

Single patient record: confidentiality and access safeguards

The clause leaves who may access the record, and what a patient may restrict, almost entirely to regulations. This briefing sets out the gap, and the amendment we are asking peers to move at Committee stage.

If you say one thing on this clause, say this

The single patient record will be switched on first for maternity and frailty patients — those for whom a breach of confidence is most dangerous — yet the Bill contains no requirement on who may see the record, no audit a patient can check, and no way for a patient to restrict access to sensitive information. Ministers gave assurances in the Commons, but those Ministers have since changed and the Bill has not. Safeguards that depend on who holds office belong in the Bill, not in a departmental undertaking.

Two sentences, liftable verbatim. Everything below is supporting material.

The ask at Second Reading

The clause leaves its central safeguards — who may see the record, and what a patient may do to protect it — to regulations Parliament has not seen and, once made, cannot amend. **At Second Reading, we ask peers to name this gap, to press the Minister on whether the access and confidentiality safeguards will be placed on the face of the Bill, and to signal an intention to return to it in Committee.** The amendment we are asking peers to move in Committee is set out in the Annex, so the intention can be trailed now.

Detection is not protection

The risk this amendment addresses is neither hypothetical nor historical. In the days before this Second Reading, NHS England's chief executive wrote to all 205 acute trusts in England instructing them to act at once against staff who had accessed patient records without a legitimate reason. Reporting based on freedom-of-information responses put the recent scale in the thousands — more than two thousand staff sanctioned and over two hundred dismissed — and included a case in which a member of staff accessed the record of a woman who had fled a violent partner. That is the current state of access discipline across many separate systems. The single patient record would gather all of it into one.

The response — audit, identify, dismiss — is detection after the fact. It is necessary, but it is not protection: a confidence once breached cannot be restored by disciplining the person who breached it, and two thousand sanctions are the measure of how often detection alone comes too late. What prevents the breach is the architecture this clause does not require — access confined to those with a reason to look, a restriction a patient can invoke, and a design that does not betray that restriction by its own operation. There is a further point the House will not miss: the body now enforcing this discipline, NHS England, is abolished by this same Bill. Who will hold access discipline over a single national record, and by what authority, is left exactly where the safeguards are — to regulations not yet seen.

Why this House, and why now

The single patient record will hold information about every person who receives NHS care in England. The clause that creates it settles, in detail, how information will be compelled into the record and how non-compliance will be penalised. It says almost nothing about who may read it, or what a patient can do to protect what it contains.

The elected House did not resolve this — it did not reach it. At Report stage the new clauses and amendments concerning the record's confidentiality and access safeguards were not called: the day's time was taken by the abolition of NHS England, maternity, dentistry and workforce, and the data provisions fell away undebated. This is not a point the Commons weighed and rejected. It is a point the Commons was not able to weigh at all.

That is the classic office of this House. A whole-population data system is being established with its central safeguards left to regulations Parliament has not seen and cannot amend. Scrutinising exactly this kind of provision — and asking that more of the substance sit on the face of the Bill — is work the Lords is constituted to do, and which, on this Bill, the Commons had no time to do.

The record starts where the stakes are highest

This is not a distant or theoretical risk. The record is to be rolled out first in two pathways: maternity and frailty. Those are among the most confidentiality-sensitive areas of care that exist — concealed pregnancy, termination, and the disclosure of domestic abuse in maternity; safeguarding, fluctuating capacity, and the involvement of family members in frailty. The design is to switch the record on first for precisely the patients for whom a confidentiality failure is most consequential, and to do so before any of these safeguards exists in law.

What the clause leaves out

The clause does not require role-based access, so nothing on its face limits what any professional may see to what their involvement in a patient's care requires. It does not require an audit trail, so nothing guarantees that a record is kept of who has looked, still less that a patient can see it. It gives a patient no means of restricting routine access to information they have particular reason to protect. And the words child, young person, competence and capacity do not appear anywhere in it.

