

Executive summary

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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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.

The NHS acknowledges the importance of sex to safe healthcare. It also understands the difference between sex and gender identity and the risks inherent in using the ambiguous term 'gender' in medical records.

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.

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, alongside self-reported gender identity, and data purporting to be about sex but which in some instances actually reflects gender identity.

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.

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 records.

This creates patient safety risk, reduces data quality and is a right not afforded to any other patient group.

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.

While 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.

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.

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.

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 gives documented examples where patients with a trans identity have suffered serious or potential harm due to confusion about their sex in a healthcare setting.

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Risks of inaction / continued...

Undermines safeguarding

The Cass Review identified a range of serious safeguarding risks arising from issuing new medical records to patients who change their recorded 'gender'.

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.

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. It also 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.

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.

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.

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.

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:

- 1 Require a clear, accurate and readily accessible record of patient sex to be held in NHS patient record systems:** Completing 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.
- 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.
- 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.
- 4 Review data linkages between NHS digital systems on sex and gender:** Cease making data linkages between NHS digital systems that feed data from a 'gender' or 'gender identity' field into a 'sex' field, and vice versa.
- 5 Revise the current response to patient requests to change 'gender' (ie gender identity) on medical records:** It is important that relevant medical information is no longer lost, and an accurate record of patient sex retained. The NHS should resume responsibility for inviting patients with a trans identity to sex-based population screenings.
- 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.
- 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.
- 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 with the Public Sector Equality Duty.



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