

**LONG TERM CONDITIONS****CASE STUDY**

## Improving patient access to records and understanding

Dr Amir Hannan tells us how he rebuilt patient confidence and trust in the wake of the Shipman case by improving access to records and understanding and encouraging patients to take charge of their own health.

We live in an age when access to information has never been easier. From shopping and banking to keeping in touch with friends and family, the internet has revolutionised not only how and when we make decisions and interact with others, but has forced many organisations to be more responsibly open in the way they operate. Yet while we can learn more about the world at the click of a button, access to that most personal of data – our health records – is still often complex and frustrating.

For those with multiple long-term conditions access to information about their health is often made all the more difficult by different specialities and departments holding that information. The NHS commits to put the patient at the heart of everything it does; to support individuals to promote and manage their own health. Yet can we truly say we do that if patients do not have easy access to information about their health?

Twelve years ago I made the decision to offer my patients electronic access to their records. I joined Haughton Thornley Medical Centres, in Denton and Hyde, at an extraordinarily difficult time for patients. Their previous GP, Harold Shipman, had left many of them confused and fearful. Their confidence in their health care professionals was in tatters and the world was in shock with what had happened there.

While this situation was unique, the way in which we have tackled patients' fears and restored confidence is something that can be used in all practices and healthcare institutions around the world.

**“Allowing patients to feel more in control of their own health will not just save money but is morally the right thing to do.”**

## Supporting patients to be experts on their own health

Patients and carers often do not know what is going on with their health. They assume that everything is as it should be and that everything is in order. Unfortunately this is not always the case and mistakes sometimes happen, with Shipman being an extreme example. With the advent of the internet, it is easy for people to find out more about their condition and, increasingly, patients living with long-term conditions want to know more about what they can do.

Patients, families and carers would like to:

- Increase their own knowledge about their health and healthcare needs
- Be involved in the shared decision making
- Review consultations they have had with clinicians in the practice
- Check details in their records including when tests, investigations or letters have come back
- Identify any errors or information that is missing in their record and ask for them to be corrected
- Monitor their own health by seeing trends in their care or learning about what works for them
- Offer choices they may wish to make as part of their own care plans working with the practice and their clinicians
- Share their records with others when the need arises for example out of hours, A&E or in outpatients to provide the latest comprehensive information
- Complete forms asking for details about their health without having to contact the surgery
- Save time for themselves by gaining knowledge and understanding of their condition. It's easier if they can read it for themselves than have to see the doctor or book an appointment to find out what they can just as easily do themselves
- Save time by absorbing the detail of a consultation – it is always there for them to review at a later date too
- Free up resources for the practice by choosing not to book an appointment, thereby allowing somebody else to take it instead
- Avoid unnecessary telephone calls checking for test results – instead they can see if the results are back and then make the decision themselves as to whether a consultation with their GP is necessary
- Have continuity of care as well as improved access to clinicians and information when needed
- Share their knowledge with others when asked “What can we do to help you?”
- Increase their confidence in the care they receive by being active partners in their care
- Build a *Partnership of Trust* which involves recognition of their unique expertise of their condition and how it affects them and their families but also recognises the knowledge and experience of their clinician. This relationship can be enhanced by the computer system which includes their electronic health record and other information.



## Why should we make changes?



National drivers including the principle “No decision about me without me” and the *Five Year Forward View* which recognises the need for patients and service users to be able to do this. Local drivers have been scant to date as other priorities have taken centre stage. However with the need for better outcomes and recognition this has to be done with patients and their families and the need for increased sharing of records within an integrated care system, there is now a greater impetus for practices to enable patients to access their records and understand them too.

This is needed because morally it is the right thing to do to allow patients to feel more in control of their own health and wellbeing and to be partners in their care. It may also save some money, possibly reduce the risk of litigation and in the longer run may improve outcomes for all with improved shared decision making and improved confidence in self-care as well as understanding how to use the health services better.

## Using YouTube to explain how records could be accessed

We originally started 12 years ago by giving patients individual copies of their electronic health record on floppy disk or CD rom. In 2005, we changed over to electronic access to the record via the internet. Initially patients were invited to come to a meeting and meet me face-to-face so that I could explain to them what “records access and understanding” means and to answer their questions.

As word spread and demand for access increased, it became apparent that some patients were unable to come to meetings to find out more. I responded by making a series of YouTube videos which they could watch at a time of their convenience.

View Dr Hannan’s YouTube videos: <http://tinyurl.com/pyayf8l>

This included not just the doctor’s view but also the patient’s view as well. This was important because people need to see both perspectives and know what it is like as a patient, not just what the doctor thinks is important. Also it was important to have both views “on the same page” delivered by people who had a doctor-patient relationship too. This relationship is the Partnership of Trust which only exists between a patient (and or carer) and their clinician.

