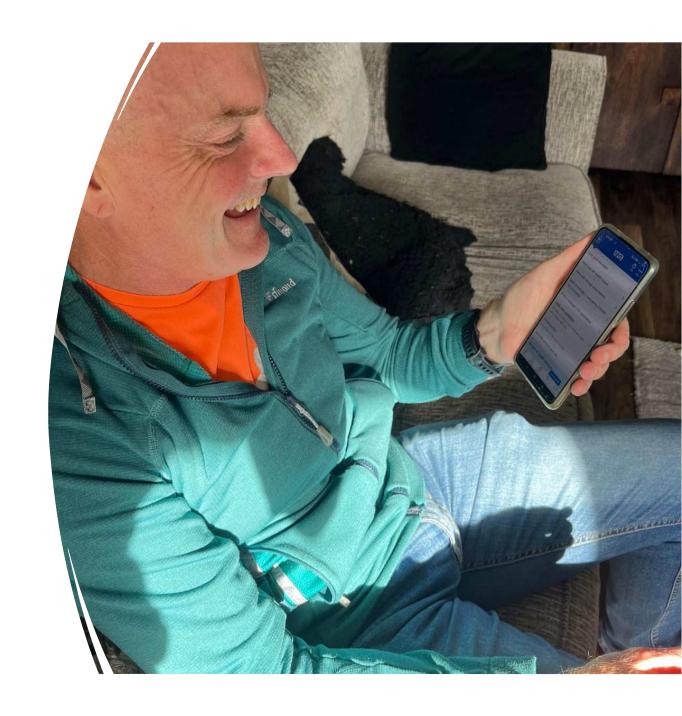


Access and Prospective Access

- Dr Amir Hannan, @amirhannan
- Full-time General Practitioner
- Haughton Thornley Medical Centres, Hyde, Cheshire
- Chair West Pennine Local Medical Committee
- Chair Association of Greater Manchester Local Medical Committees
- Chair, World Health Innovation Summit

Summary

- My personal journey
- Patient access to records and understanding
- Partnership of Trust
- Responsible Sharing
- Prospective Access
- The future











BBG HOMEPAGE | WORLD SERVICE | EDUCATION

low graphics version | feedback | help

B B C NEWS

UK Politics with new GPs **Business** Sci/Tech Background Briefings **Medical notes** Education Entertainment Talking Point

In Depth

AudioVideo

Wednesday, 4 October, 2000, 00:57 GMT 01:57 UK World Shipman surgery open



Patients must stay at Dr Shipman's old surgery

Two GPs taking over the practice of killer doctor Harold Shipman are seeing patients again at the surgery where several of his victims died.

Though West Pennine Health Authority agreed early this year that the surgery would move from its location in Market Street in Hyde, two new GPs are continuing to see patients there.

It is believed that at least five of Shipman's victims died in the surgery and the local community health council had argued the building would hold too many memories for patients and relatives of those he murdered.

But it has proved difficult to find alternative premises and so the two GPs have been forced to take over Shipman's rooms as well as his

Shipman is currently serving life imprisonment for the murder of 15 of his patients.

On their first day at the Market Street surgery Dr Amy Cumming and Dr Amir Hannan faced chaos as Shipman's children had stripped the premises of all its equipment over the

Dr Cumming told Doctor magazine that practically everything, including computers, phones, desks and chairs had been taken and equipment had to be borrowed from other local surgeries.

Unhappy

Dr Cumming also acknowledged that there may be a number of patients who may be unhappy about returning to the building where Shipman practised.

West Pennine Health Authority has confirmed that it will continue to assist any of the 3,000 patients to transfer to other surgeries and that a new surgery will be built within the next year.

Dr Cumming added: "It is going to be a good practice, a smoothly-run practice and we are going to regain the trust and confidence of the patients, as far as anyone can."



- BBC RADIO NEWS
- BBC ONE TV NEWS WORLD NEWS
- BBC NEWS 24 BULLETIN PROGRAMMES GUIDE

- 24 Feb 00 | Health
- 'Move Shipman's surgery' 21 Sep 00 | Health Shipman inquiry to be held in public
- 26 Sep 00 | Health Shipman patient 'unlawfully killed
- 31 Jan 00 | UK Shipman jailed for 15 murders
- ▶ 31 Jan 00 | The Shipman How many did Shipman

Internet links:

General Medical Council

The BBC is not responsible for the content of external internet sites

Top Health stories now:

- Postcode lottery in GP services
- IVF mix-up heads for court
- Transplant first for cancer patient
- · Costly wait with dementia symptoms
- Chicken checked for BSE
- New hope for Aids vaccine
- · Campaign to end stigma of mental illness
- Parents to sue over epilepsy row

Links to more Health stories are at the foot of the page.

Dr Cumming added: "It is going to be a good practice, a smoothly-run practice and we are going to regain the trust and confidence of the patients, as far as anyone can."

http://news.bbc.co.uk/1/hi/health/955009.stm

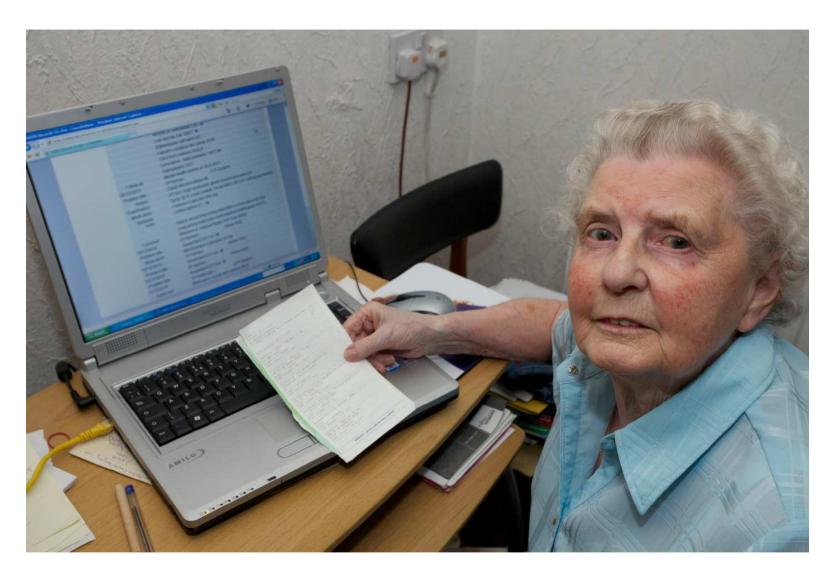
One day in 2003....



