

“No longer a passenger - being prepared to be a future patient navigated Medical Records” Stories and adventures of modern digital pioneering patients.

Ingrid Brindle, Yvonne Bennett, Cheryl Ashton, Oliver Crowton, Bruce Elliott, Edna and Abigail Davies

Introduction by Ingrid Brindle and Dr Amir Hannan



We are delighted to see this collection of patients' stories. Electronic health 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, carers 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 or does it mean patients and carers have a greater responsibility to access their

records, understand them and then share them where care is needed at home and when presented to a clinician?

On the 27th April 2017 both myself and Dr Hannan were invited by the International Forum on Quality and Safety in Healthcare to present 12 years of empowering patients, improving lives, feeling fabulous – “empowerlution”. Don Berwick in his keynote speech during a discussion with Ara Darzi, Anya de Longh and Margaret Murphy said “If I had to think of a transformative change in the way we do business.... I sometimes think we should make the whole medical record to be owned by the patient. It is theirs, not ours. Everything is right there that they can see and if they want to write, they can write. If we just change that assumption, that would be a keystone change”.

Today in the UK, the electronic GP record sits in a central site and the access to the record can be activated and viewed on the day that the patient registers with the GP. In the past when a patient registered with a new doctor, the new doctor notified the FHSA at the end of the week. It took eight weeks for the old notes to arrive at the surgery.

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 and those who have as yet managed to get through life without the need to get online, may find it difficult to manage complicated security technologies or even understand why it is important for them or their loved ones to be able to view their records and understand them– yet, as they are least able to represent themselves and their conditions, they may stand to benefit most from the sharing of electronic records.

A UK House of Lords report wrote “One of the major challenges of utilising genomic information within the NHS is linking genomic databases and informatics platforms with electronic medical records. This will have benefits both for patients directly by improving patient care and decision making and indirectly by enabling research for the public good to unravel the role of genetic, environmental and lifestyle factors in disease.”

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, corrects the record so it is accurate, knows who has seen the various parts of the records, understands that data cannot be deleted from the record but can be hidden, quarantined or annotated.

They need to 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, and understand the clinician’s responsibility to disclose information when the public is at risk.

The record is a reflection of the encounters that patients between patients, carers and clinicians. Patients with record access gain a better understanding of their healthcare needs leading to a Partnership of Trust, empowering patients, clinicians and organisations – (“empowerlution”).

Honesty, openness and transparency are paramount: clinicians 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. Clinicians are able to record some data so that only they can see it. Patients may now request that socially sensitive information is not shared – and data about a third party should never be shared without that third party’s consent. Existing legal safeguards 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, carers, IT specialists, clinicians, administrators and clinicians 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.

Clinicians have many difficult decisions to make. Patients have lives to lead but are responsible for their lifestyles and have choices to make.

We wish all patients good luck with this new patient journey and remember: “Health is what you do, not what you say, see, or what others are doing. Health is not what is discussed in conferences or written in papers, policy documents or strategies. It is what YOU do. When this is community led and supported by healthcare, the process becomes more vibrant and sustainable.

Ingrid Brindle and Dr Amir Hannan

Margaret Rickson RIP

On September 2014 Margaret Rickson sadly passed away. She was one of the original patients on the Haughton Thornley Patient Participation Group who had been voted one of the top 50 NHS Innovators in the NHS as judged by Health Service Journal. Margaret was featured in “Which” Magazine in 2008. (“Which? magazine is the UK’s bestselling monthly, trusted by more than 600,000 subscribers. Which? offers a range of products, services and advice to help its readers with life’s big decisions and important moments.”)

After the article appeared in the magazine patients all over the

country were taking the magazine into their doctors demanding they had what she had (Records Access). Those of us who loved Margaret would refer to her as our pin up girl. We often finished with bruises where she hit us and told us not to be so daft. She was awarded a certificate of achievement by the practice. Margaret was a very modest person and didn't want to blow her own trumpet. In her teens she was a member of the Red Cross and her interest lasted throughout her life.

Which Magazine February 2008



“When Margaret Rickson first heard she could order her prescription online rather than have to walk uphill to the surgery, she could not use a computer. After lessons at the local library, she went on to use her new laptop to access her medical records online. Margaret’s growing confidence

even encouraged her to challenge her hospital consultant using a printout of her records.” “The consultant was not angry but surprised, and began to answer my questions.’

As a patient at Harold Shipman’s former practice in Hyde, Cheshire, Margaret needed to build trust with her new GP. Being able to access her records online means she was able to see the same information as her GP, and this provided Margaret with the information she needed to discuss her healthcare.

“Take charge ; Margaret said: ‘It puts me in control rather than the doctors. You feel like a person, not a piece of paper or a number.’ She also signed up for the NHS’s online personal organiser HealthSpace (www.healthspace.nhs.uk) – this can record health information for any NHS patient in England. Rather helpfully, it also provided Margaret with email alerts so she didn’t forget about any future appointments.