Ministers in the last Government gave assurances on several of these points in Committee — role-based access control with an audit trail, clinician redaction of sensitive information, and proxy access set out in regulations on the patient's consent. Those assurances were welcome. But they were given by a ministerial team that has since changed, under a change of Government, and none of them binds the Department in law. **An assurance that depends on who holds office is precisely the thing that belongs in statute rather than in a departmental undertaking. The Ministers have changed; the Bill has not.**

The gap for children and for those acted for

The clause permits information to be made available to people other than the patient, on the patient's behalf. For most children, most of the time, the person exercising that access will be a parent, and that is entirely as it should be. But the law has long understood that a young person's confidence is sometimes owed to the young person: a teenager seeking contraception or sexual-health care, disclosing

abuse at home, or being treated for self-harm or an eating disorder relies on confidentiality as the condition of seeking care at all. *Confidentiality here is not a constraint on the record; for these patients it is the condition of the record working at all* — a point the National Data Guardian has pressed directly with members. The clause does not say at what age or in what circumstances access on a patient's behalf is reviewed or withdrawn, whether a competent young person may ask for anything to be restricted, or whether they could do so privately — without the request travelling through the very household it concerns.

The same silence surrounds every person for whom another acts: those under a lasting power of attorney, adults with fluctuating capacity, people living with a controlling partner. The Bill widens the category of who may hold access on a patient's behalf without saying what that access permits, how it is scoped, or how it ends.

Silence is not neutral

A record need not state something for it to be disclosed. Consider a young woman whose record carries no diagnosis flagged as sensitive, but whose appointment history shows an early-pregnancy assessment unit, a follow-up, and a prescription — from which the fact of a termination can be read plainly by anyone with routine access, including a family member acting on her behalf. Appointment histories, clinic names, prescribing data and referral routes carry information, often more legibly than the notes themselves. A restriction that conceals a diagnosis but leaves the pathway visible has protected no one — nor has a system that signals, to the very person a patient is protecting themselves from, that a restriction has been applied. These are the ordinary design problems of any system holding sensitive information about people who are not always safe. They have known and workable solutions — but only where something requires them to be built. The clause requires nothing.

The amendability point

Because the access regime, the confidentiality gateway, and every protection for the patient are left to regulations, the safeguards will arrive in a form Parliament can approve or reject as a whole but cannot amend. If the access regime were wrong in one respect, the only remedy would be to reject the entire framework — which is no remedy at all. That is the core reason for placing the substance of these safeguards in the Bill, where this House can scrutinise and refine it. The delegated-powers dimension is developed separately in our submission to the Delegated Powers and Regulatory Reform Committee.

The confidentiality gateway

The National Data Guardian — the statutory office-holder for patient confidentiality — told the Public Bill Committee that the power to set aside the duty of confidence should be removed, or narrowed so that it lifts the duty only for the supply of information into the record, on the model of section 259 of the Health and Social Care Act 2012. The amendment to remove it was not moved; her narrower alternative was never tabled. Subsection (1) of the attached amendment gives that narrower alternative statutory form. The National Data Guardian's office continues to engage on this clause; the amendment is drafted to support that engagement, not to cut across it.

What the amendment does, and does not, do

It narrows the confidentiality gateway to the supply of information into the record, leaving subsequent access subject to the ordinary law of confidence. It requires the regulations to provide for least-privilege, role-based access; an auditable access record the patient can see; a patient-exercisable restriction on routine access to sensitive information, exercisable personally and confidentially by a competent young person; and regulated, reviewable proxy access. It preserves clinical safety absolutely: no deletion, no absolute concealment, a lawful and proportionate route through wherever access is necessary for safe care, safeguarding or the prevention of serious harm, and nothing limiting disclosures required by law or by a court. It does not amend the clause, does not delay the record, and — since much of it restates access arrangements the Department has said it intends to build — asks the Government to secure its own stated policy rather than to change it.

New clause and explanatory statement

Offered as policy drafting; final wording would be a matter for Parliamentary Counsel.

