

Getting It Write: What To Do Now That Patients In England Can Read Their GP Notes



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Welcome



Charlotte Blease, PhD



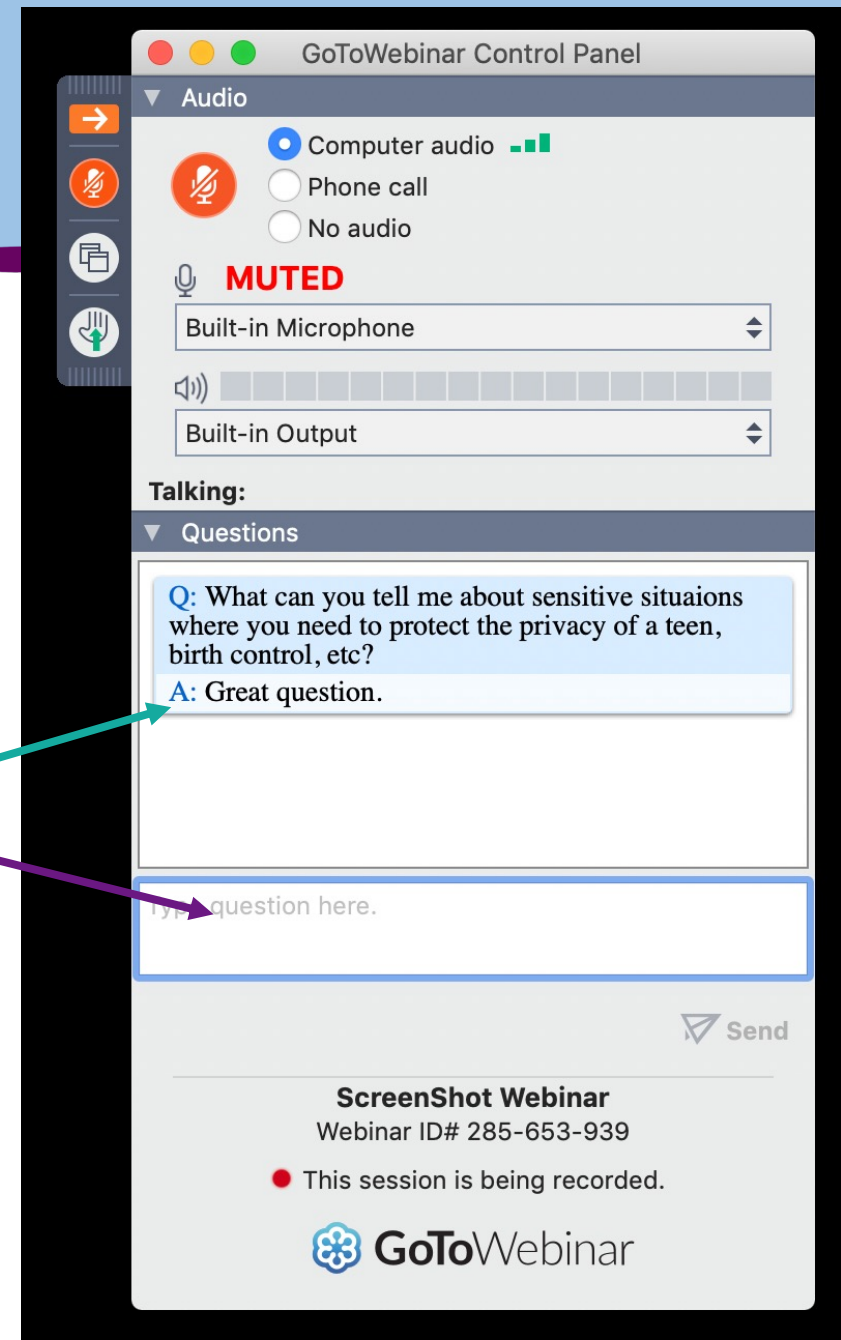
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Housekeeping

- Attendees are muted.
- During the session, **type questions into the “question” section**, and we will address them at end of prepared comments.
- Some answers may be provided during the presentation. Those answers will appear underneath your question.
- The presentation recording will be available at **opennotes.org** and **youtube.com/myopennotes**
- You will receive an email with links to these presentations.



About OpenNotes

OpenNotes is NOT a product or software.

About OpenNotes

Based at the Beth Israel Deaconess Medical Center in Boston, a major Harvard Medical School teaching hospital. **OpenNotes studies** the effects of open and transparent communication on patients, care partners and clinicians.