Patients have choices to make



Oliver's Story



“I read with interest the recent editorial on ‘Implementing Person Centred Approaches’, (BMJ 2017;358:j4126). I must first of all clearly state that I am neither an academic nor a health professional, I am a builder - a builder with a chronic disease (Ulcerative Colitis) that I have lived with for the last 5 or so years.

“I am also aware, to an extent, of the pressures facing the NHS and the medical profession. Only what I see in the hospitals that I visit and hear through mainstream media channels, but enough to understand that to succeed the system needs to evolve and I think that the person centred care approach is a positive step.

“It is encouraging to hear of building communication and relationships between healthcare professionals and the people receiving care as this can surely only serve to improve engagement and mutual understanding. (The healthcare professional’s understanding of the patient and the patient’s understanding of their condition/treatment).

“I do however feel that in an organisational and system context (as well as a patient context) the article neglects to acknowledge an extremely valuable tool, that of the ability to share patient data. I refer not only to the appropriate and controlled sharing of patient data within and across relevant organisations which has its own merits, but also and importantly the sharing of patient data directly with the patient to which it relates.

“During the years following my own diagnosis my relationship with my healthcare professionals (doctors, nurses and consultants) has quite suddenly and accidentally become more ‘patient centred’.

“Two years ago I was at a stage in my understanding of my condition and treatment that was so limited it placed the entire weight of responsibility for my care on the doctors treating my condition. At that point in time I had lived with my diagnosis for three years and I was a passenger, along for the ride feeling I did not have a part to play.

“Quite by chance I was then offered the opportunity to sign up for digital access to my records through ‘Patient Access’ by EMIS.



“I have found that access to my medical data, including test results, consultation details, diagnosis history etc. has empowered me as a patient and given me a platform for the sort of communication with my healthcare professional that Person Centred Care appears to seek to achieve. I ask questions, discuss options for treatment and associated side effects, as well as assisting with the management of my regular scheduled treatments. I am able to feel a better level of care with less contact with the surgery. I can manage prescriptions and view test results without the need to take up time talking to the surgery staff. I can review treatment dates to ensure that my blood tests and treatments are scheduled appropriately without the stress of wondering when they are due. The access to EMIS has allowed me to take some ownership of my condition and work pro-actively with my various healthcare professionals in the management of my disease and its treatment both short and long term.

“I have no doubt that I would not have had the confidence required to begin discussions with my doctors without the access to my records as a basis for communication.

“I find the quarterly visits to my Consultant at hospital are also now far more useful. I am able to discuss the results of my GP surgery visits and test results and draw directly upon them at the consultation from my smartphone if required, adding depth to our discussions.

“In short I am no longer a passenger, I am now very much part of the management team for the effective treatment of my condition and I am pleased to say that I am managing to remain in good health.

“I understand that not everyone will have the capacity to use their data in this way but there are very many who will and I can see access to patient data being a very powerful tool indeed in achieving patient centred care.

Yvonne's Story



Handling My Family's Health Care & Data - Everyone has a right to life

In 2010, I wrote "I'm 65, I've been married to John for 46 years. We are both patients at Thornley House Medical Centre in Hyde. We both have access to our full GP records online. No we don't spend all our time checking our records."

About Me

Now, I'm 71

I've been married to John for 52 years.



We were both patients at Thornley House Medical Centre in Hyde and I am still. Both of us have access to our full GP records online. No we never spent all our time checking our records.



Our Family - where does it Start?

Where does it end? What is as family? So where does our family start and end. Is it just with the living? It will always be ongoing from one generation to another.



Interestingly, on my side there are 2 boys & 7 girl cousins (in case you are counting, 1 was missing as she lives in Spain). All the girls have asthma varying from mild to severe. Underneath the cousins are my mother and myself. Reminds me of the Siamese cats in Lady and the Tramp. We look alike, we think alike and our medical history is a like a duplicate.



There are our two sons and our grandson who is nicknamed 'sporty kid at school and college'. You name it and he more than likely plays it.



Is it complicated? No it's not! From the very start of records access we shared each others' records. John wasn't computer literate so we sat on the settee and accessed the together. Its keeping information. It could be but remember anything is always better than nothing! It all helps us to maintain our health. Many people have more than one condition but we all have one body and we are able to share information that one doctor or hospital may not have access to. Its keeping information. It could be written but it could also be on a computer. Websites allow you to search for information on relatives' including death certificates. Perhaps people are too busy or there are too many distractions these days. People don't talk about family history the same unless someone wants to check their heritage.

The Start – John has a family History of Cancer any form both sides and heart Disease

The Start- Yvonne has a family History on both sides of heart Disease, strokes, asthma, Parkinson's disease, and Ehlers Danlos Syndrome - EDS

Information I have to hand

Death certificates for both John's parents, for both my parents, family knowledge of other relatives and on-line access to both mine and John's medical records.