Example photo – not a true patient

Margaret Rickson Patient of Haughton Thornley Medical Centres





Mrs Margaret Rickson



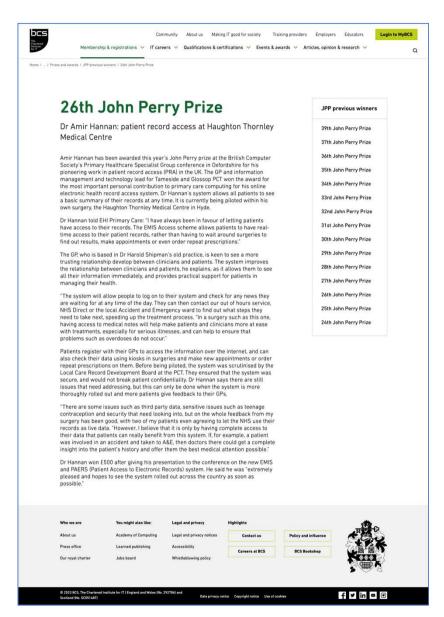
Yvonne Bennett





Margaret Rickson – Health's Top 50 Innovators in 2013





https://www.bcs.org/membership-and-registrations/member-communities/primary-health-care-specialist-group/prizes-and-awards/jpp-previous-winners/26th-john-perry-prize/



Dr Hannan

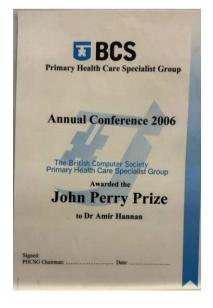
General Practitioner Clinical Governance Lead Information Management & Technology Lead Access, Booking and Choice Lead Tameside & Glossop PCT

Amir.Hannan@nhs.net

23rd May 2006

Please see NOTES that accompany the slides

Download





Medical and Care Compunetics 4 L. Bos and B. Blobel (Eds.) IOS Press, 2007 pp. 108-116 © 2007 The authors and IOS Press. All rights reserved.

Towards a Partnership of Trust

Dr Amir Hannan, B.Sc., M.B. Ch.B, M.R.C.G.P. a & Fred Webber, B.Sc., Ph.D. b a General Practitioner, "Information Management & Technology lead", "Clinical Governance lead", "Access, Booking & Choice lead", "Professional Executive Committee member", Tameside & Glossop Primary Care Trust. Member of the Records Access Collaborative. Member of the Clinical Leaders Network. b Patient.

Abstract: The relationship between doctors and patients is changing as patients live longer but with a greater incidence of chronic disease. An increase in the availability of information about health coupled with the Choice agenda and a patient-led NHS has encouraged patients to learn more about their own health. Patient access to their own OF-held records has led to the development of a Partnership of Trust whereby patients and their clinicians develop as shared understanding of their health and what each do for each other. This could potentially lead to significant patient and clinician benefits ultimately leading to better outcomes for individuals and societies.

Keywords: Records Access, Patient Empowerment, Trust, Doctor-Patient relationship

The traditional concept of the relationship between a doctor and patient is something that has remained relatively unchanged for generations. Generally speaking, this has taken the form of an adult/child, or teacher/pupil relationship. In such relationships the doctor has been the dominant component and the patient the usually passive recipient of the doctor's advice and guidance. Often the doctor was held in awe by the patient and typically there was little or no discussion during the consultation. When feeling ill the patient would visit the doctor and the main concern was to ask the doctor to "make it better" or to be given some medicine to ease the condition. This may partly explain why up to 40% of general practice consultations are for relatively minor conditions that could be managed without the need for a clinician or managed without a specific treatment [1].

However the nature of the relationship between doctor and patient is changing. Modern medicine is enabling patients to live longer but with a greater burden of chronic disease. The incidence of obesity and with it the risk of developing hypertension, diabetes, ischaemic heart disease and cerebrovascular accident [2] continues to rise in the main due to a poor lifestyle, poor diet, lack of exercise and genetic factors [3]. But it is also widely perceived to be readily controllable by the individual [4]. Patients and the medical profession have responded by trying to find pills for every ill [5] with little gain. At the same time, patients are increasingly being managed by teams of people from different disciplines and in different care settings. This may result in patients getting different messages depending on what information the clinician has before him [6].

Journal of Communication in Healthcare Volume 1 Number 1

The paradigm shift in healthcare — Overcoming challenges in giving patients access to their electronic records

Amir Hannan

Received (in revised form): 27th September, 2007

Thornley House Medical Centre, Thornley St, Hyde, Cheshire SK14 1JY, UK Tel: +44 (0)161 367 7910; Fax: +44 (0)161 367 1799; e-mail: amir.hannan@nhs.net

Amir Hannan is a full-time general practitioner in Hyde, UK. He is the information management & technology lead for Tameside & Glossop Primary Care Trust having recently stepped down as clinical governance lead and as a PEC member. He is also a founding member of the Records Access Collaborative, having enabled his natients to be able to have full access to GP-held records if they so wish for over one vear. He is a member of the local Care Record Development Board. He has written and lectured extensively on health informatics matters and his experience to date. He is also a member of the HealthSpace Reference Panel as well as the National Clinical Reference Panel within NHS Connecting for Health. He is a member of the Clinical Leaders Network and a GP adviser to www.OnMedica.net. He is a co-opted member of the Primary Healthcare Specialist Group, a branch of the British Computer Society. He is a member of the editorial board of the Journal of Communication in Healthcare.

ABSTRACT

As the delivery of healthcare by an increasing number of service providers becomes more complex, there is an increasing need for patients to understand their treatment plans and to compare them with what they should expect to receive. Changes in society mean that patients may now have the opportunity and desire to view their electronic health record and share it with others electronically. This is the basis of the paradigm shift in healthcare. But patients, clinicians and managers need to consider how to do this safely and responsibly. There are a number of challenges that need to be overcome including informing patients and empowering them, understanding the financial model to support this as well as the change management and data protection issues, understanding how information is recorded in the record, producing tools to encourage patients to be active participants, reducing the digital divide, enabling easy identification of high-quality information, producing a framework for enabling safe sharing of information, understanding the role of a local care record development board which helps to manage the change, enabling semantic interoperability in a global market and understanding how we can assess its success. This heralds a new era of 'real-time digital medicine'.

Keywords: records access, partnership of trust, digital divide, semantic interoperability, patient and public involvement

INTRODUCTION

'Everyone has a doctor in him or her; we just have to help it in its work' Hippocrates (460–377 BC)

Taking an aspirin a day in someone who has suffered a myocardial infarction (MI) reduces the risk of a further MI or death by 15–30 per cent. Taking a beta-blocker

Journal of Communication in Healthcare
Vol. 1 No. 1, pp. 7–19
© Henry Stewart Publication



Informatics in Primary Care 2010;18:41-9

© 2010 PHCSG British Computer Society

Refereed paper

Providing patients online access to their primary care computerised medical records: a case study of sharing and caring

Amir Hannan MBChB BSc MRCGP

Primary Care IT Lead, NHS North-West and General Practitioner, Haughton Thornley Medical Centres, Hyde, Stockport, UK

ABSTRACT

Background Healthcare systems are struggling to deliver high quality care and constrain costs as more people live longer with a greater burden of disease. Providing patients with access to their records and with practice specific health information may improve the quality of care.

Objective To describe one practice's experience of providing patients with access to their primary care records.

