Written evidence submitted by Eden Openly to the Health Public Bill Committee (HB130)

About this submission

This submission is made on behalf of Eden Openly, an independent clinical health-education platform concerned with evidence-based information on transgender healthcare and dermatology. It is authored by a practising clinician writing under the platform's name, and is submitted in an organisational capacity.

We support the single patient record. We do not oppose it, and we take no position on the remainder of the Bill.

We are conscious that the Committee has ordered clause 47 to stand part of the Bill. We therefore do not ask the Committee to revisit it. We propose instead a **new clause**, which imposes requirements on the regulations to be made under new section 250E without disturbing the clause itself. Draft text a member could table is at paragraph 17.

Summary

- We do not ask the Government to change its policy. **We ask Parliament to secure, in the Bill, the safeguards the Minister has already described.** On 2 July she told the Committee that proxy access — which "includes carers, parents or care home staff" — requires "consent and involvement" and will be "set out in regulations"; that "clinicians will be able to redact information that is too sensitive to share" under a protocol with professional bodies; and that the record "is expected to operate roles-based access control … with an audit trail". Each is welcome. **None is secured by the Bill itself.** As the hon. Member for Farnham and Bordon put it in the same debate, "there is nothing in it about role-based access controls, audit logs or whether patients would be able to see who had looked at their records … they are not guaranteed in the Bill".
- The **National Data Guardian** told the Committee that section 250E(3) — the power to provide that processing "does not breach any obligation of confidence" — should be removed, warning against lifting the duty "wholesale", and noting that implied consent, section 251B of the Health and Social Care Act 2012 and Caldicott Principle 7 already permit sharing for individual care. She proposed a narrower alternative on the model of section 259 of that Act. **The amendment reflecting her recommendation appeared on the amendment paper but was not put to a decision before clause 47 was ordered to stand part.** Subsection (1) of the new clause we propose implements her alternative directly.
- The gap for children is specific. The Minister's answer on sensitive information gives the power to redact to the **clinician**. When asked whether patients could "give consent for part of the record to be shared, but not the complete record, where they have reasons to want extra privacy", she replied that this was "an enabling power" and that "all the details will be brought forward in regulations". **The question was asked. The Bill does**

not answer it. The words *child*, *young person*, *competence* and *capacity* do not appear in clause 47.

- This is not speculative. The National AIDS Trust has told the Committee that one in fourteen people living with HIV reported avoiding healthcare because of stigma. The National Data Guardian warned that a record "perceived as not confidential, and therefore not trustworthy" would be less able "to achieve its intended benefits". **Confidentiality is not a constraint on the record. It is a condition of it working.**

Why a new clause

1. The Committee has ordered clause 47 to stand part, and we do not seek to reopen it. But much of the substance of the record lies in regulations authorised by clause 47, which Parliament has not yet seen. A new clause may impose requirements on those regulations without amending the clause. The argument is not that clause 47 is wrong; it is that clause 47 is **incomplete**, and the missing part can be supplied without disturbing anything the Committee has agreed. Draft text a member could table is at paragraph 17.

The National Data Guardian's recommendation

2. We do not make a novel point. We support one already made to this Committee by the statutory office-holder responsible for patient confidentiality, and not yet acted upon. New section 250E(3) provides:

> *"The regulations may provide that the processing of information in accordance with the regulations does not breach any obligation of confidence owed by the person processing the information."*

3. The National Data Guardian **strongly supported** the amendment to remove that provision, warning that lifting the duty of confidentiality "wholesale" from the Government's flagship record "risks eroding the culture of confidentiality within care relationships, as well as public and professional confidence in the NHS's ability to safeguard confidential information".

4. She also answered the justification for the power. The stated concern is that organisations may not supply data for fear of breaching confidence; but the existing framework *already* supports sharing for individual care through implied consent, the duty to share under section 251B of the Health and Social Care Act 2012, and Caldicott Principle 7. The provision therefore "goes significantly further than is necessary", and "would allow confidentiality to be removed from further processing of data once it is held within the SPR". Her proportionate alternative — lifting the duty **solely for the supply of information into the record**, on the model of section 259 of that Act — achieves the Department's objective while leaving subsequent access and use subject

to the ordinary law of confidence and any other applicable legal gateway. Subsection (1) of our new clause gives effect to it.

5. The amendment reflecting her recommendation appeared on the amendment paper but was not put to a decision before clause 47 was ordered to stand part. We ask the Committee to consider whether the considered position of the office-holder who gave it expert evidence on patient confidentiality should remain unaddressed merely because that amendment was not moved.

The Government's own commitments, and where they sit

6. On 2 July the Minister gave the Committee a series of assurances, and we accept them. She said that NHS proxy access "already allows for people other than patients — which includes carers, **parents** or care home staff", that "setting up proxy access requires the consent and involvement of the individual and the person they care for", and that the Government "will set out in regulations how proxy access will work". She said that "clinicians will be able to redact information that is too sensitive to share" under a protocol to be agreed with professional bodies. And she confirmed that the record "is expected to operate roles-based access control … with an audit trail of who has accessed the patient's data".

