

Accelerating Citizen's Access to GP Records

What is happening?

From 1st November 2022, all PROSPECTIVE data (i.e., data entered after 1st November 2022) held within the GP records will be visible to patients (aged 16+) within their patient facing apps (See appendix 1). Whereas previously patients had to apply to their GP practice to access their online record, this will now be offered as standard to all patients without needing to pro-actively apply, in order to make patient empowerment the standard.

What will be included in the online view?

- Appointments
- Medication lists (Both acute and repeat in all apps, whilst past drugs also show in the NHS App)
- Allergies
- Documents / letters
- Test results
- Coded data, including Problem lists
- Consultation entries – codes and free-text
- Immunisations

What will NOT be included in the online view?

- Any data entered onto the consultation screen prior to the launch date in November
- Any data entered before the date that the patient registered with your surgery.
- Any data entered before the patient turned 16.
- Tasks (e.g., Admin notes; Patient notes – though bear in mind these could be requested to view by the patient via a Subject Access Request) and internal communication in practice (e.g., Emails, screen messages)
- Major alerts / “Warnings”

Why is this happening?

Under the Data Protection Act (2018), patients have a right to access data and information held about them. More importantly than this however, a patient that can access, review and track their own data can be empowered to better manage their own health. For example, knowing an HbA1c or blood pressure reading result and being able to see and monitor this whenever necessary can enable a person to track their progress and to feel more motivated and empowered to improve it. A patient with access to the free-text of a consultation with someone from the surgery in a morning can review the summary of that consultation the same day to recap what was said, to revisit the management plan and to hold ownership over the next steps in that plan. They can also view the safety netting information recorded and act on it when necessary.

What are the benefits?

A patient with access to their own health data can better understand their own health, can research their own conditions, can have better ownership of their management and can be more responsible for their health outcomes. The patient may also be better enabled to monitor prescriptions, book and cancel appointments all via the same platform, and to check results and referrals which can save the practice time answering incoming phone calls.

Over time, the apps are likely to evolve to incorporate more information & support, so widespread engagement with the platform will enable future developments to have wider reach and thus be more effective.

What are the possible risks?

There are a number of potential risks from the programme to be aware of, but these can largely be managed. For example:

A patient may discover something on their records that they were unaware of, such as a new diagnosis or an abnormal test result before the GP has had chance to discuss it with them.

A patient's confidential data might end up being seen by another person. There are a number of scenarios where this might happen (this list is not exhaustive):

1. A person with capacity might allow another person to view their record, without realising which data would be visible. This could especially be an issue where someone is reliant upon another person to read their records for them, for example if they are not confident with

using technology, have limited literacy, have a disability such as dyslexia or being partially sighted, or where English is not their first language.

2. The person might lack capacity, for example through dementia, learning disability, acquired brain injury or addiction to understand what information is being shared and might allow someone else to access their record without recognising the consequences. For example, someone with a learning disability or dementia might have someone act on their behalf and not understand the risks to their privacy of sharing their access.
3. People in abusive situations might be pressured, coerced or forced to grant access to another person or people. Examples of such situations include:
 - a. A victim of domestic abuse may be coerced to reveal their records to their abusive partner.
 - b. A victim of modern slavery may be forced to reveal their records to their abuser to ensure they have not disclosed their enslavement
 - c. A young woman might be pressured by her family to reveal her medical record to prove she was not seeking contraceptive or sexual health advice out of wedlock, for example, in situations of so-called Honour-Based Abuse.

Patients might be concerned about the security of their data, especially if they know an abuser has access to their record, and thus they might be reluctant to disclose abuse.

The doctor-patient relationship might be harmed if a patient sees something written about them that they feel is inaccurate, judgmental, or inappropriate. In extreme circumstances, a patient might become aggressive or abusive towards members of the practice team in relation to such entries.

How can these risks be reduced?

Letters and results will only become visible once the data has been fully filed or “completed” through Docman or the clinical system. This will prevent a patient from seeing the data before the surgery has had opportunity to contact them about them. If you plan to contact a patient to discuss a letter or result, leave the report “unfiled” until you have done so – it will still be visible to the practice in this situation, just not to the patient.