Subjects and setting Approximately 12 200 patients, registered with a semi-rural practice based on two sites, have been offered online access to their records.

Method A description of strategies used to encourage patients to sign up for access to their records. This includes the development of a practice-based web portal regularly updated with health advice.

Results Six percent of the patients in the practice now have access to their records via an explicit consent process. There are over 100 000 viewings of the practice web portal. There have been no problems as a result of providing access. Further developments include developing a new process for patients unable to provide consent in nursing

Conclusions This case study provides a model of how to set up patient access to electronic records.

Keywords: computerised medical records systems, confidentiality, medical informatics, patient access to records, personal health records

Introduction

Our work as clinicians is becoming more challenging, with greater demands on our time, a greater need to demonstrate quality and an increased risk of litigation if things go wrong. More people are living longer with a greater burden of disease and increasing financial pressures on the system to deliver. ^{1,2} Healthcare systems seek to deliver high quality care, control costs and balance patient expectations and experience.³ The General Medical Council advises UK doctors in Good Medical Practice (2006): Patients must be able to trust doctors with their lives and health.⁴

It is incumbent upon the medical profession to practice safely and effectively, and continually improve the patient experience. However, as Sir Cyril Chantler states: 'Medicine used to be simple, ineffective and

relatively safe. It is now complex, effective and poten-

The benefits that good information technology (IT) implementation has brought to health care are improvements in quality and safety² as well as the opportunity to provide patients access to improved health information and to their records. In the UK, health-care organisations are now being challenged to focus on quality, innovation, productivity and prevention (QIPP),⁸ and to achieve improvement through IT, including patient access to their records.⁸ Developments in primary care IT systems mean that it is now possible for at least two electronic patient record (EPR) systems in the UK to enable patients to access their full GP electronic health records – EMIS¹⁰ and

Partnership of Trust









Dr Richard Fitton



Ingrid Brindle







Ingrid Brindle and Dr Hannan at the International Forum on Quality and Safety in Healthcare 2017

Glen Griffiths
ex-Vice Chair
Primary Healthcare Specialist Group,
British Computer Society





A practice-based web portal for 21st-century patient healthcare

Haughton Thornley Medical Centres won the 2009 Management in Practice IT Award for their interactive practice web portal, which features an array of information to help patients manage their health. **Dr Amir Hannan** explains why he thinks the web is a vital tool to support self-care, and how this can be used by GP surgeries



Join our

practice

now

Haughton Thornley Medical Centres

Haughton Thornley Patient Participation Group | Staff

Haughton Vale Surgery 0161-336-3005 Thornley House Medical Centre 0161-367-7910 Out of Hours

ENHANCED BY Google

Inspected and rated

Outstanding CareQuality

Commission

We are welcoming new patients. Please click here to join us now!

NEWSFLASH: The NHS is under massive pressure. Please be KIND to our patient advisers who are trying their best. Getting the best from the practice - be prepared for now & the future! Be the BEST you can be with our help!

Group A Streptococcus and Scarlet Fever and when you should worry about your child Click here if you are worried and want to know what to do

Going on holiday abroad? Here is all the advice you need including info about vaccinations

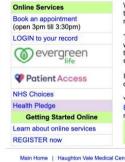
General Practice has remained open throughout the pandemic and we have continued to see patients face to face and offer home visits where clinically needed and appropriate. Click here to read full statement and listen to BBC Radio Manchester interview 14th October 2021 now.

Learn how we are engaging patients (and staff) through the use of technology. We encourage all patients / carers to sign up for online services and Register Now. If you are having problems registering then access support via Evergreen Life and Patient Access. Please email us on htmcpatient@nhs.net if you have any further IT problems.

Want to lose weight and feel great? Learn about the Pioppi Diet now

CQC rating: Outstanding I PPG Chair's Report 2017-18 I 82% (10,382 patients) have records access and understanding Can I have an appointment with the doctor, please? I Watch the talk Sign up for access to records English & Bengali Over 10,000 patients have done questionnaires for records access and understanding I Keep uptodate I Radio 4: Aftermatt Shipman

Donate to food bank I Latest newsletter I #Empowerlution at HTMC & local neighbourhood



Welcome to our Home Page which has been compacted to provide you with the most essential information for most of your needs as a patient.

The main website offers more information for those who wish to learn more about what they can do for themselves supported by resources we have gathered to support you and your family's needs.

If you or your loved ones would like to sign up for FREE online services including apps then please click here.

You can send secure non-urgent messages online via Evergreen Life, Patient Access or send an email about non-medical matters to htmcpatient@nhs.net

mmon Care Appointment System Pledge



Main Home | Haughton Vale Medical Centre | Thornley House Medical Centre | Tameside and Glossop CCG | Health information in other languages | Privacy Policy | Terms and Conditions



Glen Griffiths, Ingrid Brindle and Bruce Elliott



Dr Brian Fisher, Dr Richard Fitton, Dr Amir Hannan at the General Medical Council



Issue 14 July/August 2007

A new partnership of trust



Electronic data is now theoretically available anywhere in the world at any time and at any place and – unlike doctors' handwriting – it can be read or used by clinicians, patients and computers alike.

But what should patients confide to the doctor and with whom should the doctor share this data? Hospital doctors, GPs and nurses treat patients using separate records that are unable to link with one another – so does this mean confidentiality actually reduces the safety and effectiveness of care?

A change in doctors' attitudes about sharing data is necessary – records should follow the patient around, with the patient controlling the access.

Of course, there are very real issues here: for example, vulnerable people, such as the elderly or those with mental disabilities, will find it difficult to manage complicated security technologies – yet, as they are least able to represent themselves and their conditions, they may stand to benefit most from the sharing of electronic records.

So how do we build and maintain trust in electronic records?

Among other things, doctors and patients need to:

- → be able to identify who stores, uses and manages data
- → know who has seen the various parts of the records
- → understand that data cannot be deleted from the record but can be hidden, quarantined or annotated

- → know that some data cannot be seen at all without the patient's consent
- → know who can use the care record in the patient's absence
- → understand the clinician's responsibility to disclose information when the public is at risk

Honesty, openness and transparency are paramount: doctors are contractually obliged to make a record of their consultations and patients should be able to see this information as soon as it has been recorded. Doctors will be able to record some data so that only they can see it. Patients may request that socially sensitive information is not shared – and third party data should never be shared without that third party's consent. Existing legal safeguards will protect this sensitive information.

Patients must be able to access their complete record in order to reduce the fear that ill-health can cause and to allow them to make informed decisions about their care. Patients, IT specialists, clinicians, administrators and doctors need to come together to create, publish and update a new, liberal and emerging regulatory framework for the data that is to be disclosed, recorded, shared and corrected in electronic records.

About the authors

Dr Richard Fitton and Dr Amir Hannan are both GPs and members of the Record Access Collaborative. Fred Webber and Yvonne Bennett are patients who have been consulted in the creation of patient-centred medical services in the Tameside and Glossop PCT.