## Using technology to build the Partnership of Trust

Patients are asked to complete a questionnaire which confirms their understanding of what accessing electronic health records means and how they would react to certain situations that they may face now or in the future. Questionnaires were initially done on paper but as the numbers signing up began to rise, it became apparent that we needed an IT solution for this. We set up the practice-based web portal [www.htmc.co.uk](http://www.htmc.co.uk) that allowed us to easily produce our own content and signpost people to trusted information to work alongside what we did in the practice.

The website was designed from the ground up to support the Partnership of Trust – not a standalone website. It was designed to provide rich content relevant to patients who could be referred to it from the practice or find information when they needed it. Patients are informed why they should go there as well as what to find, when and how and to share what they learnt with others. Healthcare is a team sport!

We switched to Survey Monkey to allow patients to complete the explicit consent questionnaires at any time they wished and for us to collate the answers electronically. See [www.htmc.co.uk/GetAccessNow](http://www.htmc.co.uk/GetAccessNow). This also provided us with data on trends and also to see if there were any problems arising e.g. increased patients feeling panicky if they saw their records or concerns about seeing third party data. We started to share data on how many patients and what types of patients had been granted access to their records (quantitative data) <http://tinyurl.com/7renb99> as well as qualitative data describing patient stories in their own words <http://tinyurl.com/6lnh2he>.



## How do my patients access their records?

Patients are invited to sign up for online services (including full access to the GP electronic health records) by collecting their pin numbers for registering online at my practice. They also have to visit [www.htmc.co.uk/GetAccessNow](http://www.htmc.co.uk/GetAccessNow) which shows a video of what to do and complete an online questionnaire which checks their understanding of viewing their GP electronic health record before full access is granted. They are signposted to trusted information which we have gathered from



patients in the practice as well as produced our own material alongside local, regional and national information too. Patients are then regularly informed about new developments, services and other information during consultations, via the Patient Participation Group (PPG) and via the TV screens in the waiting room, posters, regular updates via email, text, on twitter and Facebook.

We have contributed to the policy to enable patients to access their records including the recent guidance produced by the Greater Manchester Transformation Team on enabling patients to get access to records and online services <http://tinyurl.com/p42vw9q> and it is now in the *Five Year Forward View*.

### **What did it cost to set up the system?**

The work has been done completely inside the practice with no extra funding from elsewhere. The greatest investment has been our time as we listened to patients, families and our own staff, reflected on what they were saying and then came back to show them what we could do. There were fixed costs including the setting up of the practice website [www.htmc.co.uk](http://www.htmc.co.uk) and Survey Monkey. We continue to write material for the practice website as the need arises and continue to keep it up-to-date with new information added regularly. We have continually invested in providing information to help patients understand what their records mean to them (for example diabetes care <http://tinyurl.com/7bs5tmu>). This provides very specific information about the practice which patients value greatly and which increases their confidence in the practice and shows how much we care for them.

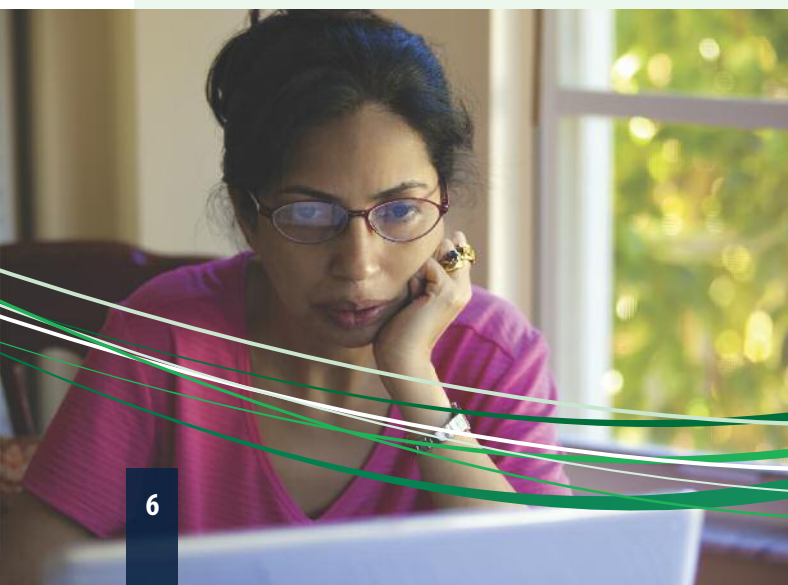
### **What difference has this approach made?**

Patients had lost a great deal of trust in the medical profession after Shipman's arrest and subsequent conviction. Listening to patients and their families helped to inform me about the need to better understand their needs and that they were pleased to see we wanted to share the electronic health records with them. Patients responded positively to encouragements for them to view their electronic health records and found it helped them to get a better understanding of their own health. We would check this during individual consultations when patients would report back how it had helped them and how easy it was to check. The PPG also started in 2005 and from its inception, it made enabling patients to access their records and gain understanding a priority. This was always seen as a joint effort between the practice and the PPG. <http://tinyurl.com/7bs5tmu>.