About OpenNotes

OpenNotes vs open notes

About OpenNotes

- For the last 11 years, we've worked with collaborators around the country and overseas to foster and evaluate the spread and implementation of shared clinical notes (which we call “open notes”).
- Today, in addition to research, we also focus on advocacy and education—like this webinar.
- We're funded entirely by federal and philanthropic grants and gifts.

A Note On Terminology



Visit notes



Free text entries

Visit



Appointment or Consultation

Primary care offices



GP's surgery

Presenters



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A Patient's Perspective



Kay Gallacher
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A Patient's Perspective

What I'm Going To Cover:

- My experiences so far in trying to get access to my notes
- Nothing about me, without me – Sharing information
- Why I will find it valuable to have access to my online notes
- What I want to see in the notes
- What I don't want to see in the notes



Gaining Access To Notes

My Experience

- Salford primary and secondary care notes linked for several years
- Several friends already had access to their notes
- Why couldn't I have access to mine?
- No information on GP website about access to notes



Sharing Information

Nothing About Me Without Me

- Gaining access all seems so complicated.
- I want ownership of my own notes
- I want to be a partner in my own health care
- I want easy access to the notes
- But....Is this going to create another class of patients?



The Value of Having Access

Why I find it valuable to have access to my online notes:

- Improve patient safety
- Reduce time demands on practice staff
- Test results – immediate
- Reassuring
- Provides easy links to other online health information
- Security of data (check)



What I Want To See In My Notes

YES:

- Language I can understand
- Accurate straightforward record of consultation
- Information about the medications / treatments prescribed
- Dates and descriptions – referrals, tests etc



What I DON'T Want To See In My Notes

NO:

- Acronyms
- Jargon
- Language I can't understand
- Technical or medical terms without a lay explanation
- Value judgements



Final Thoughts

Overall Approach

- A positive, proactive response
- Please COMMUNICATE with patients
- Think “patients first”



Thank You.



Kay Gallacher
Public Contributor,
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Patient Access To Online Primary Care Records In England: The Story So Far



Gail Davidge, PhD
Research Associate,
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Patient Access

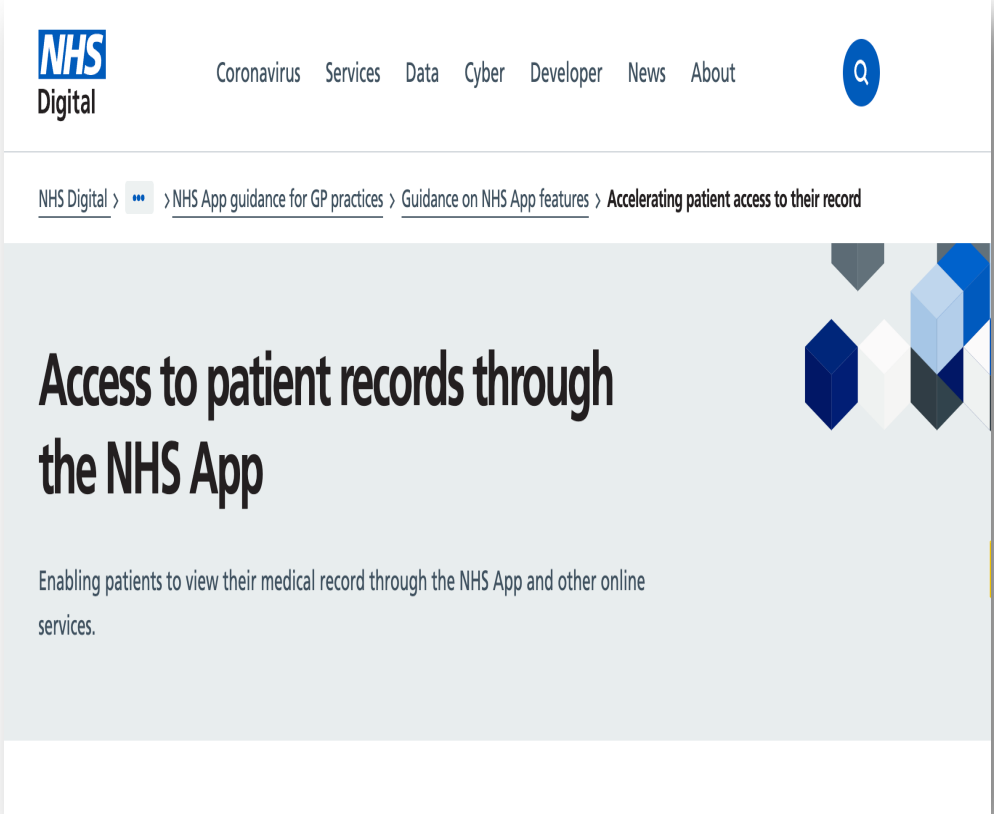
Access By Request

- Patients have to request online access themselves
- Variable and inconsistent levels of access