Case study: Painful feet presented serious problem

On a typical busy day a young African male came to AEE, complaining about his very painful feet. He was unable to weight bear and his feet were very tender. X-ray and routine blood tests were done. There wasn't any history of trauma and the X-ray turned out to be normal.

A provisional diagnosis of plantar fasciitis was made. On blood tests we found his hb was very low and there was some sickling of his RBCs. Surgical causes were ruled out. Thinking of it as a sickle cell crisis, the patient was transferred to the medical assesment unit.

The patient was further diagnosed while having a blood transfusion. He had cervial and axillary lymphadenopathy and hepatosplenomegaly. The CXR showed miliary shadowing. Now the entire diagnosis was questioned and, after counselling, an HIV test was carried out which turned out to be positive.

The patient was later started on antiretroviral and antituberculos therapy.

There were some complaints of low grade fever, rigors and chills for weeks but he came into A&tE because of his very painful feet. This was later explained as HIV Neuropathy and the low Hb was explained by alpha thalassemia trait.

I just wonder how many doctors have come across a presentation that has ended up with such an unexpected diagnosis.

Dr Farooq Usman, SHO Surgery, Ysbyty Gwynedd, Bangor

5





Enabling Patients to Access Electronic Health Records

Guidance for Health Professionals

Version 1.0 | 1 September 2010





Download

Evergreen Life PHR

Records

Tests

Q

Search

① Test Patient Eight

Ö Food

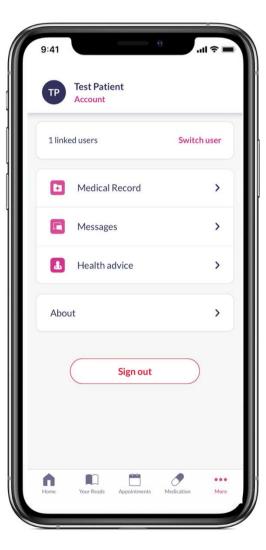
Happiness

COVID Check

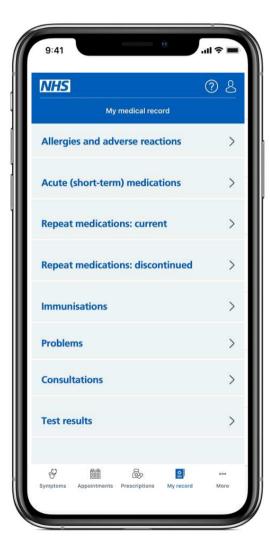
(53)



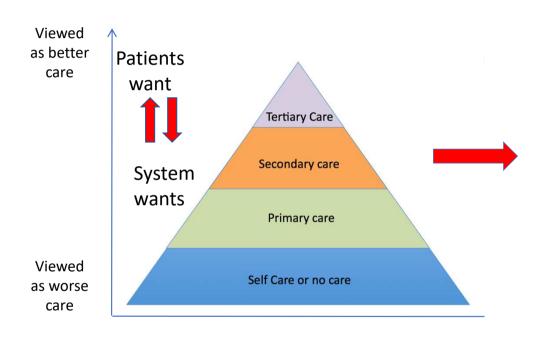
Patient Access



NHS App

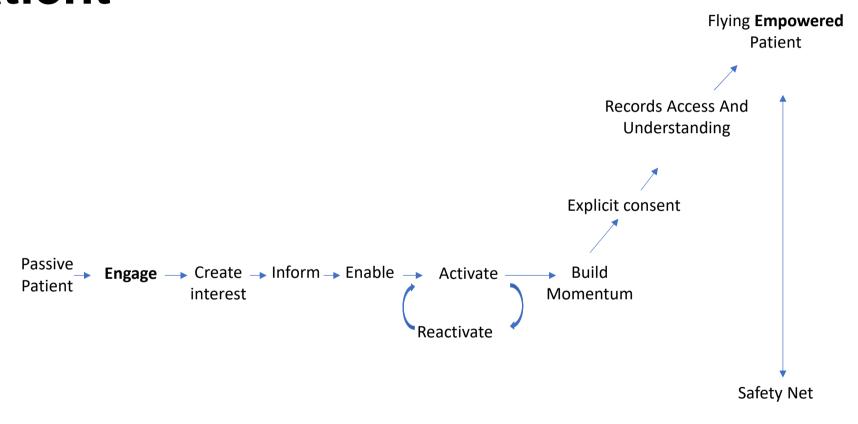


Paradigm Shift in Healthcare

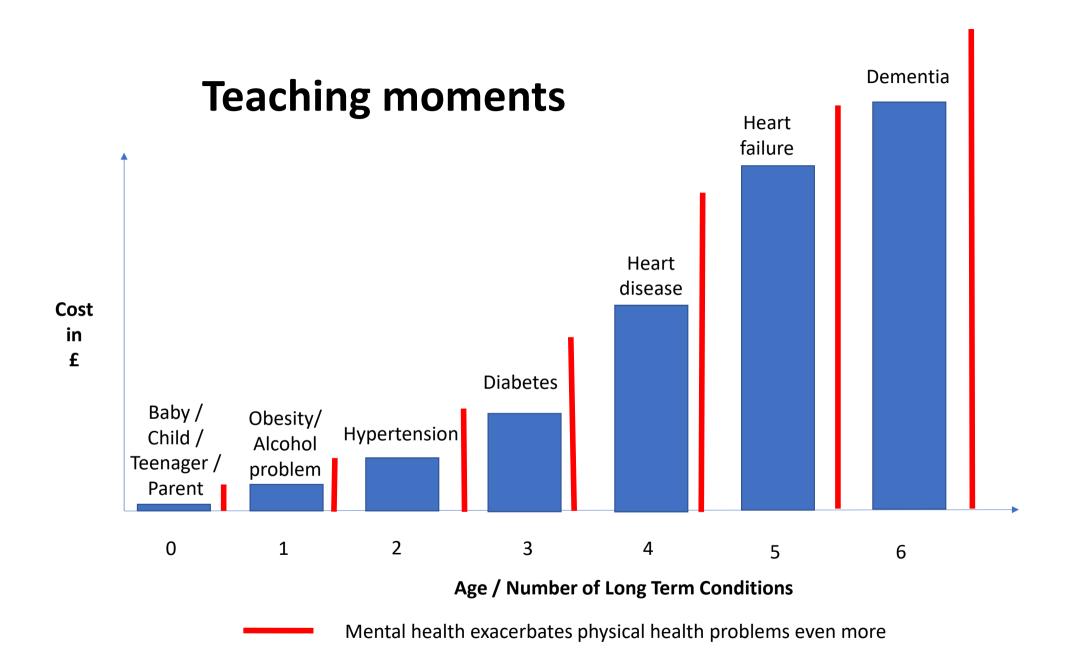


"Industrial Age" healthcare

Passive Patient to Flying Empowered Patient



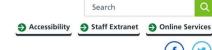
With thanks to Glen Griffiths @griffglen



Our process







f

Home

Patient Cont

Practice Services

Health & Wellbeing

Our Practic

Contact

Home > Do you want to see what your doctor or nurse has written about you or check your GP Electronic Health Record ?