7. Every one of those commitments is welcome. **Each was placed in regulations, in a protocol, or in an expectation. None of them is secured by the Bill itself.** That is the whole of our submission. We do not ask Parliament to overrule the Minister; we ask it to **secure her own commitments** in the statute, where they will bind her successors and be legally enforceable according to their terms. **To the extent that these safeguards are already intended, placing them in the Bill cannot frustrate Government policy. It merely secures them.**

8. A member of the Committee said as much. The hon. Member for Farnham and Bordon observed that setting aside the duty of confidence is "a significant legal challenge and change", and that "where Parliament is creating a new legal basis for disclosure, it is reasonable to expect strong safeguards alongside it". The Bill requires the Secretary of State to have regard to "adequate safeguards", but **"the Bill does not say what those safeguards are. There is nothing in it about role-based access controls, audit logs or whether patients would be able to see who had looked at their records … they are not guaranteed in the Bill."** The answer offered in Committee was that these are matters to work through "through the regulations". With respect, that is the difficulty rather than the answer.

9. We note, and welcome, that regulations under section 250E are subject to the affirmative procedure. We do not ask for more. We observe only that an affirmative instrument may ordinarily be approved or rejected as a whole rather than amended. If the access regime were defective in one respect, Parliament's practical remedy would

be to reject the framework entire, notwithstanding the broad support for establishing the record. That is not an adequate means of correcting a discrete deficiency, and it is why these requirements belong in the Bill.

The question that was not answered

10. The Minister's assurance on sensitive information was that **clinicians** will be able to redact it. We do not doubt that clinicians will try. But a clinician's discretion is not a patient's right, because it depends on the clinician recognising the issue before disclosure occurs. A fifteen-year-old's confidence should not depend on whether the clinician in front of her happens to notice that her father can read the record.

11. That distinction was put to the Minister directly. On 2 July the hon. Member for Sleaford and North Hykeham asked her to *"confirm whether the intention of the Government is to separate parts of the record out so that people can give consent for part of the record to be shared, but not the complete record, where they have reasons to want extra privacy"*. The Minister replied that "we are talking about an enabling power in the Bill" and that "all the details will be brought forward in regulations".

12. That is not a criticism of the Minister; it is an accurate description of what the Bill does. **The question was asked, and the Bill does not answer it.** Whether a patient — including a young person entitled to exercise the right — may consent to part of the record being shared and not the whole is, on the current drafting, entirely a matter for regulations. Our new clause requires the regulations expressly to answer it. The Royal College of Paediatrics and Child Health has likewise asked the Committee to consider "when a young person will be given access to their own health record" and "the proxy access for parents/carers"; the Bill answers neither. And on 9 July, when new clause 6 was not pressed to a vote, its mover said she hoped that "when we get to Report stage, the Government will be able to give us a little more detail on what safeguards they intend to put in place". The question is open, and is expected to return.

What the Bill gives a patient

13. Clause 47 makes detailed, mandatory provision for a person facing a financial penalty: section 250F(3) requires the regulations to provide for a notice of intent, an opportunity to make representations, a decision, a final notice, and an appeal to the First-tier Tribunal. It creates no comparable patient-facing procedure — no express right to be told before access is granted to a person acting on the patient's behalf, no route to object to it, no express power to seek restriction, no right to intelligible information from an access record, and no review before disclosure. The only express substantive access safeguard on the face of clause 47 is section 250E(4), which requires the Secretary of State genuinely to consider the need for adequate safeguards, but does not prescribe their content, require any particular safeguard to be adopted, or confer any right on an individual.

14. We do not say a patient is without legal remedy. Data-protection law, Article 8 of the European Convention on Human Rights as given effect by the Human Rights Act 1998, public law and the law of confidence continue to operate, and in an appropriate case a prospective remedy may be available. **But litigation or regulatory complaint is not equivalent to an accessible control operating within the system itself.** Such remedies may be slow, costly, or practically unavailable to a child, and will often arise only after information has been made available. Confidentiality, once lost, cannot be fully restored by a later remedy. In England and Wales a person aged 16 or 17 may consent to treatment under section 8 of the Family Law Reform Act 1969, and a younger child may do so where they have sufficient understanding (*Gillick v West Norfolk and Wisbech AHA* [1986] AC 112); a young person able to exercise the right in question will ordinarily control whether a parent may access confidential information about them, subject to safeguarding and other lawful exceptions. This is reflected in GMC and ICO guidance, and is consistent with Articles 12 and 16 of the UN Convention on the Rights of the Child, which we cite as reinforcement rather than as directly enforceable domestic authority.