Access ranges from:

- Transactional functions
- Summary care record
- Detailed coded record
- Full record

Access By Default



The screenshot shows the NHS Digital website interface. At the top left is the NHS Digital logo. To its right is a navigation menu with links for Coronavirus, Services, Data, Cyber, Developer, News, and About. A search icon is located in the top right corner. Below the navigation is a breadcrumb trail: NHS Digital > NHS App guidance for GP practices > Guidance on NHS App features > Accelerating patient access to their record. The main content area features a large heading: "Access to patient records through the NHS App". To the right of the heading is a decorative graphic of blue and white geometric shapes. Below the heading is a sub-heading: "Enabling patients to view their medical record through the NHS App and other online services."

How Can Patients Access Their Record?

NHS Search My account

Health A-Z Live Well Mental health Care and support Pregnancy NHS services

Home > NHS services > Online services

About NHS login

NHS login allows you to access a range of health and care websites and apps with one set of login details.

Where you can use NHS login

You can use NHS login to access many health and care websites, apps and services.

This includes:

- health and wellbeing services
- maternity and child health services
- online pharmacies
- online and video consultation services
- patient access services

evergreen life | Start your wellness journey today

Providing NHS services

NHS Digital

NHS App selected screenshots

Access your NHS account

Log in Create an account

My appointments

Book an appointment

My repeat prescriptions

Order a repeat prescription

Register for Patient Access today

- Beat the phone queue
- Online 24 hours a day
- Appointment booking
- Repeat prescriptions
- Free mobile app
- **To register, just ask at reception**

Patient.co.uk

CMK Medical Centre Providing NHS services

The way we access healthcare is changing. The free Airmid UK app puts you in control.

- Simple Registration**
Self-registration using the NHS Login service. Existing SystemOnline users can use their existing username and password.
- Manage Appointments**
Book appointments with your GP. Receive appointment reminders. View and manage your upcoming appointments.
- Video Consultations**
Direct video consultations with your GP practice and other NHS organisations.
- Medication Management**
Easily request your repeat prescriptions. Set up reminders to take your medication and record what you have taken.
- Your Medical Record**
View your complete medical records at CMK Medical Centre. See your current medication, referrals and test results. Tabbed and easy-to-use.
- Personal Health Record**
Add your own data directly to your personal record from your smart device - readings, medication, symptoms, documents and other notes.
- Customised Care**
Communicate directly back-and-forth with your doctors and wider care team.

You can login with your SystemOnline username and password.

Google Play App Store

Current Research

InPAct - Increasing Patient Activation by encouraging and enhancing online records access in primary care

- Semi structured interviews
- 25 practices: Mix of locations, demographics and levels of records access
- 30 Primary care staff (clinical & non-clinical)



What Did We Find Out?

Overarching Theme: In theory it's a good thing, but...

Most healthcare professionals support the principle of patient access but also express concern and anxiety about implementing the practice.

Sub-Themes

Healthcare professionals . . .

- see both opportunities and challenges for **patient-centered care**.
- are concerned about **their own safety and their patients' safety**.
- want **help navigating** this change.



Optimism, ambivalence and resignation

I genuinely believe that, you know, it is their health, they deal with it 365 days a year, they should be able to have access to it. (P02, GP)

It's coming, whether we like it or not, so it's just getting ready for it really (P25, GP)

I'm not anti it as a fundamental concept...but it feels it's been done too quickly and without the right people involved and without thinking...and for the minimal benefits that we are likely to get, the risks are huge and pretty much guaranteed that things are going to go very wrong. (P28, GP Trainee)

Sub-Theme 1: Opportunities & Challenges for Patient-Centered Care

Clinicians recognize opportunity for:

- Patient ownership, empowerment and control
- Patient activation & health literacy
- Confirmation & reassurance
- Communication, integration and involvement of others in patient-centered care