So what makes us digital patients different?

We take care of our own health. We are part of a 'partnership of trust' with our doctor. We have access to a computer, not necessarily our own. We are NOT STUPID, we are aware of security issues. We tend to, shop online, check insurance quotes, book holidays, use internet banking and many more. So WHY NOT maintain our health online!



A consultation with the doctor

We discuss with the doctor our health problem. We listen to their advice. We may question their suggested medication.

This isn't to challenge the doctor but to find what is best for us. We may not accept the medication just then, We may want to do our own research. We may have personal moral issues with some medications. We DO get back to our doctor. Once we have decided, we go back to see our doctor and we then discuss our findings. We could have a different medication to the one suggested or we just accept the offered medication.

So what next? What do we need to do? We now take charge. We decide to try the new medication. We fit this into our regime.

What do I need for my care?

I want to be able to do everything I can to the best of my ability. I want to know the bigger picture and not just the next step. I want to review things in my own time so that I can better monitor my own health and that of my loved ones. I want to become EMPOWERED by being enabled, informed, listened to and given choices. I want the best healthcare around me!

So where do we go?

Everybody has their own favourite sites. We are encouraged to use trusted websites. These could be Our Practice website www.htmc.co.uk, patient.co.uk, NHS Choices, BBC.

Self Care for family and friends

[Common problems YOU can solve](#)

[NHS choices](#)

[HealthSpace](#)

[NHS Direct](#)

[Map of Medicine](#)

[Patient.co.uk](#)

[Out of Hours advice](#)

[Choose and Book](#)

[Getting the most from this site](#)

Important Messages

[Computer course for beginners](#)

Practice Services

[Pre-consultation Care HV TH](#)

[Depression Care HV TH](#)

[Diabetes Care HV TH](#)

[Hypertension Care HV TH](#)

[Pregnancy Care HV TH](#)

[Eczema Care HV TH](#)

[Immunisations Care HV TH](#)

[Heart Disease Care HV TH](#)

Health Record Access

[What is Records Access?](#)

[Is Record Access for me?](#)

[About Records Access](#)

[You Tube videos on RA](#)

[Benefits & Challenges](#)

[Example health record](#)

[Keeping your information safe](#)

It was January, it's 2010 and it was snowing.....here's a video of pictures taken on Tuesday 5th January and how we are supporting patients despite the snow. This website is open 24 hours a day, 7 days a week enabling YOU to get the best care you need, wherever you are, whenever you need it. Enjoy the video and tell us what you think of it by sending an e-mail to htmcpatient@nhs.net.

Now February has come and we thought we would ask Margaret Rickson aged 83, member of the Haughton Thornley Medical Centres Patient Participatin Group if she would like to show us how easy it is to get access to your records. Watch the video and tell us what you think by e-mailing us on htmcpatient@nhs.net!

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What's new ?

New home page launched

Swine Flu

Click here for further information

How?

We do whatever works for us. Where does it end? It doesn't! It's up to my children to pass on the information to the next generation and the next. I have made sure that my family are aware that I want my records shared with any nursing home/hospice. My family are also aware of any healthcare that I want or do not want. My husband has also done the same. We are both happy for our sons to have access to our records whether we are alive or dead. We have made Health and Welfare and Financial EPAs as well as wills.



To us, this is common sense and we would encourage others to do the same.

Things have changed in 13 years...It's not just everyone being older. John is 74, I'm 71 and sporty kid in now 20. Despite John's healthy life style things have changed. John has advanced (end stage) vascular dementia, is on a section 3 of the Mental Health Act and lives in an independent Hospital. I still look after his health which is now complex. After 52 years of marriage it still hasn't changed. I still download data from his pacemaker. John had stipulated to his former GP that that like me he wanted family access to continue if health changed. I have access to his records with his new GP.



My health has altered. Following a fall, chest examination revealed I had a heart murmur. Echocardiogram showed Stage 1 diastolic dysfunction and mild mitral regurgitation. My GP explained it to me, some of which - I promptly forgot. By printing off the echo I have been able to access information from reliable sources from our practice website Health A-Z and the BHF (British Heart Foundation) website on how to help myself.

I have always had a healthy lifestyle but there is always way to improve it such as regular Blood Pressure (BP) checks, weight management, healthy diet and exercise perhaps a little more keenly than before. This is what Records Access

is all about – having the tools to empower you to take charge of your own and your family's health to the best of your ability as part of the relationship with your Healthcare Professionals.

