboratory reference ranges which are used to interpret some diagnostic tests. Here the most concerning risk is that an abnormal reading may go undetected if the reading falls within the normal range when assessed based on self-reported 'gender' rather than the patient's sex (paragraphs 1.18 and 4.6).
- 4.12 A similar concern exists in the application of sex-based risk algorithms such as QRISK which is used to assess risk of cardiovascular disease. If the wrong sex is used in the algorithm the

patient's risk of cardiovascular disease will be misunderstood which may lead to incorrect preventative advice such as whether or not to start taking a statin.⁸⁸

Loss of invitations to sex-based screenings

- 4.13 The NHS runs several population-based screening programmes. The 'gender' data field in primary care records is used to invite people to the appropriate sex-based health screening programmes (cervical cancer and breast cancer for women, abdominal aortic aneurysm for men).
- 4.14 When patients change their 'gender' on GP records, they can request sex-specific health screenings, but they do not automatically receive invitations to all the health screenings appropriate to their sex like other patients do. For example:⁸⁹
 - Trans men whose sex is female but whose 'gender' is registered with their GP as male are not routinely invited for cervical cancer screening.
 - Trans women whose sex is male but whose 'gender' is registered with their GP as female are not routinely invited for abdominal aortic aneurysm screening.
- 4.15 The NHS does not ask other patient groups to take personal responsibility for securing invitations to screening programmes. This shift of responsibility puts trans-identifying patients at a distinct disadvantage compared with other patients and may put NHS providers at risk of claims for discrimination.

Undermines safeguarding

- 4.16 When patients change their gender on their medical record, they are issued with a new NHS number. The Cass Review of Gender Identity Services for Children and Young People reported that safeguarding professionals had described a range of situations where this put vulnerable children/young people at risk.⁹⁰ These included:
 - Children and young people being lost to follow up
 - Children and young people with a safeguarding history presenting to the emergency department, but staff having no knowledge of that history because it was not included in their new medical record
 - Records of previous trauma and/or physical health being lost
 - People without parental responsibility changing a child's name and gender

⁸⁸ (NHS Winchmore Hill Practice, 2021)

⁸⁹ (Armitage, 2022)

^{90 (}Cass, 2024)

- Children being re-registered in the opposite gender in infancy
- Children on the child protection register being untraceable after moving to a new area.
- 4.17 Inaccurate sex markers on patient records may also lead to inappropriate and unsafe decisions about inpatient accommodation. For example, a teenage girl with a male sex marker may be placed on a male ward which could create a risk to her safety.
- 4.18 It is not clear why the NHS decided it was necessary to issue a new NHS number to people wishing to register a gender identity which differs from their sex. Nor is it clear that the NHS gave serious consideration to the risks to patient safety and safeguarding resulting from this approach.

Compromises clinicians

4.19 By undermining safe clinical decision-making, the NHS's approach to recording sex and gender identity erodes the trust between healthcare professionals and their patients and leaves healthcare professionals and their employers open to legal claims.

Lack of full medical record on which to make clinical judgements

4.20 Because people who want to change their gender identity on their medical record can withhold consent for some information to be transferred to their new medical record (paragraphs 2.47-2.54), clinicians are being forced to make clinical judgements without the full set of medical information that may be relevant to that patient's care. Safe clinical judgements rely on access to relevant historical medical information. Reducing the information available to healthcare professionals risks jeopardising the professional registration of individual clinicians and leaves them and the NHS provider organisations for whom they work unfairly at risk of claims of clinical negligence and the associated liabilities.

Ascertaining the sex of a patient who does not want their sex known

4.21 Figure 8 presents the range of instances in which the sex of a patient cannot be inferred from the combination of the Gender Identity Code and Gender Identity Same at Birth Indicator. NHSE guidance notes that people who identify as non-binary may choose not to answer questions about their sex and advises that in such situations clinicians should use a patient assessment to understand the patient's sex (see paragraph 2.31). However, that guidance gives healthcare professionals no advice about how to - rapidly and sensitively - determine the sex of a patient who may not want to discuss their sex, or who may not be physically present. In the absence of a clear record of sex, clinicians are being forced to have conversations that some

patients would rather avoid. This goes against claims that this approach is more inclusive or kind.