NEW CLAUSE

Single patient record: confidentiality and access safeguards

- (1) Regulations under section 250E(3) of the National Health Service Act 2006 may provide that processing does not breach an obligation of confidence only so far as the processing consists of the provision of information for inclusion in the single patient record in accordance with regulations under section 250E.
- (2) Regulations under section 250E must include provision—
 - (a) requiring access by a person involved in the provision of health or social care to the patient to be limited to what is necessary and proportionate for that provision, having regard to the role of the person accessing the information, the purpose for which it is accessed, that person's involvement in the patient's care, and the clinical and safeguarding context;
 - (b) requiring an auditable record to be kept of access to a patient's information and, subject to prescribed exceptions that are necessary and proportionate for safeguarding, the prevention or detection of crime, or the protection of the rights of another person, for intelligible information from that record to be available to the patient;
 - (c) enabling a patient to restrict routine access to prescribed categories of information, and to other information where routine access would create a material risk of harm;
 - (d) regulating the granting, scope, review, suspension and withdrawal of access by a person acting on a patient's behalf under section 250E(2)(c)(i);
 - (e) ensuring that a child or young person who is able to exercise a right under this section may do so personally, and through a process that is confidential to them;
 - (f) requiring patients to be given accessible and age-appropriate information about access to their information, and an accessible procedure for seeking review of a decision concerning access, restriction, or authority to act on their behalf, including urgent interim restriction where disclosure may expose the patient to harm.
- (3) Regulations under section 250E must in particular make provision about—
 - (a) the criteria by which a request under subsection (2)(c) is to be determined, and the grounds on which it may be refused, which may be only that refusal is necessary and proportionate for safe care, safeguarding or the prevention of serious harm;
 - (b) access to restricted information where necessary and proportionate for safe care, safeguarding or the prevention of serious harm, and the recording and, where safe and lawful, notification of such access;
 - (c) information, including metadata, correspondence, appointment and prescribing data, capable of revealing or permitting an inference about restricted information;
 - (d) the ages and circumstances at which access granted on a patient's behalf must be reviewed, and its limitation by reference to information, function, purpose and period;

- (e) secure and confidential communications and contact arrangements for the exercise of rights under subsection (2)(e), which must not depend on the cooperation, device, account or contact details of a person whose access is affected;
 - (f) preventing the operation of the access controls, or notification of a change to them, from itself disclosing restricted information or placing the patient at risk.
- (4) Regulations under section 250E must not permit the deletion or alteration of information in a source record, and must preserve disclosures required by an enactment or by an order of a court.
 - (5) Regulations under section 250E must require the best interests of a child to be a primary consideration in decisions affecting access to information about that child, having regard to the child's views, age, maturity, confidentiality interests, clinical needs and safeguarding circumstances.
 - (6) In complying with section 250E(6), the Secretary of State must consult children and young people and persons representing their interests, the Children's Commissioner for England, the Information Commissioner, the National Data Guardian, and persons with expertise in safeguarding, in the confidential healthcare of children and young people, and in information governance.
 - (7) Before laying regulations under section 250E, the Secretary of State must publish an assessment of their effects on children and young people.

Member's explanatory statement

This new clause would limit the power to set aside obligations of confidence to the provision of information into the single patient record, reflecting the narrower approach proposed by the National Data Guardian. It would require the regulations to provide for necessary and proportionate professional access; auditable access records, with intelligible information from them ordinarily available to the patient; mechanisms through which patients may seek restriction of routine access to sensitive information, exercisable personally and confidentially by a child or young person able to do so; and reviewable, limited access by persons acting on a patient's behalf. It preserves lawful and proportionate access for safe care, safeguarding, court orders and other legal requirements.

About this briefing

Eden Openly is an independent clinical health-education publication concerned with evidence-based information on transgender healthcare and dermatology. It receives no funding from, and has no commercial relationship with, any provider of gender-related healthcare, any pharmaceutical company, or any supplier of NHS digital systems. This briefing draws on written evidence submitted to the Public Bill Committee and published as HB130. Statutory text checked against the Health Bill as amended in Committee (Bill 131), new sections 250E and 250F. House of Lords Second Reading briefing, v0.5. Contact: editor@edenopenly.com.