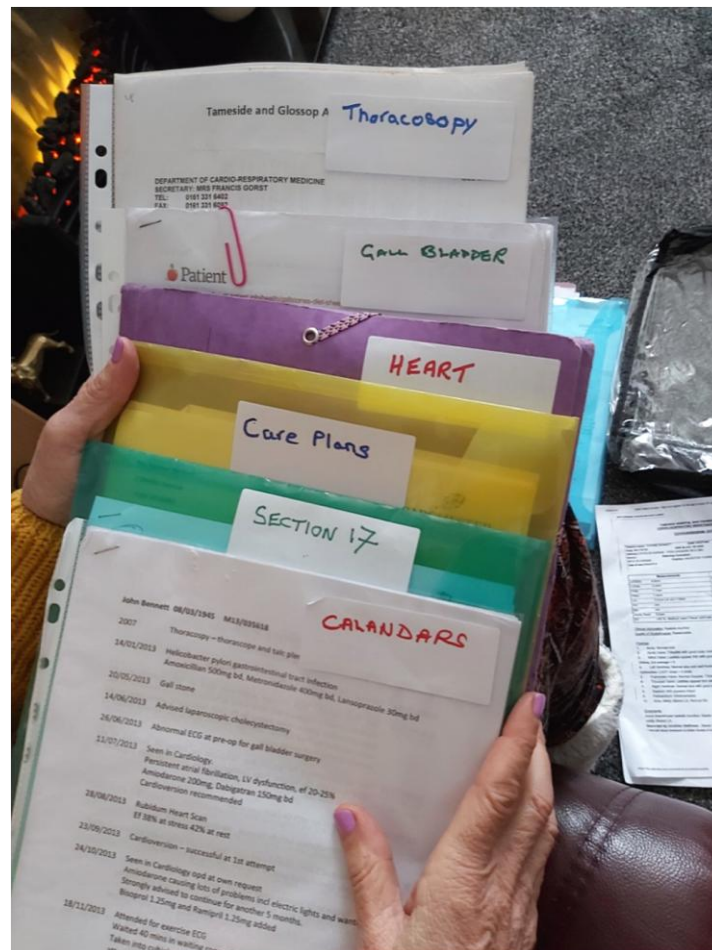


Not just a grandma moment... ... it's not only family history we pass on. Granddad moment would be that his grandson is wearing his cycling shirt that is probably nearly as old Jason himself!

Accuracy of records:

13 years on and, yes, people do make mistakes with records: The delivery systems may fail, letters may get lost, digital information may be cut and pasted incorrectly, and notes may be filed in the wrong notes. Patients don't wish to

punish the system that caused these errors but wish to see that the errors are seen and corrected.



Patients don't look for typos or spelling mistakes, they are not looking for incorrect information. While they are checking for letters etc they may find errors that only the patient can see. On very rare occasions it may be somebody else's information. In both instances the errors are immediately reported to the Practice. Patients not giving correct information. One patient didn't mention he was diabetic when attending an hospital appointment. He was given wrong medication. Question to the patient: "Why didn't you tell doctors you were Diabetic?" Answer: "I only came with my lungs!" As if he could come without them.

Accompanying friend hits patient gently and apologises to consultant.

In view of recent press regarding Stafford, Tameside and Blackpool Teaching hospitals and with more that 22 million patients now having a Summary Care Record (SCR) amounting to almost 40% of the country, is your SCR correct? With no more HealthSpace, unless you have access to your records, the only way you can check this is by going to your GP. Now more than ever patients need access to their medical records. And it isn't the hand of God either that makes mistakes with our records ...Letters not going out to patients. Costly, and will disappear altogether when the NHS goes paperless. Letters disappearing into the 'black hole'. Every hospital has one and letters, notes etc seems to disappear from everywhere in to it, letters being put into the wrong bag and sent out to the wrong GP surgery. They don't always get sent back.



Correcting inaccurate records

I went into my records to check a letter from my Consultant. The name, address and age were correct but the body of the letter was about someone else. It was only me, the patient, that was able to spot this and then it wasn't a risk when corrected. I telephoned the hospital and had them send the correct letter to my GP.

Patients with the same name: Maria ---- was admitted to hospital for an operation. She refused to admit to having Type 1 diabetes and also to be injected with insulin. The GP letter clearly stated she had type 1 diabetes. This was wrong. The Ward arranged for Dthe diabetes Specialist nurse to attend Maria. And the arrangements being made for the patient to be seen by the Mental Health Team were cancelled.

Staff from the Diabetes recognised the name and so started to investigate before the DSN attended. Despite a very unusual last name the system revealed there were two patients with the same name (they were unrelated). After getting both sets of notes, it was found the GP surgery had filed a letter in the wrong notes. Both patients also had the same GP. The patient on the ward did NOT have diabetes. WELL DONE to the patient who refused to be intimidated and not accept the insulin!!!