Do you want to see what your doctor or nurse has written about you or check your GP Electronic Health Record?

Well done. You are a couple of steps away from getting access and understanding of your GP electronic health records. Watch this short video which tells you what to do next. Scroll down to the bottom if you would like to know more



You will need to collect your PIN NUMBERS from the receptionist or ask for it to be emailed to you. You will need to speak to the receptionist who can then arrange this for you or send an email to httmcpatient@nhs.net.

Records Access and Understanding Safety Checklist Questionnaire

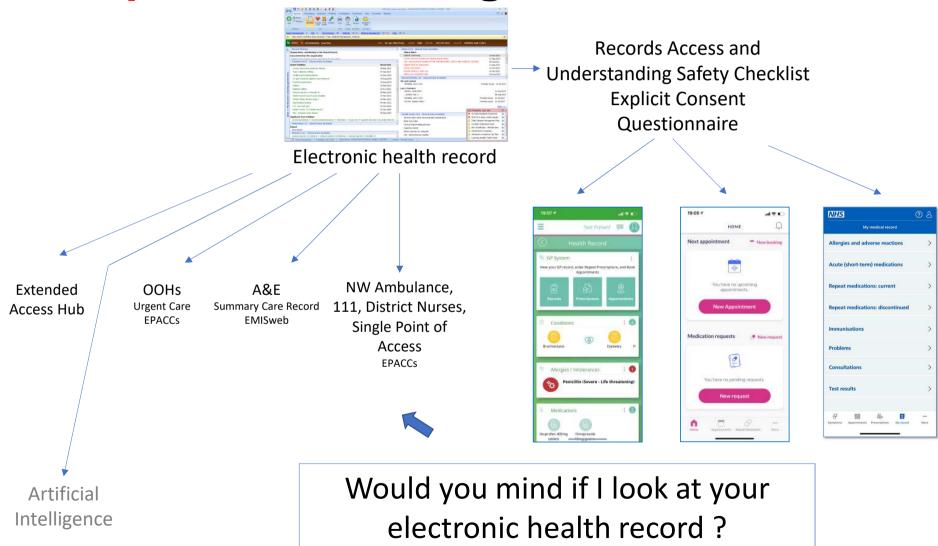
Please complete all 10 questions. We will then process your request and send a reply back to confirm you have access to your

	plete. Every person needs to complete this. If you are doing this ur relationship with the person and that you have permission to
Name	
First	Last
Address	
Postcode	
Postcode	
Email	
Email address	(G
Mobile Phone Optional	
Mobile number in case we need to contact you	
Home Phone Optional	
Home number in case we need to contact you	
1. I am doing this questionnaire for myself? Yes No 2. Can you read and understand English? Yes	
No	
3. Have you registered for ordering repeat prescription Yes	ons and booking appointments on-line?
○ No	

4. Are you happy to use passwords to access your record?
Yes
No
5. After you have been to the doctor or to the hospital, you can check if the encounter has been recorded
and what was discussed. Do you agree this is a good reason to have access to your records?
Yes
○ No
6. Would you like to feedback what you think of the Records Access system?
Yes
No

7. There maybe an instance when accessing your medical records online, you may read some info that could be shocking or upsetting. What do you do if this happens and you cannot speak to yo	
nurse immediately? Please tick all options that apply Not view the test results but wait until you see the doctor / nurse	
Panic and get worked up	
Look at some of the recommended websites under self care on www.htmc.co.uk	
Wait and contact the practice the next working day	
Speak to a friend or family member whom you trust	
Contact 111 to get further information	
Contact GoToDoc, the Out of Hours service (details available at www.htmc.co.uk)	
Go to A&E for further help	
Other	
8. You see a new letter has arrived in your electronic health record. You open up the letter to finabout another patient in the practice. What do you do?	ıd it is
Read it then tell others what the person suffers with	
Inform the practice	
Stay quiet and not tell anybody about it	
Other	
9. Would it upset you if you read something somebody else has said about you with regards to yo	our health?
This does NOT mean others can see your record without your permission.	
No	
Yes – I don't want this information kept in my record	
Yes – You should not believe what others say	
Yes – This could destroy our relationship	
I do not understand what this question means	
Don't know	
Other	
10. Do you feel you understand what Records Access means?	
Yes	
No	
Other	
Submit	

Responsible Sharing



Data Sharing

Home	GP surgery	Local Data Sharing Agreements		Care Record	Summary Care Record	? Healthbook
Patient Carer	General Practice	Primary Care Networks	Locality Social Services Acute Trust Voluntary Sector Organisations	Integrated Care System	National	Global multi-national
1-4	2,000- 25,000	30-50,000	200,000	2-3 million	? 45 million	? 2-7 billion

What is our process?

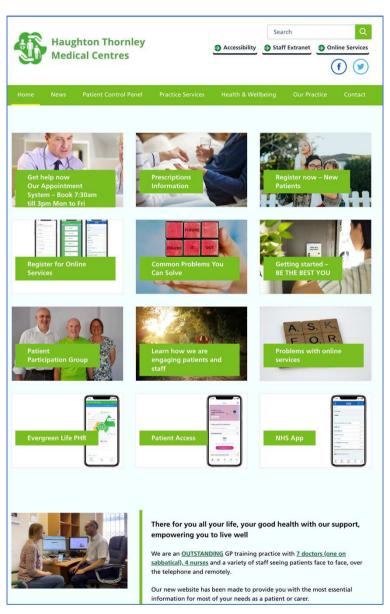
- Assume all patients / carers can have full access
- Engage our **Patient Participation Group**
- Patients are informed, engaged and activated in the consulting room
- To get the full "records access and understanding"
- Complete Safety Checklist questionnaire
- Opportunity to answer any questions
- Check GP electronic health record
- Add code "Patient Remote Record Access Enabled" to active problems list
- Switch on all the subcomponents for full records access including free text from 1/1/1900
- Send a **Text Message** to the patient informing them
- Email their pin numbers to them if not already been given them
- **Inform** them they can email the practice if they have any issues
- **Publish** our data every week to monitor the improvement

Main exclusion

- Unable to provide consent
 - Dementia
- Digital Divide & no family / carer
- No time / resources to devote
- (Lack of interest)