Many patients are still surprised 10 years on that we can do this and that others have not even heard of it yet. They tell us how it helps them to manage their long-term conditions. We hear immediately when patients are unable to access their records if the system has stopped working because it affects their ability to look after themselves and check things are in order. For many this has become completely normal behaviour and one they rely upon for their own healthcare needs rather like having a GP practice or even calling for an ambulance. Ingrid Brindle, the current chair of Thornley House PPG and a big advocate for the system has presented at numerous events including the Kings Fund <http://tinyurl.com/ngoa4bp> and is now a member of the Patient Online Team for NHS England sharing her knowledge with others too.

## Benefits for patients

- Knowing that they have been listened to and that their views have been noted and acted upon.
- Safer for them. Patients with serious health issues feel safer, are willing to travel further afield and even abroad knowing they can share their records if need be. They can check how to take treatments and have the added benefit of being able to order prescriptions, book appointments and even send secure messages if they wish. Some have even translated their records if need be in case they need somebody in a foreign country to read details.
- More effective care by knowing why they are on certain treatments or what they need to do.
- Better experience. More involved in their care and so hopefully more likely to stay with their treatment plan or know when to come back if they experience problems.
- Time saving – they can see information instantly instead of having to wait. They can check if the referral letter has gone and share the referral letter or their record if they get to the hospital and nobody knows why they are there!
- Sharing information and knowledge between specialties in hospitals or between hospitals as information is not easily accessible to all.
- Saves money – no need to take time off work or to travel to the surgery to see test results or find out how they last managed the same problem if it recurs. The record contains details for them to refer back to whenever they need!
- Helps patients to understand their test results. See <http://tinyurl.com/q8h5znp>
- Currently 37% of our patients (4,423 patients) have access to their records and understanding. In terms of long-term conditions, 44% of our diabetes patients (56% of our Type 1 diabetes), 38% of patients with ischaemic heart disease, 34% of patients with heart failure, 52% of patients with obesity, 51% of patients with rheumatoid arthritis, 43% of patients with asthma, 46% of patients with back pain, 34% of patients with COPD, 64% of patients with anxiety and depression, 40% of patients with cancer, 54% of pregnant women (although not a long term condition!), 22% of patients with learning difficulties and 37% of Bengali patients have signed up for access to their records. <http://tinyurl.com/qd2qa4w>
- Greater understanding of healthcare needs.
- In Case of Emergency app on their smartphone can include passwords for anybody to access their records if they become unconscious and need urgent care. (The patient has to put this in beforehand so the control always remains with the patient)
- More fun – patients like to describe their understanding and knowledge of what they think is going on.
- Reduction in repeat tests – patients have described when tests have not been needed to be repeated because they could share their results to others.
- Identified errors in records as well as information that is missing so that records can be corrected.



## Benefits for carers

- Easily being able to check details about the care for those they care for when in the past it was very difficult to do so due to the patient's right to confidentiality. Families have found this very useful particularly when loved ones are unwell and not always able to look after themselves but want to be cared for.
- Very easy for carers to view their records. Patients simply give anybody they wish their passwords. They can always revoke access if they wish by contacting the practice and change their passwords. The patient has the right to share their passwords with whom they like without needing permission. We do not recommend the patient sharing their password with health or social care professionals though as this could put the professional at risk of inappropriate access to the records without patient consent.
- Bengali patients who do not speak English or have poor English have benefited by enabling their children or grandchildren to do this on their behalf. This is done on an individual basis where the GP determines what is in the best interests of the patient with the consent of the patient.
- Similar benefits have been found for patients with learning difficulties, people with memory problems and also people with severe mental health issues. The latter is done in conjunction with the psychiatrist looking after the patient and not done in isolation.
- Reduction in health inequalities (at least in relation to access to information about services) and promotion of equality (by active promotion of the service to all patients).

## Benefits for staff

- Saves time if patients have a better understanding of their health and are able to share their knowledge for others to use.
- Patients can do more for themselves, for example order prescriptions online, book appointments, send secure messages which frees up staff time to do other things instead of answering the phone or dealing with face to face queries. This also frees up time so that staff can spend more time with those who are unable to or choose not to use online services or who need more help to navigate the system because they are unable to do it on their own.
- Makes the job more enjoyable and variable for staff. Staff report enjoying supporting patients and love hearing how it has helped them to get great care.
- Provides staff with new skill sets and allows them to interact with patients on a different level.