Case study

A Paediatrician told us, "I had a referral from a GP because a child's blood test results were highly unusual, though when meeting them I quickly established it was because they were presenting as their preferred gender. This appointment could have been given to another child, but my colleague didn't feel comfortable asking mum about their child's sex."

4.22 On the contrary, this approach is negligent of front-line staff who are doing a complex job, often in high-pressure environments. It is also negligent of patients who deserve informed care from those treating them.



- 4.23 Some healthcare tasks (such as remote reviews of images or test results) are carried out by healthcare professionals without any direct contact with the patient. Nonetheless, the patient's sex is a variable that the clinician may need to know to make a sound clinical judgement. How is a clinician expected to proceed without clear information about the patient's sex when they cannot observe, or ask the patient? This poses two clear risks: clinical judgments could be delayed while the sex of the patient is confirmed, or, in a medical emergency, a clinical judgement may have to be made without the full range of facts.
- 4.24 This entirely avoidable situation has come about as a direct result of the lack of clear, reliable data about patient sex.

Risks acting unlawfully

4.25 The NHS's current approach risks legal challenge on the grounds of unlawful discrimination, contravention of data protection principles and the inability to monitor equality.

Unlawful discrimination

- 4.26 In an attempt to accommodate the wishes of patients who subscribe to a gender identity, the wishes of those who do not have a gender identity have been ignored. The NHS's approach risks discriminating against people who do not have a gender identity but who may feel compelled to declare one to ensure that their sex can be inferred from their medical records (see Figure 8).
- 4.27 In addition, people without a gender identity may have one unknowingly ascribed to them when data about their sex is input to a 'gender' data field (since the NHS defines 'gender' as self-declared). It is inappropriate for the NHS to ascribe a gender identity to people who do not believe in gender identities or say they don't have one.

It is inappropriate for the NHS to ascribe a gender identity to people who say they don't have one

Contravenes data protection law

4.28 The NHS is required to comply with data protection principles, which include the principle of data accuracy. The UK General Data Protection Regulation requires that personal data are:

"accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay."⁹¹

- 4.29 The NHS fails to meet this requirement when it gathers data about a baby's sex at birth but then processes it in such a way (by mixing sex data with self-declared gender identity data within a 'gender' data field) that renders this data unreliable.
- 4.30 The act of ascribing a self-declared gender identity to infants and to people who do not have a gender identity (by entering sex data into a 'gender' field) also renders data inaccurate.

⁹¹ (Information Commissioner's Office, 2024)

Inability to monitor equality

4.31 Under the Public Sector Equality Duty, NHS bodies are obliged to monitor equality in the provision of their services. If NHS organisations do not have clear, reliable data on the sex of the people they are treating they cannot monitor whether or not they are discriminating on the grounds of the protected characteristic of sex when they provide services. The same applies to the monitoring of potential discrimination on the grounds of 'gender reassignment', since clear, reliable information on patients with this protected characteristic is similarly not available.

Undermines public trust and confidence

4.32 The NHS's approach to data on sex and gender identity undermines public trust and confidence in four ways.

Concealing the importance of sex in healthcare

4.33 Concealing the importance of sex in healthcare undermines public faith in the NHS's honesty and integrity. The public expects the NHS to be guided by the best available scientific evidence. They also expect the NHS to comply with its professional Duty of Candour - the duty to be open and honest with people who use its services. Prioritising 'gender' and 'gender identity' in patient records and de-prioritising 'sex' suggests that sex is not important to healthcare, when quite the reverse is true. Concealing the reality of sex and its importance to healthcare is patronising, paternalistic and is a disservice to all patients.

Highly contested ideas

- 4.34 NHSE guidance on data about sex and gender identity adopts highly contested ideas and language.⁹² It:
 - refers to "cisgender" patients, "cisnormativity" and suggests that sex and gender are "assigned at birth",
 - wrongly implies (through the use of the terms 'male' and 'female' for gender identity) that humans can change sex, and
 - claims that everyone has a self-declared gender identity.
- 4.35 Ideas about gender have emerged very rapidly. They lack an evidential basis and are highly contested. The NHS is an evidence-based healthcare service and contested social ideas have no place in it. When the NHS adopts contested ideas, it fails to demonstrate the neutrality and

⁹² (NHS England (Digital), 2024)

objectivity required of a publicly funded service which is subject to the Public Sector Equality Duty and the Nolan principles.