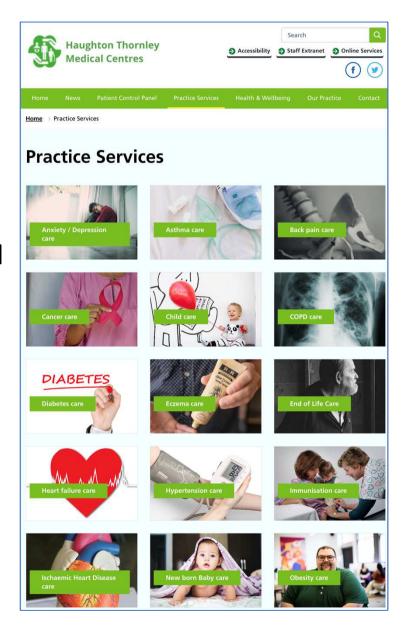
Problem areas

- Severe mental illness
- Child protection
- Coercion

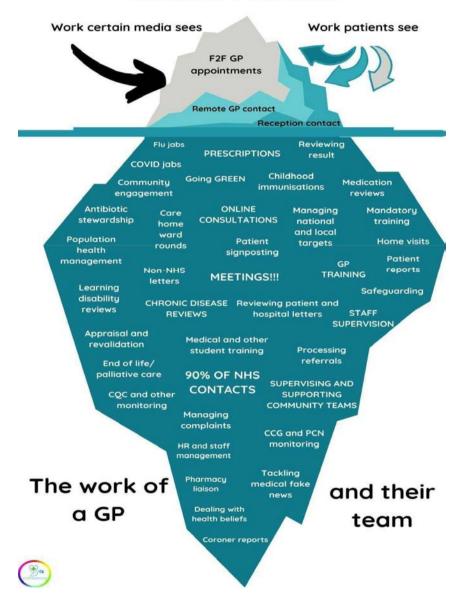


Practice-based web portal

www.htmc.co.uk



General Practice

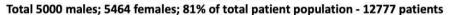


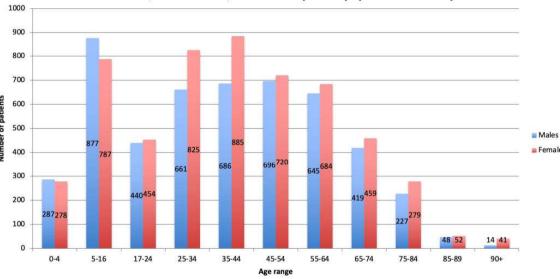
Challenges

- Ongoing issues around not able to sign up,
- Forgotten passwords,
- patients unsure what it means especially blood results,
- when signing people how to onboard so patients get the best from the practice,
- maintaining easy access for patients with the practice,
- digital divide,
- releasing admin staff to process requests
- redaction software easy to just default to no access but this creates trust issues
- turnover of staff,
- clinicians leaving
- Trainees and medical students have no education or training

Patients with access to their GP electronic health records at Haughton Thornley Medical Centres 31st October 2023

Total 10,464 patients





https://www.htmc.co.uk/do-you-want-to-see-what-your-doctor-or-nurse-has-written-about-you-or-check-your-gp-electronic-health-record-2/how-many-have-signed-up-for-full-records-access-and-understanding/

Type of patient	How many have signed up	%
Asthma	1725/1952	88%
COPD	304/397	76%
Diabetes	846/993	85%
Cancer	379/468	80%
Depression / Anxiety	3589/4134	86%
Rheumatoid Arthritis	67/78	85%
Heart disease	368/471	78%
Pregnant	94/96	97%
Learning disability	61/82	74%
Bengali patients	1427/1622	87%
Medications ordered online	4244/12777	33%
Total patients	10464/12777	81%



Online access to GP health records

Enabling patients to view their GP health record information through the NHS App and other online services.

Prospective Access

Patients with online accounts such as through the NHS App will be able to read new entries, including free text, in their health record. This change only applies to future (prospective) record entries and not historic data.

Following <u>proposed changes to the 2023/2024 GP contract</u> which were announced in April, <u>legislation</u> has now been passed so that new health information is available to all patients (unless they have individually decided to opt-out or any exceptions apply) from 31 October 2023.

What is wrong with prospective access

- Viewing your records including free text is not the same as booking an appointment or ordering repeat prescriptions or even sending a message
- Different knowledge, skills and attitudes needed with knowledge development
- Clinical role that has been made into administrative
- No trusting relationship developing or seen as part of a clinical experience Royal Colleges, GMC, NMC need to get behind this with education, training, setting expectations, KPIs for Trusts / Boards
- Needs overhaul of NHS Choices and also all other "health education" outlets
- Not just about safeguarding concerns. What about breaking bad news, those lacking capacity, severe mental illness / personality disorder, in coercive relationships
- What about poor record keeping and "failing practices" that have significant other problems too eg lacking staff, run by locums where there is no continuity
- No risk sharing onus lies completely with data controller whose thoughts are not being registered
- Access to a clinician is currently very difficult and getting worse
- Mixed economy of "lite" access and "full access to whole record"
- What happens when patients continually complain about minutiae?
- No investment and hence no "must dos" but "nice to have" for those who have time (which nobody does) no perceived
 importance by those looking at what to do next
- Health inequalities will widen unless somebody invites them

OPINION



- North Middlesex University Hospital, London
- 2 Haughton Thornley Medical Centre

Cite this as: *BMJ* 2023;380:p247 http://dx.doi.org/10.1136/bmj.p247 Published: 31 January 2023

Empowering underserved groups through access to electronic health records

Patients need support to ensure that access to electronic health records doesn't create another digital

Aleena Hossain, 1 Amir Hannan2

Giving patients access to their electronic health record (EHR) enhances their understanding of their care, empowering them to make informed decisions and better manage their own health, which can ultimately improve outcomes. ^{1,2} Moreover, it can increase efficiency in primary care. ³ Patients in England were promised full access to their GP medical record by the government, but these plans to enable access across all practices through the NHS app from November 2022 were curtailed after concerns were raised about clinical safety and the redaction software tools available. ⁴

The covid-19 pandemic has exacerbated the already weighty demands on primary and secondary care, and improving patient access to EHRs could help to alleviate some of these pressures. Yet, as we continue to roll out patient access to EHRs, we must take care not to perpetuate existing healthcare inequalities, sinstead aiming to minimise these by engaging with patient groups who are under-reached and underserved by healthcare services. § 7

Haughton Thornley Medical Centre in Greater Manchester has successfully encouraged EHR uptake over the past 17 years, and 81% of patients currently have full access. The centre has learnt five key lessons on how healthcare professionals and policy makers can enable under-reached patients to access their EHR.

Key lessons

Define and identify under-reached groups for the local area

The groups of patients who are underserved by healthcare services will vary from practice to practice depending on the local context and community. Patients may, for example, face language barriers that impede their interaction with healthcare services, or they may have a disability that limits how they can access healthcare or information. 67

A database search of patients without EHR access can give practices greater insight into the demographics of those whose needs aren't being considered in that particular area, 8 enabling practices to devise targeted solutions to help these patients easily access their EHR.

Draw patients' attention to their EHR at every encounter

Many patients will have minimal interaction with healthcare services, making them less likely to be aware of EHRs. Every patient encounter, from in-person appointments to remote consultations.

should therefore be used as an opportunity to spark interest in the EHR. At the Haughton Thornley centre we have also created an infographic and short video that patients are directed to when they apply online for an e-consultation, a faising their awareness of the benefits and risks of EHR access and providing simple registration instructions.