Regarding patients at risk of abuse, it is impossible to identify all patients that might be at risk from record access, and peoples’ situations and risks change over time. For some people, the practice may be aware of a patient at potentially higher risk of being coerced into allowing access to their record. In such cases, online access to the record can be temporarily withheld pending a discussion with the individual concerned to explain what information will be visible, and then the access reopened after that discussion if appropriate.

The key way to moderate risk is to ensure that all staff making entries into the medical record are aware that the patient will be able to see what is written and to bear this in mind whilst consulting and documenting. It is always possible to withhold an individual consultation entry from the online viewer if it is felt that not to do so could potentially risk significant harm to that individual or another person. Please see Appendices 2-4 for walkthroughs of how to do this on EMIS, TPP SystemOne & Docman.

With regards the doctor-patient relationship, be mindful of the words you write and how these might be interpreted. "Complaining of chest pain" for example, may have different connotations for patient and doctor.

What do you need to do now?

1. Ensure that ALL staff entering information onto the GP records are aware of these changes & how to hold back individual data entries when felt appropriate. Think also about how you will manage this for new joiners, locums and trainees going forwards. Also consider any other colleagues writing onto the record who are employed by other agencies (e.g. midwives, mental health workers).
2. Ensure that all staff processing incoming correspondence know how to hold back the document from online visibility and the circumstances where this might be necessary (e.g. CP Case conference minutes, domestic abuse notifications, letters containing third party information etc.)
3. Identify any individuals that you think should have access to their online record temporarily withheld on grounds of identified risk & add the SNOMED code 1364731000000104 "Enhanced review indicated before granting access to own health record" (aka the "104 code"). **Adding this code must take place BEFORE 1st November 2022.** A suite of searches has been developed, which you can import into your clinical systems to run and then add the "enhanced review" code to all within the search. These searches and associated instructions on how to use them can be found at [this link](#) on the NHSE implementation site. These are example searches only. The GP practice remains the data controller, and therefore it is recommended that the practice team reviews the lists of codes within the searches and adds or deletes any codes as the practice feels is appropriate.
4. Take opportunities to discuss this programme with patients where appropriate (See Appendix 5 for flowchart):
 - a. What information may be visible
 - b. How to protect their data, e.g. by not sharing access to passwords etc
 - c. How you can help protect their data, e.g. by withdrawing access to some or all of the elements they can see via their app or by redacting specific entries
 - d. Who they can contact if their circumstances change and they wish to amend their access in the future
 - e. Where they can access support if they are vulnerable to, or victims of, abuse

5. Consider discussion about online access in cases where you have reason to suspect the patient may lack capacity to understand what information is being shared. Think about whether you need to hold a Best Interests decision & whether proxy access or withholding access might be appropriate. In patients that presently have capacity, ascertain what they would like to happen to their access if and when they lose capacity.
6. Ensure that the whole practice team is aware of where to signpost people to for support in the event that they disclose that they are a victim of abuse.
7. **MOST IMPORTANT: Change your mindset. Consider that every patient may have access to their online record and use this to inform what you record & whether you need to withhold each entry from the online viewer on an individual basis.**

Some specific pitfalls identified in pilot testing

During pilot testing of the programme there are a few specific issues identified that could create a risk for a data breach to be aware of:

1. If medication is prescribed within a consultation and the consultation then withheld from the online viewer, the medication issued will still be visible online. This can be overcome on some apps by moving the medication into past drugs, but notably does not hide the drug on the NHS App.
2. People who you have already withheld online access for will continue to have this access withheld after launch ONLY if they have the 104 code added. Any previous steps to prevent access will be voided from 1st November if the 104 code is not in place as well.
3. Adding the SNOMED code “Enhanced review indicated before granting access to own health record” will only prevent release of prospective data if on the record at the date of launch. Any changes to online access made after 1st November 2022 must be made through the usual way via Registration > Online Services > View online user > Edit online user access.
4. If you use referral proformas etc on EMIS that pull in the problem page or last consultation entries into merged fields, these documents may pull in data that was intended to not be displayed on the online viewer. If these documents are then saved within the consultation module then all data will be visible within them online. To reduce this risk, ensure that you deselect or delete any data that you do not want online before saving the document, or else withhold the completed document from the online viewer.
5. If you withhold a consultation entry from online viewing there will be no evidence that a person had a consultation at all when viewing on their online app. There may be circumstances where it could be appropriate to enter 2 consultation entries – one to withhold containing the sensitive information (e.g. about domestic abuse) and the other to leave for online viewing about another issue, so that if a perpetrator of abuse is aware the patient is coming to the doctor there will be an entry to view.
6. GP2GP. When a patient moves practice, entries previously marked as “do not display on the patient’s online care record” will no longer be flagged as such. As the date from which prospective entries can be seen on the patient facing app resets to the date of registration at the new practice, these entries will not be visible to the patient. Should the patient approach the practice requesting to reset their visibility date back to 1st November 2022, having had