If the NHS can't get sex right, what else might it be getting wrong?

4.36 Sex is a highly salient variable in healthcare. When it is clear to patients that the NHS does not have a reliable record of their sex, patients can, quite reasonably, question its ability to meet their basic expectations of a safe healthcare provider. For example, The Telegraph reported last year that NHS staff at multiple hospitals now ask men waiting for an x-ray whether they might be pregnant.⁹³ This situation is a direct result of the lack of a reliable record of patient sex and the de-sexing of language in statutory regulations around x-ray provision.⁹⁴ Asking a man - indeed any boy over the age of 12, as many NHS Trusts now insist their staff do - if he might be pregnant comes across as ignorant of basic human biology. The question is pointless for patients who do not have capacity to respond, and for those with capacity it may be experienced as insensitive and undermining of the trust between radiographers and their patients. A small number of men are so baffled or concerned at being asked whether they might be pregnant that they refuse to answer or leave in frustration without having had their x-ray. This can cause harm by delaying diagnosis of their health condition.

Case study

A Radiographer told us, "We had a male patient who was being treated for cancer leave the department without having his scan as he was so angry at being repeatedly asked if he was born male or female every time he came for a scan over his abdomen."

- 4.37 It is not unreasonable for patients to wonder how the NHS could be unclear about something as fundamental as the sex of its patients. What else might the NHS be getting wrong if it can't get basic data about patient sex right? This undermines the reputation of the NHS as a science-based healthcare service.
- 4.38 These are very reasonable patient concerns, and they arise because NHS data systems no longer provide clear, reliable information about patient sex.

⁹³ (Searles, 2024)

⁹⁴ (*The Ionising Radiation (Medical Exposure) Regulations*, 2017) require healthcare professionals providing x-rays to "make enquiries of individuals of childbearing potential to establish whether the individual is or may be pregnant". This language obscures which sex can get pregnant. To comply with this regulation, many NHS trusts have introduced procedures which require patients of both sexes aged between approximately 12-55 years to be asked if they might be pregnant.

Misrepresents the law

4.39 The PRSB misrepresents the law on the disclosure of trans status in its implementation guidance for the Core Information Standard 2.0 (see paragraphs 2.56-2.61). It is not within the gift of the PRSB to rewrite the law. This undermines public trust and confidence in the PRSB, and ultimately the NHS which follows this flawed guidance.

Weakens research and policymaking

4.40 Medical records are used to support research and inform health policy. If the data in medical records is inaccurate, this undermines the research findings and policies based on those data. It also impacts the reliability of NHS statistics generated from information held in medical records.

Negative impact on research

- 4.41 Sex data in NHS records can no longer be relied upon because the sex data field has been de-prioritised, and the 'gender' data field used in many health records is now a blend of sex and gender identity information. This renders the data set much less useful for research purposes. This has a negative impact on health research for the whole population. For instance, NHSE plans to trial an Artificial Intelligence tool that predicts a patient's risk of heart disease.⁹⁵ The British Heart Foundation notes that the "inequalities in the way women with heart attacks are cared for compared to men are costing lives."⁹⁶ The task of understanding sex differences in heart attack and why inequalities of care in diagnosis, treatment and aftercare exist, will be hindered by muddled data about the sex of patients.
- 4.42 Ironically perhaps, one of the most serious negative effects is likely to be our impaired ability to conduct research into the healthcare issues which specifically affect people with a trans identity, such as the impact of the use of cross-sex hormones and issues arising from gender-related surgeries.
- 4.43 Dr Hilary Cass noted that the practice of creating a new medical record when someone changes their 'gender' on their medical record makes it harder to conduct long term research on healthcare issues affecting people with a trans identity.⁹⁷

⁹⁵ (Gregory, 2024)

⁹⁶ (British Heart Foundation, 2019)

^{97 (}Cass, 2024)

4.44 Changing the 'gender' marker (without any indication that it has changed and what it has changed from) leaves us in the dark about how many people with a trans identity are accessing healthcare and for what health conditions. This makes it extremely difficult to understand the specific health needs of trans-identifying patients. It makes it difficult to develop tailored public health messages, for example for trans-identifying women taking testosterone. It also undermines our ability to identify priority areas for future research into healthcare for people with a trans identity.