Direct communication with a healthcare professional is key to engagement

A partnership of trust, created through responsible sharing between healthcare professionals and patients, is invaluable in encouraging EHR uptake and engagement. When someone who is directly involved in a patient's care—from GPs to nurses, pharmacists, and physician associates—talks about EHR access with them it allows discussions to be tailored to each patient's needs, accounting for their health and digital literacy.

Furthermore, this direct contact supports under-reached patients through the registration process and initial navigation of their record, which patients often don't feel confident doing alone. ¹⁰ It also provides opportunities for any concerns to be raised, such as how to manage worrying results, ¹⁰ and to signpost patients to resources for interpreting health records. After all, providing patients with access to their EHR will largely be futile if they can't then understand it. ¹¹

Investing in a dedicated support system is essential

Practices should have a dedicated support system where all staff play a part either virtually or in person, which is guided by a designated online champion and can help continue conversations sparked by individual healthcare professionals. A support system can ensure that patients complete the registration process, it can manage logistical issues, and it can check that patients are using their EHR correctly, while also obtaining patient feedback to improve the user's experience of the EHR and engagement.

Although training all practice staff in these skills will require time and money, this investment is essential. We know that patients with low digital literacy or language barriers face substantial difficulties using online systems, often leading to them giving up on accessing healthcare altogether. ¹⁰ If practices are to prevent this happening the whole team will need to be behind this goal.

Digital services need investment to ensure sustainability

Although policies are being developed to give patients access to their EHR, this needs to be widely supported by further investment from NHS Digital and NHS England to sustain patient engagement. This ultimately depends on the accessibility and affordability of digital platforms, especially for people from underserved groups.

Platforms should have easy-to-use interfaces that allow patients with poor health and digital literacy to engage with them. Even with support from family members, people who don't speak English as a first language face barriers when accessing EHR platforms, which mainly use English. 10 In addition, ensuring that EHR platforms are compatible with inexpensive devices could improve their accessibility. Although this doesn't guarantee digital inclusion for all, it will limit the possibility of financial constraints excluding even those patients who want to engage with their EHR. 10 Investment is also needed to raise patients' awareness of the benefits of using their EHR and to help them acquire the skills to access remote care. 10

Pressures on healthcare

Increasing EHR access is one potential way to alleviate the growing pressures on primary care, particularly by focusing on under-reached groups. We're inevitably moving into an era where people increasingly engage with healthcare through digital technology, but "seldom heard" communities could be left behind if specific measures are not put in place.

Helping these patients to access their records and navigate the technology can avoid creating another digital divide and can improve access to healthcare for underserved patient groups, helping to tackle existing health inequalities.

Competing interests: none.

Provenance and peer review: not commissioned; not externally peer reviewed.

- McMillan B, Eastham R, Brown B, Fitton R, Dickinson D. Primary care patient records in the United Kingdom: past, present, and future research priorities. J Med Internet Res 2018;20:e11293. doi: 10.2196/11293. pmid: 30567695
- 2 Tapuria A, Porat T, Kalra D, Dsouza G, Xiaohui S, Curcin V. Impact of patient access to their electronic health record: systematic review. *Inform Health Soc Care* 2021;46:-204. doi: 10.1080/17538157.20211879810. pmid: 33804021.
- Mold F, de Lusignan S, Sheikh A, etal. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. Br J Gen Pract 2015;65:-51. doi: 10.3399/bios15X863941. bmid: 25733435
- BMA. Accelerated access to GP-held patient records guidance. 29 Nov 2022. https://www.bma.org.uk/advice-and-support/gp-practices/gp-service-provision/accelerated-access-to-gp-held-patient-records-guidance
- NHS Race and Health Observatory. New report haits potential of digital apps in tackling health inequalities. 6 Jan 2023. https://www.nhsrho.org/press-release/new-report-haits-potential-ofdigital-apps-in-tackling-health-nequalities.
- 6 Good Governance Institute. McCullon S. Engaging with the hard-to-reach. 22 Jun 2020.
- 7 Liljas AEM, Walters K, Jovicic A, etal. Engaging hard to reach' groups in health promotion: the views of older people and professionals from a qualitative study in England. BMC Public Health 2019;19. doi: 10.1186/s12889-019-6911-1, prind: 31122239
- 8 NHS England, Patient online: Offering patient access to detailed online records, 2015. https://www.england.nhs.uk/wp-content/uploads/2015/11/po-offering-patient-access-deta-online-records.pdf
- 9 HTMC Patient. Sign up for access to GP electronic health records and see what your doctor or nurse have written. YouTube. 29 Sep 2021. https://www.youtube.com/watch?v=lu-UeF-Npqc IV/deol
- 10 Healthwatch. Locked out: Digitally excluded people's experiences of remote GP appointments. Jun 2021. https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/Digital%20Exclusions/2004.pdf
- 11 Castle-Clarke S, Imison C. The digital patient: transforming primary care? Nuffield Trust. 2016. https://www.nuffieldtrust.org.uk/files/2017-06/1497259872_nt-the-digital-patient-web-corrected.



Aleena Hossain, Final Year Medical Student, Imperial College, London 2021

https://www.bmj.com/content/380/bmj.p247

the bmj | BMJ 2023;380;p247 | doi: 10.1136/bmj;p247

Accelerated Access to Prospective Records

BMA

Dr David Wrigley
Deputy Chair GPC England



BMA position on records access

The BMA has always been supportive of patients having access to their online records, but we have always said it must be done in a way that is safe for patients and safe for GPs

GPCE concerns in 2022 are still worrying us now

BMA

- Redaction software not fit for purpose
- Risk to patients in coercive relationships
- Risk to GPs inadvertently releasing third party or harmful data
- Risk to patients seeing harmful data
- Workload concerns
- Role of secondary / community care
- Role of GP as data controller
- Breach of Data Protection Act vs contract breach



Information Commissioner - 27th Sep 2023

BMA

"Data breaches put domestic abuse victims' lives at risk, UK Information Commissioner warns" "These families reached out for help to escape unimaginable violence, to protect them from harm and to seek support to move forward from dangerous situations. But the very people that they trusted to help, exposed them to further risk.



"This is a pattern that must stop. Organisations should be doing everything necessary to protect the personal information in their care. The reprimands issued in the past year make clear that mistakes were made and that organisations must resolve the issues that lead to these breaches in the first place.

"Getting the basics right is simple – thorough training, double checking records and contact details, restricting access to information - all these things reduce the risk of even greater harm.

"Protecting the information rights of victims of domestic abuse is a priority area for my office, and we will be providing further support and advice to help keep people safe."