Finding Mistakes In Notes

For most patients it's not a problem. The patient is there from the beginning and usually knows what right and

wrong. Over the 6½ years we have had access to our GP records, nobody has wanted to sue the doctors because of inaccuracies in the notes. Patients just want any errors corrected and accept that mistakes can happen. Most patients don't even want an apology. Not one person has made a complaint to our Local Care Records Board.

Access isn't just about errors!

It's about taking charge of our own health. It's about using access to read letters, check results, consultations. It is about using the access to fill in an insurance form or a form before attending hospital. It's about saving time. It's about leaving a doctor/nurse appointment for those who really need it. Record sharing has been happening for a while. Remember everyone is also a patient. Think how record access could benefit you & your family.



Badly summarised notes

My husband had a pleural effusion and a mass in his left lung. He had a Thoracoscopy and open pleural biopsy.

Fortunately the biopsy was benign. 6 months later a review letter sent to GP started with this man had a Thoracoscopy... and then went on to say he was reviewed in clinic. This appeared in 'significant clinical problems' and so it appeared as if he had the same operation twice. We were able to point this out to our GP and have the review letter removed from that section of his notes and from his Summary Care Record.

Partnership of Trust - Patient/Doctor and Doctor/Patient



Some patients do lie. Some are intentional: “How many cigarettes do you have a day?” “Just the 1” (fail to mention that’s 1 pack). “

How many glasses of alcohol do you drink?” “Just one (most will have seen ads in magazines for wine glass that hold a full bottle)”. “Are you taking your medication?” “Yes everyday” (when I remember)

Others just ... Let me tell you about Ray, who was happy and laid back as a piece of grass. I drove him to hospital and sat down to wait for Ray outside but Ray asked me to go in with him. The doctor wanted to increase his current medication quite significantly. I started to query thisWithout giving me chance to explain the doctor went out and came back with the Consultant. I explained to the consultant that I wasn't questioning the treatment but that Ray was diabetic and I knew that the medication wasn't right for him. L

Looking through his notes the consultant assured me there was no record of diabetes or any diabetes medication. When I asked Ray why he hadn't taken all his medications with him as per his letter. His answer... "I've only come with my lungs!" (as if he could have come without them!)"

That's some patients for you!

**Using records and self taken photos for management
after John's accident**

The accident caused an Ambulance & A & E visit, a pre-op assessment & operation, 8 Visits to Fracture Clinic, 8 Letters, 8 appointments at GPs, 8+++ telephone calls, 11hrs for appts/40 mins telephone for the patients, 8 apt with the doctor @ £25 = £200 NHS Doctor. Using on line assessments and forwarding photos and self-measured wounds to clinicians (below) some of the cost could have been saved saving an 8 extra appointments for other patients.



***Hello! My name is Ingrid
Brindle***



I'd like to share some thoughts on our health and how having access to our health information can improve how we manage our health and keep ourselves healthy and safe.

I am the Chair of Haughton Thornley Patient Group Hyde, Chair of Neighbourhood Steering group, Member of Patient Exp Group GM AHSN . I am also lay member of Royal College of General Practice (RCGP) and member of the RCGP Committee on Medical Ethics. I am an ex- member of NHS Patient Online Programme and founder of "Healthpledge".

The guiding principle at our practice is that there is a strong partnership of trust. I trust my doctors to give me the best care that they can and they trust me to use information wisely to ensure the best outcomes for my health.

I want to understand the implications of any treatment and fully participate in decisions about the way forward. Good quality, relevant information and being listened to and trusted enables me to do that.

It's difficult to evaluate all the times I don't need to contact the practice but I know from statistics gathered so far that it gives more time for the practice to provide for other patients who need a different

kind of support. A fellow patient who recently broke her shoulder believes that allowing £20 per encounter, she has saved the practice around £200 by not needing to contact them!

For the last 14 years I have travelled extensively throughout the United Kingdom presenting at conferences and facilitating workshops extolling the virtues of patients having access to their health information. I have written many articles for medical and non-medical journals explaining how patients with access to their information can manage their health better and contribute more successfully in making plans about their future healthcare.

One of the journals was a book called "My data, my care" which was an influential book compiled by the Richmond group of health charities. Dr Fitton and I helped the launching of the project at the House of Lords."



Our health is our lifetime's work!

**It is our most important project and most of it done
"Home Alone!" Tom Ferguson MD, 1985, said you are**

already your own doctor. Our interactions with the healthcare system are just the tip of the iceberg. Self Care is and has always been our predominant form of health care I want to understand the implications of any treatment and fully participate in decisions about the way forward. Good quality, relevant information and being listened to and trusted enables me to do that.

It's difficult to evaluate all the times I don't need to contact the practice but I know from statistics gathered so far that it gives more time for the practice to provide for other patients who need a different kind of support.

Example: Yvonne, a fellow patient who recently broke her shoulder believes that allowing £20 per encounter, she has saved the practice around £200 by not needing to contact them!