Impairs sound policy development

- 4.45 The NHS uses population and health data to plan services and manage population health. The datasets for disease incidence rates and health outcomes, which are supposedly split by sex, are now muddled and include both sexes. This undermines our ability to understand and respond appropriately to the distinct health needs of men (males) and women (females) at population level.
- 4.46 The datasets for disease incidence rates and health outcomes according to 'gender reassignment' are also unreliable, due to a failure to track the changes when patients change their 'gender' on their medical record. Healthcare for people with a trans identity is a rapidly developing field but the absence of reliable data undermines our ability to plan these services and allocate appropriate resources.

Impairs policy implementation

- 4.47 In the absence of reliable data about patient sex, it is impossible for the NHS to implement the national policy on same-sex accommodation, which commits the NHS to a "zero-tolerance approach to mixed-sex accommodation".⁹⁸
- 4.48 And while this report is focused on the accuracy and reliability of NHS medical records of patients' sex, it is worth noting that there are several reasons why NHS providers need to accurately record the sex of their staff. These include:
 - enabling an appropriate response to patient requests for same-sex intimate care
 - enabling an appropriate response to patient requests for a same-sex chaperone
 - to meet legal obligations under the Public Sector Equality Duty to monitor equality in the treatment of staff and avoid discriminating against staff on the grounds of sex.

⁹⁸ (NHS England, 2019a)

- 4.49 Responses to Freedom of Information requests indicate that some NHS Trusts are operating policies which inappropriately substitute 'gender' for the protected characteristic of 'sex' in employee records, and which permit trans-identifying employees to change their 'gender' recorded on their staff record.^{99, 100}
- 4.50 The General Medical Council's Register records doctors' gender but not their sex, and doctors are permitted to change their gender on the Register.¹⁰¹ This creates the risk that patients could be treated by medics of the opposite sex without their knowledge or consent, which would be illegal.^{102, 103}

⁹⁹ (County Durham and Darlington NHS Foundation Trust, 2024)

¹⁰⁰ (University Hospitals Plymouth NHS Trust, 2024)

¹⁰¹ (Gill, 2024)

¹⁰² (NHS, 2022)

¹⁰³ (Care Quality Commission, 2024)

5. Conclusion

- 5.1 The NHS's current approach to recording data on sex and gender identity appears to be driven by a laudable desire to avoid distress to trans-identifying patients. Fear of discriminating on grounds of the protected characteristic of gender reassignment, and concerns about privacy and confidentiality may also have played a role.
- 5.2 However, these concerns have been given inappropriate primacy at the expense of quality of care and patient safety. The significant and wide-ranging negative impacts of prioritising gender identity over sex have been barely considered, and the NHS has failed to safeguard the accurate recording of patient sex for clinical purposes. Some of the serious negative consequences outlined in this report affect all patients, while others predominantly affect patients identifying as trans or non-binary.
- 5.3 When the benefits and drawbacks of the current approach are weighed up, it is clear that the negative impacts for all patients, and trans-identifying patients in particular, far outweigh the limited benefits realised in practice for trans-identifying patients.
- 5.4 The current approach conceals medically important information, when there is no sound medical or scientific reason to do so. The NHS is wilfully ignoring the importance of information about patient sex by de-prioritising it as a data term. The most recent development (the introduction of the gender identity data pair) is convoluted and confusing and aims to indicate a patient's sex without actually recording it. This undermines patient safety, puts the reputation of the NHS at risk and raises risks of potential litigation.