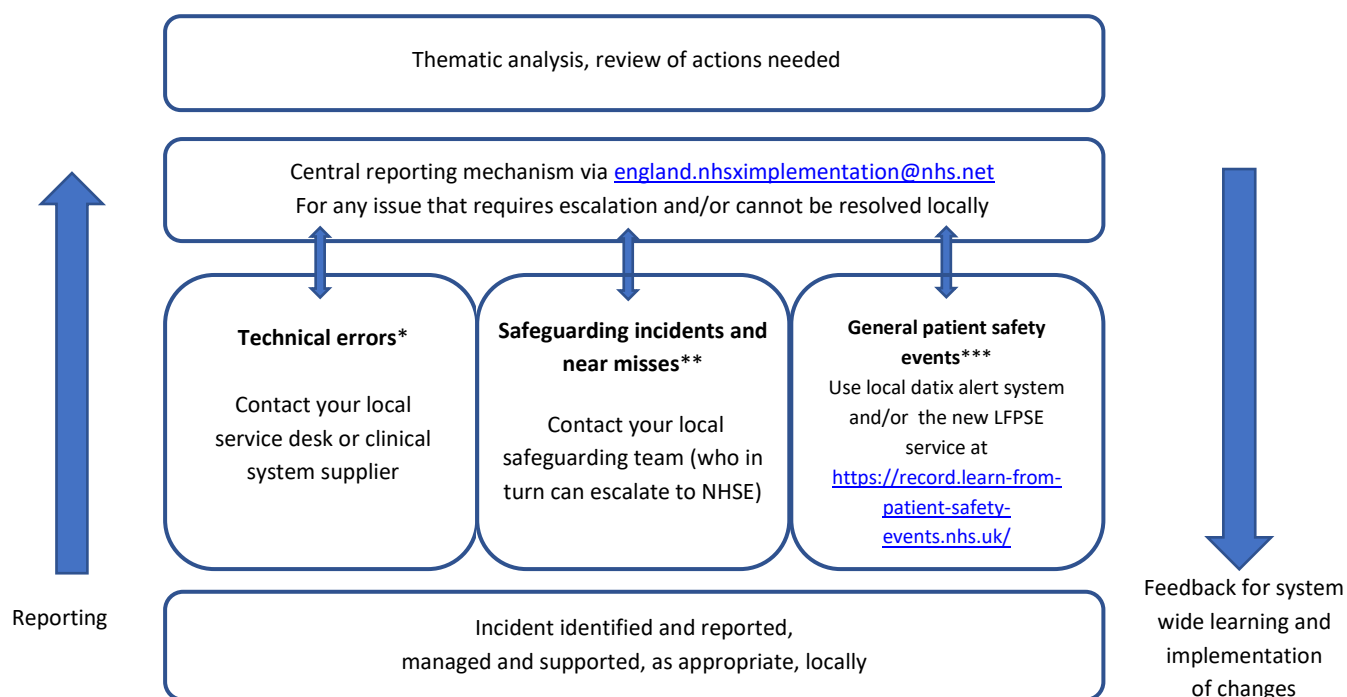
this access previously, the new practice would need to go back & redact entries entered after 1st November as appropriate, or else decline the request to change the visibility date.

If you wish to understand in more detail what patients can see & how your practice data displays onto the NHS App you may find it helpful to set up a synthetic patient on your clinical system & on the NHS App to test. Further information can be found here:

<https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/set-up-a-test-patient>

What should I do if I am concerned that harm has come from access to this data?