I thought it may be useful to share some of the ways that having full online access to my GP records has helped me and other patients in the eleven years since 2006. I have been very lucky to be at an enlightened practice which believes in empowering their patients.

I have inflammatory ankylosing spondylitis (stiff and painful joints and tendons), associated iritis (inflammation of the eye), reduced vision, heart failure and persistent atrial fibrillation (irregular heart beat). I take immunosuppressants, steroids, anti coagulants and heart regulating drugs. I have many clinical appointments & other visits and there is a lot of medical and administrative information for me to manage



There are many features of having access to my information online which help me to manage my complex health situation. (Online access allows me to book appointments with my GP, to order prescriptions and to inspect my medical record).



Ordering repeat prescriptions is very simple. A few key presses and a message if required.....the practice sends the script to the pharmacy who deliver the medication to my house. I can make sure that I have what I need when I need it.



I can now access all my GP information using an app on my mobile phone or laptop and having access to all of my records on line gives me enormous confidence.

Wherever I travel in the UK or abroad, 24/7 I take all of my GP's medical information with me.....how fantastic is that! I carry two passwords to the Patient On Line in my head. I have information in my wallet & also in my phone under "Ice ". If I need to go to hospital and am unable to speak for myself, my partner can access the records for the doctors as he has the passwords to my on line access on a card in his wallet.

Consultations can be seen which is helpful as patient retention of information can be as low as 10% so patients can check understanding & what happens next, can get family or friends / carers help if the patient has language difficulties, lives in Australia or in a nursing homes. An elderly man in A&E who was frightened could share his

record with the staff leading to safer medicine and no need to contact practice.

Example: Other patients have found having access invaluable: Margaret Rickson, 83, went down to her local hospital for a pre-op assessment. She was told that some information wasn't available and she would need to come back. She told them that she had CPoD & didn't want to come back but if they lent her a computer she could find them the information & she logged on and did just that!

Our practice website www.htmc.co.uk is a source of valuable and trusted information

Haughton Thornley Medical Centres

Haughton Vale PPG | Thornley House PPG | Search | Staff

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We are welcoming new patients. Please click [here](#) to join us now!

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Tell us what you think about the new look home page
URGENT: Learn about care.data and whether you and your family wish to opt out of sharing your data with 3rd parties without your consent

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

The [main website](#) offers a great deal more information for those who wish to learn more about what they can do for themselves supported by a large number of 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 then please click [here](#).

You can send secure non-urgent messages online by logging into [EMIS Access](#) once you have registered or send an email about non-medical matters to htmcpatient@nhs.net

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

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Example: Some patients who are not confident or whose English isn't very good give their information to family members who wish to participate in their health care. In this way, parents can monitor their children's health and

***better informed carers can give better informed support.
One man helps his mum from Australia.***

***Last year my heart became unstable when were in
France. I knew that I should see someone at a
hospital the next day but I knew that none of the
doctors spoke English.***



***So I went online to my GP records to print out the last
couple of letters from the cardiologist. A fluent french
friend speaking friend translated the letters into
French for me to take to the hospital along with
information on repeat medications. The hospital had
all the information they needed without having to
start from scratch. That's just brilliant!***

Mobile Phone ap:

***I have information available anywhere home and abroad
with just 2 passwords! How cool is that? A large percentage
of the population have a suitable mobile phone. Information
about passwords can be stored under ICE or using an ICE***

app on the lockscreen. ICE app is next to the Patient Access records access app. If someone steals the phone, passwords can be changed



Other digital devices

I have regular blood tests in order to monitor my medications. I check online a couple of days later to see if the results are back. The results page is very easy to understand and there is a link to “Labtests online” for further clarification. If I was waiting for some new results which might be upsetting or difficult to deal with on my own, I don't have to look. It's not compulsory! I can wait until I can discuss it with the support of the doctor. Quite a few of my levels come back as “abnormal” but I know that's normal for me and I can keep an eye on any trends. Perhaps I needed a little help to understand the first results that I saw but now understanding the results is just an easy routine.



My doctor is monitoring the results and will let me know if we need to do anything about them and usually I don't need to deal with the practice. I have just had a cardiac ablation procedure at St Bartholomew's Hospital in London and had my pre-op consultation by telephone as I live in Manchester. I gave the nurse all of the information she needed by logging on. The only reason that she had to contact the practice for was to arrange an MRSA swab.



I can look at my consultation history to remind myself of exactly what was said so I can make sure I've remembered everything properly and am responding correctly to the doctor's advice. Most patients only remember 10% of what has been discussed in a consultation with their doctor. I am able to confirm that management plans are completed by examining my records and I can check that the information held about me is accurate and complete. (That isn't any major kind of criticism of the system, by the way. It's just that mistakes are possible and it's easy to feel insecure when you are not confident if things have actually been done and sent off or have come backAs I have record access, I don't need to ring the practice to check. The information is always to hand and very accessible if I need dates for a travel insurance medical history form, to know when my vaccinations are due, when I finished my antibiotics had my new hip etc..