The current approach conceals medically important information

5.5 Writing about the care offered by the Gender Identity Development Service to gender questioning children and young people, Dr Hilary Cass observed that these patients:

"have been exceptionalised compared to other young people with similarly complex presentations".¹⁰⁴

5.6 As this report shows, trans-identifying patients are also being exceptionalised in the area of healthcare medical records and, as a result, the care of all patients is being undermined. Trans-identifying patients have the opportunity to change their medical records in ways that

¹⁰⁴ (Cass, 2024)

other patients do not, but they are also exposed to a risk of serious harm and detriment which other patients are not.

5.7 The Royal College of General Practitioners recommends that "NHS systems should record codes for biological sex as well as gender identity" and that the "use of a new NHS number when the gender marker is changed should be reviewed, as this carries the inherent risk of loss of relevant information."¹⁰⁵ We agree entirely.

¹⁰⁵ (Royal College of General Practitioners, 2024)

Annex 1 – NHS data systems using single 'gender' field

A large number of NHS data systems use a single 'gender' data field and have no data field for 'sex'. These include the *National Care Record* and the main EPR systems used for GP records in England, *EMIS* and *SystmOne* (see Figures 2, 3 and 4 in main report). Other digital systems using this approach include *Trakcare* (Figure 13) - a system commonly used in Scotland, *Careflow* (Figure 15), *Nervecentre* (Figure 16), *PCMIS* (Figure 17), and some versions of *Rio* (Figure 14).

Concerns with this approach include the use of the term 'gender' which creates safety risk due to its ambiguity (see paragraph 2.11).

Registration		(1)	
	Registration	Floorplan	Move
	Patient Options		
	✓ Demographic Details		
	NHS Number	L	
	Registration Number		
	Merged Numbers		
	Patient Details		
	Title		٩
	<u>S</u> urname	Unknown	
	Give <u>n</u> Name	Unknown	
	Middle Name		
(Gender	Male	٩
	Date of <u>B</u> irth		

Figure 13: Trakcare (as used by Gloucestershire Hospitals NHS Foundation Trust)

Source: (Gloucestershire Hospitals NHS Foundation Trust, 2022)

		◆ Access Rio EPR Clinical Informatio ×	Black Country Health	ic × +
s://rio.dwb	cp.cse.thirdparty.nhs.uk/r		A ^N 1	🖌 👌 🔇 🗖
₽		Search	⊘ ⊘	
	Client ID NHS Number Alternative ID/System Family name Given name Gender Sel First line of address Se Postcode Fel Ma Date of Birth No	ect ect male le Specified specified for the formation of the formati	All systems	Go Go Go
	Search for Use Soundex	Inerrus Oury O Carers Only Clients and Clients Io Search aliases Image: Search aliases Image: Search aliases	Carers Inpatients Only	⊃Yes

Figure 14: Rio (as used by Black Country Healthcare NHS Foundation Trust)

Source: SEEN in Health/ Women's Rights Network member

Name Details	Address Details	
Forename: Other Given Names:	Current address:	5
Surname: Title: Name at Birth: Unverified NHS		
Partner Datalla		
Personal Details Date of birth: 10	Estimated Age: 30 [Enter address search criteria here]	2rid Address
Personal Details Date of birth: 10 Gender:	Estimated Age: 30 [Enter address search criteria here]	2nd Address
Personal Details Date of birth: 10 Gender: Ethnic group:	Estimated Age: 30	2nd Address
Personal Details Date of birth: Cender: Ethnic group: Dvil status:	Estimated Age: 30 (Enter address search criteria here) GP Details GP (Enter GP search criteria here) Practice	2nd Address
Personal Details Date of birth: 10 Gender: Ethnic group: Dvil status: Religion:	Image: Second contents Second contents Image: Second contents	R 2rid Address

Figure 15: Careflow (as used by University Hospitals Sussex NHS Foundation Trust)

Source: (University Hospitals Sussex NHS Foundation Trust, 2024)

Figure 16: Nervecentre (example record taken from user guide)

SMITH, Terry - NC00000008						
Search/Register	Summary	Edit Details Pr	eadmit to Ward			
Patient Information	n					
Name SMITH, Terry DoB / Age / Gender Born 13 Mar 1967 (§	52y) Male		Allergies Allergy to peanuts 			
Marital Status Married		Ethnicity Mixed-White & Black Africar	Religion			

Source: (Nervecentre, 2024) N.B. This graphic does not contain real patient data.