Clinicians express concern about:

- Equity of access for all patients



Sub-Theme 1: Opportunities & Challenges for Patient-Centered Care

...the fact it's all done online, the digital divide for a start, so this isn't aimed at older adults who maybe don't have access to a computer, you know, who may actually benefit from a more in-depth conversation about their health because they have bigger problems. This is largely aimed at the worried well (P09, GP)

...they can maybe see their results, over the past few years, and then see if it's getting better, you know, it might spur them on a little bit to carry on making those positive changes to their health, and things. (P08, GP)

If they know that I've made a plan and it's all written down, they can check back and be like, okay, you said that we would see each other in eight weeks' time, so that's the plan, so I feel secure that she's not forgotten about me, kind of thing. (P25, GP)

Sub-Theme 2: Keeping Ourselves And Our Patients Safe

Clinicians are worried about:

- Potential to make patients feel worse or put safety at risk.
- How to document sensitive/safeguarding information
- Preventing unauthorised access.
- Litigation, staff well-being and increased workloads.

Clinicians recognize that:

Shared records can also improve patient safety and continuity of care.



Sub-Theme 2: Keeping Ourselves And Our Patients Safe

most patients are fantastic historians, they know...they are experts on them. And if you encourage them to say, look, if something's not right, if something's not right, tell us and we'll look at it together, I think that's the best way forward, and it works for us anyway.
(P06, Clinical Data Manager)

In terms of safeguarding, you know, I need to write this stuff in here but actually it doesn't feel safe because I know patients often give access to different people. (P02, GP)

Sub-Theme 3: Navigating Change

Clinicians recognise:

- Potential change to **relationships and power dynamic**
- **Increased transparency** can impact on **trust**
- Potential to **change the function** and **purpose of the health record**
- **Cultural shifts** will change how we work and relate to patients
- Need for **additional training & Support**



Sub-Theme 3: Navigating Change

Some people are really good at it and emotionally intelligent and some people are pretty crap at it. And I think you only need to read a section of your colleague's notes to realise that we're all very different in how we document things.

(P20, Advanced Nurse Practitioner)

Thank You.



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Top Tips For Writing Notes



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DISCLAIMER

Brian McMillan and Gail Davidge are funded by a National Institute of Health Research (NIHR) Advanced Fellowship (NIHR300887). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.



Related Research

Blease, C., McMillan, B., Salmi, L., Davidge, G., Delbanco, T. (*in press*). **Primary care adapting to transparent medical records: Suggestions reflecting international experience with 'open notes'**. *British Medical Journal*



What I'm NOT Going To Cover

- Evidence for the benefits/drawbacks of records access
 - Impact on workload
 - Impact on risk of litigation
- The current legal situation in England
- If this could have been done differently [e.g. Dr Hannan's opt-in]
- The why, when, and how of redaction
 - Disabling records access altogether (NHS Video, SNOMED codes)
 - Removing entries from patient online view (NHS Video, EMIS, SystemOne)
- Proxy access



Top 6 Tips For Writing Notes (Not Exhaustive!)

- Inform
- Involve
- Explain
- Empathise
- Reduce jargon
- Support



Inform

Raise awareness (link to patient info materials)

- Posters, texts, during consultations
- Discuss benefits (e.g. aide memoire, test results)

Discuss risks (e.g. coercion, errors, misunderstanding)

- Advise can be turned off on request



Involve

Verbalise when writing

Dictate referrals with patient in the room

Spin screen round (providing safe to do so)

- Anything to add?
- Referral forms



Explain

Differential diagnoses

- Don't be tempted to leave these out

Blood test requests

- e.g. Irritable Bowel Syndrome (Ca125, coeliac, Fit)

Medical terms

- e.g. BMI

Empathize

Would you want to read this about yourself?

- obese (BMI over 30)
- poor historian (unsure when/what...)
- refuses to (prefers not to)
- known drug abuser (reports using...)



Reduce Jargon

Use system tools

- EMIS ([link to quick codes and text example](#))
- SystemOne ([link to abbreviation dictionary tutorial](#))

Third party tools

- Text expanders ([link to eGPLearning](#))

Manually

Explain abbreviations or [provide dictionary](#)



Support

Digital champions ([link to example](#))

Desktop options

- e.g. [NHS App online](#)

How to guides

- E.g. [AbilityNet](#)

Retain non-digital alternatives



Thank you.



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Q&A

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