- Encourages doctors, nurses, health care assistants and receptionists to engage with each other as each supports the patient and the family. Everybody has a role to play and enjoys the success.
- Helps all staff to develop a real sense of achievement and pride in the practice as we all work together towards a common goal.
- Doctors and nurses are able to direct patients to read what they have written in the records so that patients and their carers can check later.
- Doctors report better discussions with patients when they have viewed their records and more proactive care rather than reactive care trying to prevent problems from arising in the first place.

## Benefits for the organisation

- Improved responsible sharing of information with patients and their families.
- Greater confidence in the practice despite all the pressures we face.
- Building trusting relationships with patients and staff.
- Improved safety by giving the patients an opportunity to share their knowledge with others.
- Streamline processes for managing patients by encouraging use of online services alongside traditional methods.
- Preparing the way for the practice to capitalise on the drive to go “Digital” as more and more services go online across health, social and community care.
- Having a lot of fun as many patients and families have really enjoyed being able to view their records and share it with others.
- Being surprised that we have not had any problems that we have not been able to solve despite all the potential risks.

## TOP TIPS

- Set up a Patient Participation Group that can provide a coherent voice and be a critical friend. The National Association of Patient Participation can help. [www.napp.org.uk](http://www.napp.org.uk)
- Invite clinicians, management team, staff and PPG to a meeting where we can offer support and guidance on how to do this and offer our own experience of how we did it and overcame challenges and identify key issues for practices to consider.
- Allow them to see all sides of the system i.e the clinical and administrative concerns but also what the patients think which allows for greater understanding of the practice's overall views and how it collectively meets the needs of the population it serves
- Identify who will champion this in the surgery – ideally a clinician, a manager and a patient with leads amongst the receptionists too. It is good to meet regularly and share ideas with each other. A problem shared is a problem halved.
- Don't expect everybody to be fully behind it at first. It is good to have some healthy sceptics who check what you are doing (so long as they do not actively block it or mock it).
- Don't become paralysed by worrying or procrastinating about what might or might not happen. Healthcare is risky and General Practice in particular deals with uncertainty very well most of the time. Hold on to important principles and ask for help if you are unsure what to do by contacting those who have done this. The chances are that somebody has already dealt with the problem you face now.



## TOP TIPS

- Listen to everybody's views. This can be challenging in the current climate but this helps to ensure nobody feels left out and sometimes simple ideas can generate the best results.
- Explain to the patient what it means for them and make it specific to the patient.
- Don't say "do you want records access". Say "would you like to be able to see what your doctor or nurse has written" for instance.
- How are you going to assess how successful you have been? Get a shared understanding of purpose and what success looks like.
- Look at the recent guidance produced by the Greater Manchester Transformation Team on enabling patients to get access to records and online services which provides useful pointers based on our experience and that of others too. <http://tinyurl.com/p42vw9q>
- Start small – perhaps just one patient but think about who is going to do what, when and most importantly why?
- Focus on quality and safety – not how many you have signed up. Better to have a few patients who you feel comfortable with and who trust you too than many signed up but then worrying about what may or may not happen to them. Remember this is about building a Partnership of Trust and about Records Access and Understanding.
- Aim for "no surprises". Try to minimise risks by managing them and maximising opportunities for success. This is an iterative process. Do little mini-projects in the practice to raise awareness amongst certain groups of patients and invite others to sign up.
- Look at your own website and see what information you are providing or could provide to help your patients and staff get the best too. See our review of 2014 <http://tinyurl.com/qg6j8u8> where we have gathered many resources together in one place for all to see.
- Find out if your CCG or Local Area Team have plans to support the roll out. It is already in the Programme but you may wish to start earlier and perhaps there may be funds made available for this type of innovative activity. Identifying funds earlier will help to sustain the change process in the longer run.
- Share what you are doing with your staff and your patients and with the rest of the world via social media.
- #Empowerlution is the key – empower patients, empower staff, empower clinicians, empower managers, empower organisations. Empowering people to do more supported by "the system" will lead to many more benefits that go beyond simply patients accessing their records. Understanding them and raising health literacy will lead to many more benefits too possibly dealing with some of the social determinants of health as we build capacity within the community for people to do more.

## Get in touch

Share your ideas and thoughts with us on Twitter [@amirhannan](https://twitter.com/amirhannan) and [@ingridbrindle](https://twitter.com/ingridbrindle) so that we can learn from you and allow others to learn too. We are keen to support you and provide further advice and guidance.