The PCMIS system, see **Figure 17**, mixes terms for sex ('male' and 'female') with terms for gender identity ('trans man', 'trans woman', 'non-binary'), e.g. "Female (including trans woman)".

Figure 17: PCMIS (as used by Black Country Healthcare NHS Foundation Trust)

Home Cases	TWELLBERNG		
Missing Da	ta Super	rvisor Alerts Tools	Myd
Marital Statu	is the second	905 OCreate Anoi	ther Ne
Nationality			-



Source: SEEN in Health/ Women's Rights Network member

Many trusts use a system called Datix to record incidents, see Figure 18, which has a 'gender' field.

Figure 18: Datix (as used by Harrogate and District NHS Foundation Trust)

	Contact Details
	* Forenames
	Test
	* Surname
	Patient
	Date of birth (dd/mm/yyyy)
	Age band
	Risk Flags
	Gender
© RLDatix Ltd 2024	

Source: SEEN in Health/ Women's Rights Network member

Many local NHS areas (known as Integrated Care Systems) operate a shared care record. These records give health and care staff access to a summary of a person's relevant heath and care information. These shared care records often show 'gender' only, see **Figure 19** and **Figure 20**.

Figure 19: London Care Record (test example of shared care record used in South East London)

The London Ca	re Record
KEREVA, DUNCAN NHS No 966 05 7 9622 Gender Male Bcm 28/02/1979 (43y)	This is test patient data.

Source: (London Care Record, 2024)

Figure 20: Somerset Integrated Digital e-Record (test example of shared care record used in Somerset)

@nhs.net (Admin)	Somerset Clinical	Commissioning Group	Endor - eSP - SIDeR (Test Environment)
	You have 0 unsent notifica	itions. Click here to see the dashboard.	
RHYS, MARGARET MS	Born 13-Oct-1936 (85y)	Gender F	NHS 944 930 3789
Address 25 IMBER CLOSE, ESHER, SURREY, KT10	BED	Phone and email Not Known	1

Source: (NHS Somerset, 2024)

Annex 2 – NHS data systems using gender identity question pair

Some NHS data systems use two questions about gender identity. This is usually: a) self-reported gender identity, and b) a question about whether that identity aligns with the sex registered or 'assigned' at birth, or alternatively whether "you consider yourself to be a trans person", see **Figure 21** and **Figure 22**. The idea is that this should enable healthcare professionals to infer someone's sex. However, some combinations of answers do not enable sex to be inferred (see Figure 8, main report).

These questions incorrectly assume that everyone believes in or has a gender identity and in some cases these are 'required' questions which must be answered, see **Figure 21**. However, there is no option for respondents to record that they have 'no gender identity'.

Figure 21: Staunton and Corse GP surgery, Gloucester

l register-with-gp.ht1.uk	
How would you describe your gender	
The answer does not have to match the sex registered at birth.	
Female	~
Is your gender identity the same as the	sex
you were registered at birth? (required)	
This information helps us find your GP record	<u>.</u>
Yes	
No	/
Y	

Source: SEEN in Health/ Women's Rights Network member

Figure 22: Prescription prepayment certificate - online patient-facing application

	NHS Prescription Prepayment Certificate (PPC)
ŀ	About you
$\langle \rangle$	Which of the following best describes your gender?
5	O Female
3	Non binary
	I use another term
\subseteq	Do you consider yourself to be a trans person?
	Unsure Prefer not to say

Source: SEEN in Health/ Women's Rights Network member

Annex 3 – NHS data system using 'legal sex'

The EPIC system gives prominence to something it calls 'legal sex'. EPIC defines 'legal sex' as the sex as listed on official documents. Legal sex and biological sex may not be the same. 'Legal sex' is therefore of minimal clinical value. UK citizens can change the sex marker on their passport and driver's licence without a gender recognition certificate, so this data field in fact represents self-declared gender identity.

Figure 23 shows a clinician-facing version of EPIC. Concerns with this system are that it assumes the patient has a gender identity – there is no option to record 'no gender identity'. It also inappropriately combines terms for sex with terms for gender identity ("transgender female", "transgender male").