Example: One patient had a son with severe haemophilia. She used access to his records to download all the information she needed to apply for special nursery provision. One patient had a hip replacement at a hospital 50 miles from her home. It later fractured and she was then involved with two more hospitals. She was driven all the way to the original hospital for a review & was told they

couldn't do the review as they needed information from one of the other hospitals which they didn't have. She would need to come back..... She asked them to wait for a moment, logged on to her GP records on her mobile phone and showed them the information they needed. They were astonished!

Other digital devices I can use to manage my health



I have an ECG recorder on my mobile phone that is useful when my heart arrhythmia (irregular heart beat) is spasmodic. The monitor gives an ECG which can be assessed and emailed to the GP or cardiologist. That way I can get help straight away if necessary.



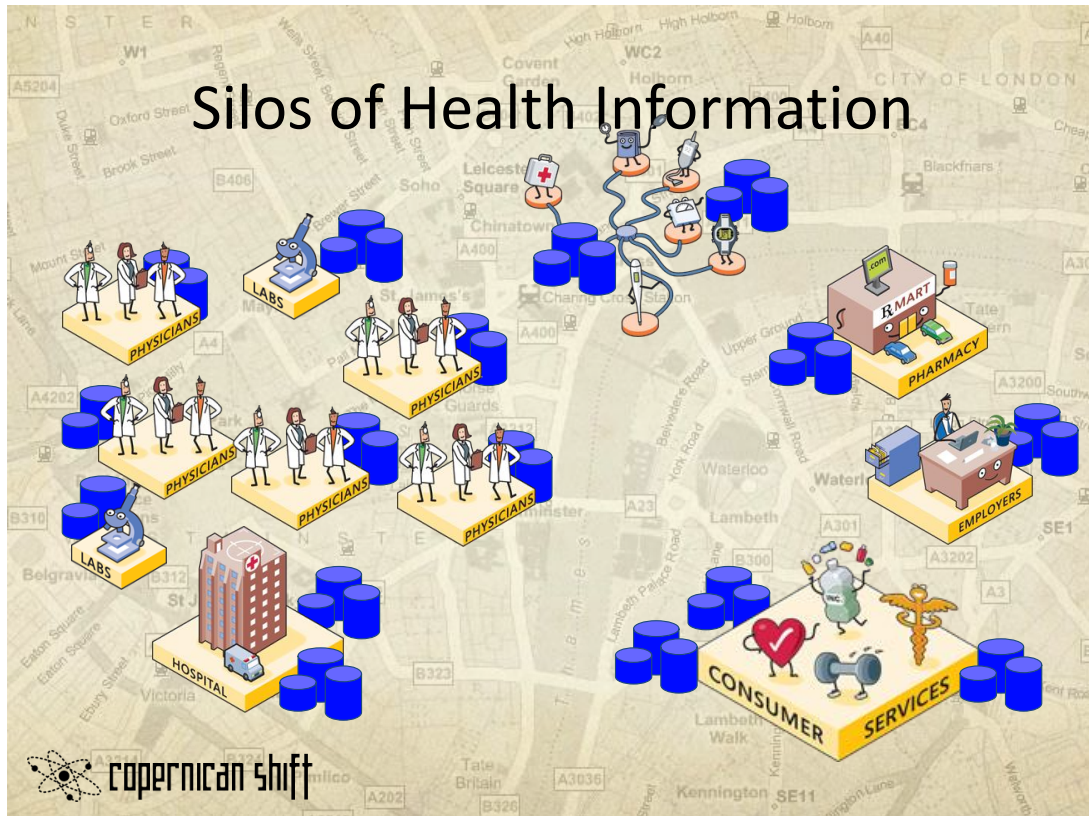
Silos of Health Information

I've recently had some medical problems and been involved with 3 different local hospitals. I have had several tests done at each. As they all use different systems none of the information can be shared. This means that in some instances some tests have needed to be repeated. What a ridiculous waste of resources.

I am involved with 6 consultants at the same hospital but most of the time they don't communicate with each other even though there are inter-disciplinary implications. As I have access to all my consultant letters I can check that I understand everything and share the information with other health professionals where required to make sure we are all up to date.

I can discuss the results from my GP with clinicians in other hospital departments. They are also involved in

my prescribing and may not need to repeat tests when they have the necessary information from my on line GP record. What is needed is for all the patient information to be ‘joined up’



As a nation we need to aim to keep GP records, self collected information (blood pressure, glucose levels, etc.), in-patient information, out-patient information, information from other agencies such as social care, physiotherapy, chiropody etc), information from carers and significant information summary together. The simplest way of doing that is to hold all the relevant information under a patient “hub” which can be accessed by anybody to whom the patient gives

permission. In Finland a child is given a number at birth and all their information is stored under that number. It works brilliantly!