- John Edwards, UK Information Commissioner

BMA & Refuge

In October, GPC worked with Refuge to author a joint statement expressing concern that NHSE was moving forward without the support of domestic abuse organisations and highlighting the inherent risks of remote access

24 October 2023 - 3-min read

BMA Q Views 🗸 | Clinical | Pulse Ref Remote access to GP records risks do abuse survivors' safety, BMA warns GP record access could Remote access to medical records could put d NHS: Concerns mount over with violence enable abuse against women, charities and pr prospective medical records' access from 31st GP record access could This process is a mess, say campaign enable abuse against women, charities and BMA october warn groups **INDEPENDEN** New NHS remote medical records Women's campaigners warn of safe endanger domestic abuse victims, Aine Fox, PA Social Affairs Correspondent campaigners claim

TRENDING

BMA

NHSE response

The joint statement advised any patients experiencing domestic abuse to delete the app if they had any concerns.

NHSE responded ----->
However it has been made clear in discussions with colleagues at Refuge that they do not feel they have been adequately consulted



A spokesperson for NHS England said they have worked alongside domestic abuse organisations during the last 18 months to "develop guidance for GP practices" on how to approach relevant cases - noting patients can opt out of the new measures.

The representative said the NHS "takes patient safety seriously", explaining an "expert safeguarding group has also been established, comprising National Safeguarding Network, IRISi and Women's Aid among others, to monitor implementation and ensure any concerns are acted on."

Data Protection Impact Assessment (DPIA)

BMA

The BMA has produced a DPIA that has been circulated to practices — this highlights some of the aforementioned risks involved with provisioning access and provides members with a template on which to carry out their own DPIA.

GPCE advised practices that until 31st October, they were free to employ an opt-in model in order to provide their patients with the opportunity to consent to viewing their medical records. Now we are after this time, as per the regulations, they will be required to provide automatic access to prospective records – but their DPIA is important...

Continued engagement

The BMA has continued engagement in recent months and into this week to secure support for GPs to safely and effectively rollout access.

Continued lobbying includes....

BMA

- Providing flexibility for practices who are seeking consent from patients
- Acknowledging the enhanced risk resulting from prospective access
- Seek to use CNSGP for data breach coverage
- Amending the wording of the regulations (our contract)
- Improving the content and signposting in the records access section of the NHS App

What next?

BMA

- Website guidance is updated.....
- As of Tuesday, the contractual requirement has now come into force
- We remain in discussion with NHSE and encourage practices who have not provisioned automatic access to contact their ICB to communicate their plans.

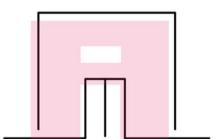
Home > Advice and support > GP practices >

Accelerated access to GP-held patient records 2023

From 31 October 2023, practices are contractually obligated to provide online records access for their patients. GPC England has written guidance to address common questions, key deadlines and practical considerations to extending online access.



Start viewing guidance



Topics:

- 1. Carrying out a DPIA
- 2. Implementing an opt-in model
- 3. Implementing an opt-out model
- Providing access to patient records

Following the Government's decision to impose the GP contract in England this year, all practices are contractually obliged to provide patients with online prospective access to their records. Practices' contracts require them to abide by this from 31 October 2023.

This prospective online access will include the following for all patients:

- the coded record and any associated free text
- records of consultations along with any associated free text

Data Protection Impact Assessment for the NHS England Accelerated Access Programme

amirhannan - 17th October 2023

The NHS has announced that <u>patients with online accounts such as through the NHS App will be able to</u> <u>read new entries, including free text, in their health record. This change only applies to future (prospective)</u> record entries and not historic data.

Full access to the GP electronic health record is better than prospective access when responsibly shared

Haughton Thornley Medical Centres goes much further and safely by responsibley sharing the information we have about you. We have been providing full access to the GP electronic health record since 2004 which includes prospective access as well as retrospective access through an explicit consent process.



The late Ingrid Brindle talking about a patient perspective on shared electronic health records at The Kings Fund in 2014 at Realising the potential of primary care. The role of general practice



"We are fortunate at Haughton Thornley Medical Centres who responsibly share our records with us. We have full access to our records and can share them with whom we like anywhere in the world as well as checking up on our health whenever we need to. It is increasingly important for us and our loved ones to self care and support the NHS as best as we can"

Dominic Sexton

Chair, Haughton Thornley Medical Centres

Over <u>10,000 patients (81% of all our patient population)</u> have already done and this and now we want those who have yet to do this, to do the same.



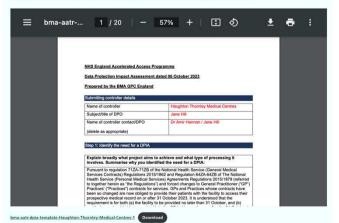
If you or your loved ones have not yet done so then please

- 1. Complete a short 2 minute questionnaire
- We will review your answers, check your GP electronic health record, answer any questions or queries you may have and then switch on the access and send you a personalised text message to confirm this for you

We encourage you to sign up for full access to the records and understanding and then use the resources found on this website that signpost you to trusted information to help you get the best from the practice. We try to write in the records in a way that helps you to understand them and offer advice and support if you find errors or information that is missing as well as making it easy for you to contact the surgery if you need more help.

This is the Gold Standard for patient access to records and we have been doing this for over 18 years now, sharing our knowledge and experience with others. You can view our Fair Processing Notice here.

Haughton Thornley Medical Centres formally completed its Data Protection Impact Assessment (DPIA) for the NHS England Accelerated Access Programme on 11th October 2023 following a meeting of the Partners present, practice manager, members of the <u>Patient Participation Group</u> and our Data Protection Office. It was a robust meeting lasting 1 hour where we discussed the scenarios and potential risks and also considered the mitigations that could help reduce the risk. Following this we determined a course of action that best fits the needs of our patient population whilst remaining within the law.



It was a useful exercise to understand the risks and has led to a 6 point plan for what we do next including:

- ✓ updating our practice website to inform patients what we have done,
- invite all patients to register for full records access and understanding through our explicit consent process (over 2,000 patients) who will be put into a waiting list for us to process with the limited resources we have at our disposal.
- ✓ add 103 codes for those who do not want access under any circumstance and
- review our processes for redaction to ensure all staff (clinical and admin) are aware of what we should do when we see letters in docman and
- share our DPIA with others so that all are aware we have done this and encourage other GP practices to go through a similar exercise before 31st October.

Posted in Practice News

https://www.htmc.co.uk/2023/10/17/dpia/



I feel

- 104 code for all patients to block access unless consented safely to do so.....
- ...as long as practice has a process to enable access to records safely...
- ...and is enabled to do so with funds / training / ongoing support in place at practice / PCN / locality / regional / national level
- Support is needed for Boards who have to take ownership of this and penalties for those not complying (incompetence, unsafe, not In line with NHS values / purpose, salaries linked to performance)

The future challenges

- Not just access but also understanding with appropriate consent and responsible sharing
- Mixed economy of access with lite, prospective access to full access
- Retrospective access needs to be looked at – electronic + paper records
- Artificial intelligence alongside human intelligence