Figure 23 uses terms which are extremely unclear: is a 'transgender female' a female with a trans identity, or a male with a trans identity? This lack of clarity creates a high cognitive load for clinicians, which in turn creates patient safety risk. Figure 23 also refers to 'cisgender' which some people who do not believe in gender identities find offensive.

Clinician-facing versions of EPIC (such as Figure 23) contain a data field for 'sex assigned at birth'. Although the terminology 'assigned at birth' is factually inaccurate, this field is likely to be the most clinically valuable information since it ought to be an accurate record of biological sex. However, this will only be the case if the field is not populated by data from a 'gender' data field in another IT system.



Figure 23: EPIC (as used by Guy's and St Thomas' NHS Foundation Trust)

Source: SEEN in Health/ Women's Rights Network member

Figure 24 shows a patient-facing version of the EPIC system.

Figure 24: EPIC patient-facing application 'My Care' (as used by Royal Devon University Healthcare NHS Foundation Trust)

ersonal Information				
his is the personal information nsure ALL information shown i uestions please 'Contact Us'	we hold about you, submitting s up to date and accurate. We a	g changes will update your medica im to process change requests wi	al record with the details thin 5 working days. Sho	shown below, pl ould you have any
ndicates a required field.				
Contact Information		Your legal sex is what is listed o includes passports, driving lice and other forms of official iden	n your ID. This nces, residence cards, tification	
		Preferred Forename (j) Not entered	Legal Sex (1) Female	>
	Work phone not e	Gender Identity Not entered	Sexual Orienta Not entered	tion
Menu 🗖 Visits 🕅	Messages 🗸 Test Results	A Medication		
ersonal Information				
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Source: SEEN in Health/ Women's Rights Network member

Annex 4 – NHS data fields per NHS Data Dictionary and Core Information Standard

The NHS Data Dictionary defines the terms that can be used in NHS medical records. Taken together with the PRSB's Core Information Standard v.2.0 this guides digital systems developers and NHS organisations in how to record sex and gender identity in NHS medical records, see **Figure 25**.

The Data Dictionary uses terms for sex ('male' and 'female') to describe gender identity. This implies an erroneous belief that it is possible to change one's sex. The possible responses to questions about gender identity do not include an option to record 'no gender identity'. This may be discriminatory to people who do not have a gender identity.

Data Class	Data Item names	Data item description	National Code and Definition*	Notes
Person Phenotypic – Sex	Person Phenotypic Sex classification	A classification of the observed sex of a person, relating to the biological, physiological and physical characteristics that differentiate men and women, determined by endocrine influences. Person Phenotypic Sex is observed by a person (such as a care professional), and is not self-stated.	 Male Female Indeterminate (unable to be classified as either male or female) 	Not classified as 'Mandatory', 'Required' or 'Optional' by the Core Standard, so this field is often left blank.
	Gender Identity Code	The gender identity of a person as stated by the person	 Male (including trans man) Female (including trans woman) Non-binary Other (not listed) Not known (not recorded) Not stated (person asked but declined to provide a response) 	Priority data item
Person Stated Gender (The stated gender of a Person. Person Stated Gender is self-declared, or inferred by observation for those unable to declare.)	Gender Identity Same at Birth Indicator	An indication of whether the patient's gender identity is the same as their gender assigned at birth	 Y Yes - the person's gender identity is the same as their gender assigned at birth N No - the person's gender identity is not the same as their gender assigned at birth X Not known (not asked) Z Not stated (person asked but declined to provide a response) 	Priority data item
	Person Stated Gender Code	The gender of a person. Person Stated Gender Code is self-declared or inferred by observation for those unable to declare their Person Stated Gender	 Male Female Indeterminate (unable to be classified as either male or female) Not known (Person stated gender code not recorded) 	A low priority item, retained only for data linkage purposes. "It is not safe to make assumptions about an [individual's sex] using the Person Stated Gender Code."

Figure 25: NHS data fields on sex and gender identity, as per the NHS Data Dictionary, PSRB Core Information Standard v.2.0 and NHS Digital guidance

*The responses which can be entered into the data field.

Source: (Professional Record Standards Body, 2021b; NHS England, 2024c; NHS England (Digital), 2024

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