Clinical safety

15. We state the strongest objection to our own case. Clinically relevant information must remain available where necessary for safe care. Medication, mental-health history, substance use, eating-disorder care and other sensitive information may bear on diagnosis, prescribing, the interpretation of laboratory results, safeguarding and emergency treatment. **Preventing a clinician from obtaining information necessary for care may create a risk of error, and we do not ask the Committee to accept that risk.** We therefore propose no deletion and no absolute concealment, but **differentiated access**: the right information, to the right professional, for the right purpose, recorded, with a lawful and proportionate route through where access is necessary for safe care, safeguarding, or to prevent serious harm, and with nothing limiting disclosures required by an enactment or a court order.

16. The clinical-safety argument runs *towards* this new clause. The National AIDS Trust evidence does not measure the effect of the proposed record itself, and its population is not confined to children; it demonstrates the *mechanism* — that stigma and fear of disclosure can deter engagement with healthcare. The National Data Guardian applied that mechanism directly to this record. A person who does not trust it may delay care, avoid it, or disclose less; a clinician uncertain about its confidentiality may record less. The resulting record may be incomplete while appearing comprehensive — which is more dangerous than an obvious gap. **Confidentiality is therefore not incidental to the clinical purpose of the record. It is one of the conditions of achieving it.**

Proposed new clause

17. We invite any member to table the following. It imposes requirements on the regulations under section 250E. It does not amend clause 47, does not delay the record, and does not require the Department to abandon any stated policy — subsection (2)(a) largely restates the "tiered, role-based access" the Department has already said it intends to build. It is 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.

Conclusion

18. The purpose of the single patient record is sound and its clinical value may be considerable. The defect is not one of intention but of statutory architecture. **Clause 47**

builds detailed machinery to compel disclosure into the record and to enforce that duty, and leaves the principal safeguards governing subsequent access — proportionate access, the authority of those acting on a patient's behalf, patient restrictions, access histories and review — to regulations and technical design.

19. The National Data Guardian has told the Committee both what is wrong with section 250E(3) and how its legitimate objective can be achieved more narrowly. The amendment reflecting her concern was not put to a decision. The new clause proposed here would preserve the power necessary to require information to be supplied into the record, while leaving its subsequent access and use subject to the ordinary law of confidence, and requiring practical safeguards on access.

20. We ask the Committee to require that the record be built in a way that a child or young person can trust — **not because confidentiality invariably overrides safety, but because for some young people confidentiality is a condition of seeking care, disclosing risk, and remaining safe.**

Annex: Government commitments, expert recommendations, and safeguards raised in Committee

The left-hand column records safeguards already stated by the Government, recommended by the National Data Guardian, or expressly raised during the Committee's consideration of clause 47. None is expressly guaranteed in the form described by the Bill. The proposed new clause would place those safeguards on a statutory footing, or require the regulations expressly to address them.

Safeguard, and its source	Where secured in the proposed new clause
Role-based access. Minister: the record "is expected to operate roles-based access control" (PBC, 2 July 2026).	Subsection (2)(a)
Audit trail. Minister: "with an audit trail of who has accessed the patient's data" (PBC, 2 July 2026).	Subsection (2)(b)
Redaction of information too sensitive to share. Minister: "clinicians will be able to redact information that is too sensitive to share", under a protocol with professional bodies (PBC, 2 July 2026).	Subsections (2)(c) and (3)(a)–(b) — and, additionally, accompanied by a patient-exercisable restriction mechanism
Proxy access set out in regulations, on consent and involvement. Minister: proxy access "includes carers, parents or care home staff", "requires the consent and involvement of the individual and the person they care for" (PBC, 2 July 2026).	Subsections (2)(d), (2)(e) and (3)(d)–(e)
Patients able to see who has looked at their record. Identified as absent from the Bill by the hon. Member for Farnham and Bordon (PBC, 2 July 2026).	Subsection (2)(b)
A narrower confidentiality gateway. National Data Guardian: lift the duty of confidence solely for the provision of information into the record, on the model of section 259 of the Health and Social Care Act 2012.	Subsection (1)
Consent to part of the record being shared, but not the whole. Asked by the hon. Member for Sleaford and North Hykeham (PBC, 2 July 2026); answered "all the details will be brought forward in regulations".	Subsection (2)(c), with the criteria for determination in (3)(a)

Where safeguards are already Government policy, placing them in the Bill cannot frustrate that policy. It secures it.

Notes

Declaration of interests. Eden Openly is an independent educational publication. 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.

Publication. We consent to the publication of this submission.

Sources. Health Bill (Bill 9, 2026–27) as introduced, clause 47 (new NHS Act 2006 ss.250E, 250F); Explanatory Notes (Bill 9–EN), paras 384–406; National Data Guardian, supplementary written evidence to the Committee (position on Health Bill amendments, following oral evidence of 16 June 2026); Royal College of Paediatrics and Child Health, written evidence (HB75); National AIDS Trust, written evidence (HB121), citing UK Health Security Agency, *Positive Voices 2022*; Public Bill Committee, Official Report, 2 July 2026 (clause 47 debate) and 9 July 2026; Public Bill Committee proceedings to 9 July 2026, and the amendment paper for 13 July 2026; Family Law Reform Act 1969, s.8; *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112; GMC and ICO guidance on children's confidentiality and data rights.

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