Any significant or learning events that happen following launch of this programme should be reported. Any safeguarding issues identified should be shared with your ICS safeguarding team, who can then escalate to the safeguarding team within NHSE to ensure national oversight of any evolving issues. Additional support can be accessed by emailing: england.nhsximplementation@nhs.net



* System not functioning as expected

** A vulnerable adult coming to harm, or near miss, as a result of accelerated access

***Patients coming to harm, or potential for harm, poor outcomes, future risks

Where can I obtain further information?

NHSE guidance relating to the ACAGPD programme can be found at:

<https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/guidance-on-nhs-app-features/accelerating-patient-access-to-their-record>

They have also developed some resources, including videos outlining the programme aimed towards both patients and staff. These can be found at: <https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/guidance-on-nhs-app-features/accelerating-patient-access-to-their-record/resources-to-support-staff-with-providing-online-services#films-to-support-general-practice-staff>

In addition to this, the RCGP have developed a toolkit relating to the ACAGPD programme, which can be found at: <https://elearning.rcgp.org.uk/mod/book/view.php?id=13455&chapterid=768>

All resources will also be available in the NHSx Implementation section on NHS Futures.

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Created for and endorsed by the National Network of Named GPs for Safeguarding, NNNGP

Appendix 1: Online access providers

Service provider	Website
Patient Access	https://www.patientaccess.com
Evergreen Life	https://e-life.co.uk/
Co-op Health	https://www.coop.co.uk/myhealth
myGP	https://mygp.com
digi.me	https://digi.me/nhs
Echo Pharmacy	https://echo.co.uk/signup
AT Tech	https://dr-iq.com/
Pharmacy2U Ltd	https://im1.pharmacy2u.co.uk
Medloop	https://medloop.co/uk-app/
Boots UK	https://boots.com/nhs
My Way Digital Health	https://patient.diabetesmyway.nhs.uk/register/
C Sharp Solutions	https://patally.co.uk/
Patients Know Best	https://patientsknowbest.com/gp
Redwood Technologies	https://portal.practiceplus.co.uk%20/ https://portal.practiceplus.co.uk
Healthera Ltd	https://healthera.co.uk
Doctorlink	https://www.doctorlink.com/patients/
Digital Medical Supply UK LTD	https://kry.se/api/im1-service/
Nurturey - the digital PinkBook	https://www.nurturey.com
Nye Health	https://meet.nye.health
My Cohens	https://www.cohenschemist.co.uk/
Avicenna	https://www.managemymeds.co.uk
Medicalchain.com Ltd	https://hp.medicalchain.com
Medicinechest Limited	https://medicinechest.co.uk/nhs-pharmacy-search
MedAdvisor App	https://app.medadvisor.co.uk
MedAdvisor Day Lewis	https://www.daylewis.co.uk/repeats
Chemist 4U	https://www.chemist-4-u.com/prescription
Charac Limited	https://app.charac.co.uk
Barkerhouse Pharmacy (Appconnect Ltd)	https://appconnect-portal.azurewebsites.net/
PATCHS	https://patches.ai
Substrakt Health Limited	https://patientpack.co.uk/
Voice Connect Limited	https://www.voiceconnect.co.uk

Appendix 2: Walkthrough of consultation redaction in EMIS:



How to withhold a
consultation from onli

Appendix 3: Walkthrough of consultation redaction in SystmOne (also contains EMIS examples):



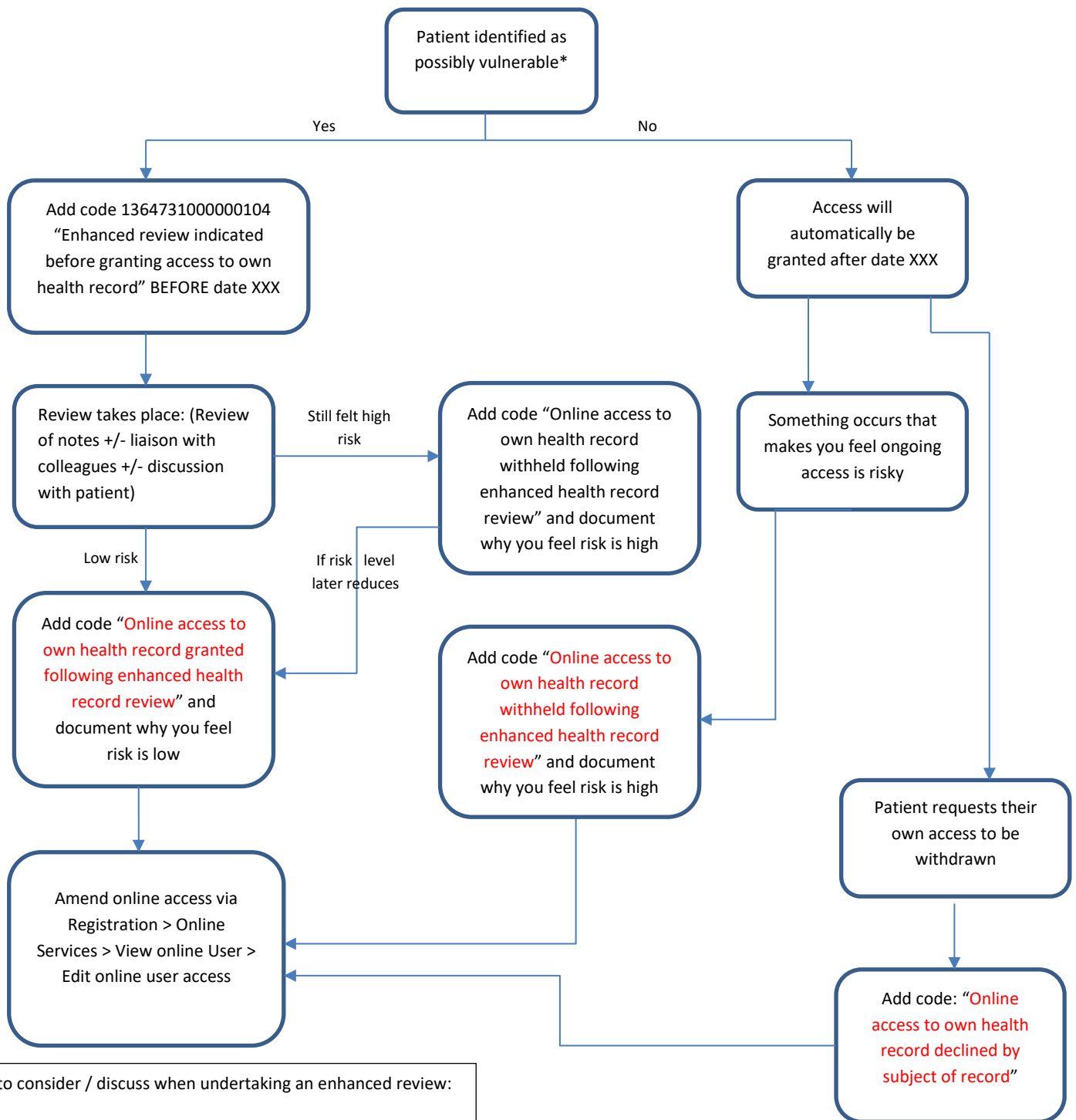
SystmOne Guidance
- Patient Online Recor

Appendix 4: Walkthrough of letter redaction in Docman



Docman10PatientVisi
bilityUserGuide1.5.pdf

Appendix 5: Flowchart to guide enhanced reviews regarding access to the online record



Things to consider / discuss when undertaking an enhanced review:

- Who needs to be present? (And who should NOT be!)
- Is face to face conversation required?
- Why was access initially withheld?
- Is this an ongoing issue or concern? (And if so, is the person accessing adequate support?)
- Explain:
 - What can be seen via the patient facing app
 - How data can be withheld if appropriate
 - Password safety
 - How the patient can request a change to online access in future if desired

*Consider the following when considering vulnerability:

- Diagnoses that might impair capacity to understand sharing of record, e.g dementia, LD, TBI, substance dependence
- Risk of coercion by another
- Past or ongoing domestic abuse
- Past or ongoing safeguarding concerns (child / adult at risk)
- Other possibilities may apply...