I understand that the practice needed to spend time initially to enable patients to have access but much time is saved when patients are more independent and don't need to contact the practice so often. I hope that in the future many more patients will have the benefits that I enjoy and be empowered to participate more fully in decisions concerning their precious health.

Ingrid Brindle

Bruce Elliott

Trying to make a difference in the ways we manage our own health and care.



This photo was taken in 2011. It has history and a mass of underpinning hope and opportunity too. After introducing you to all the individuals in this picture I'd like you to tell me who is able, if they wish, to understand all their past diagnoses, view all their test results, add comments and updates to their records, see the value and costs of their medications to ease their stress and improve their health? These are the challenges and solutions for today. I hope you will all be dreamers, but realistic, optimistic, pragmatic, energetic dreamers and, at the end of the day, dreamers who will be keen to take some practical steps to help others, and yourselves.

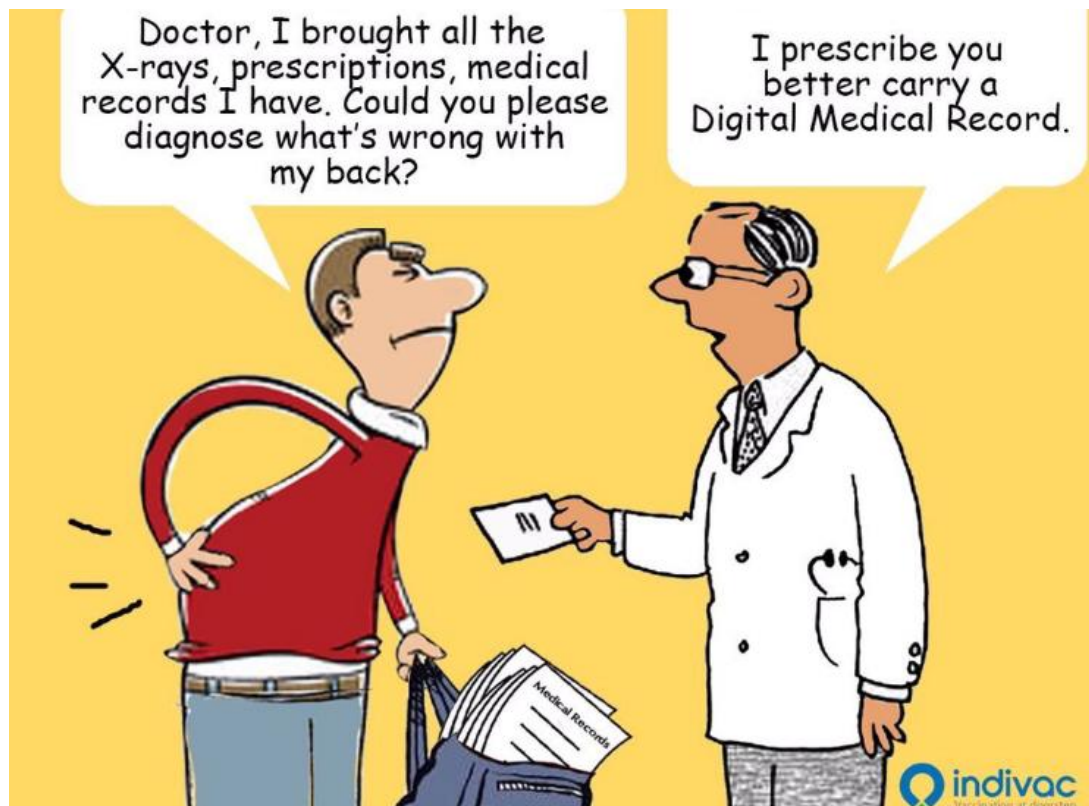
- 1. 'Boy in a coma' – I was diagnosed with Type 1 Diabetes at the age of 6. My mam had shared with the GP information about my rapid weight reduction, constant***

thirst and sugary urine and yet no link was made, and the Doctor referred to things passing in conversation. Still along with insulin injections it introduced me to ‘a diet without tears’, getting blood tests and being given the results in hospital clinics. But now in the digital age are things any better?. How many of us have access to our GP records, or our full Medical Records? How many of us can share details of our own exercise regimes and test results? But one of the most important aspects to me is how many of us can support our elderly relatives and loved ones via encouraging them to ‘try digital’ and/or through having proxy access to records? The final picture is of my mother-in-law, Maureen whose experience perfectly demonstrates this.



The majority of patients have no access to information about their treatment and care in hospital. However the majority collect information about their health, even though they can't access information about their sickness, and are interested in proxy access to be able to care for family members. An even larger majority are interested in

Personal Health Records (PHRs) - which would help them to understand and take action?



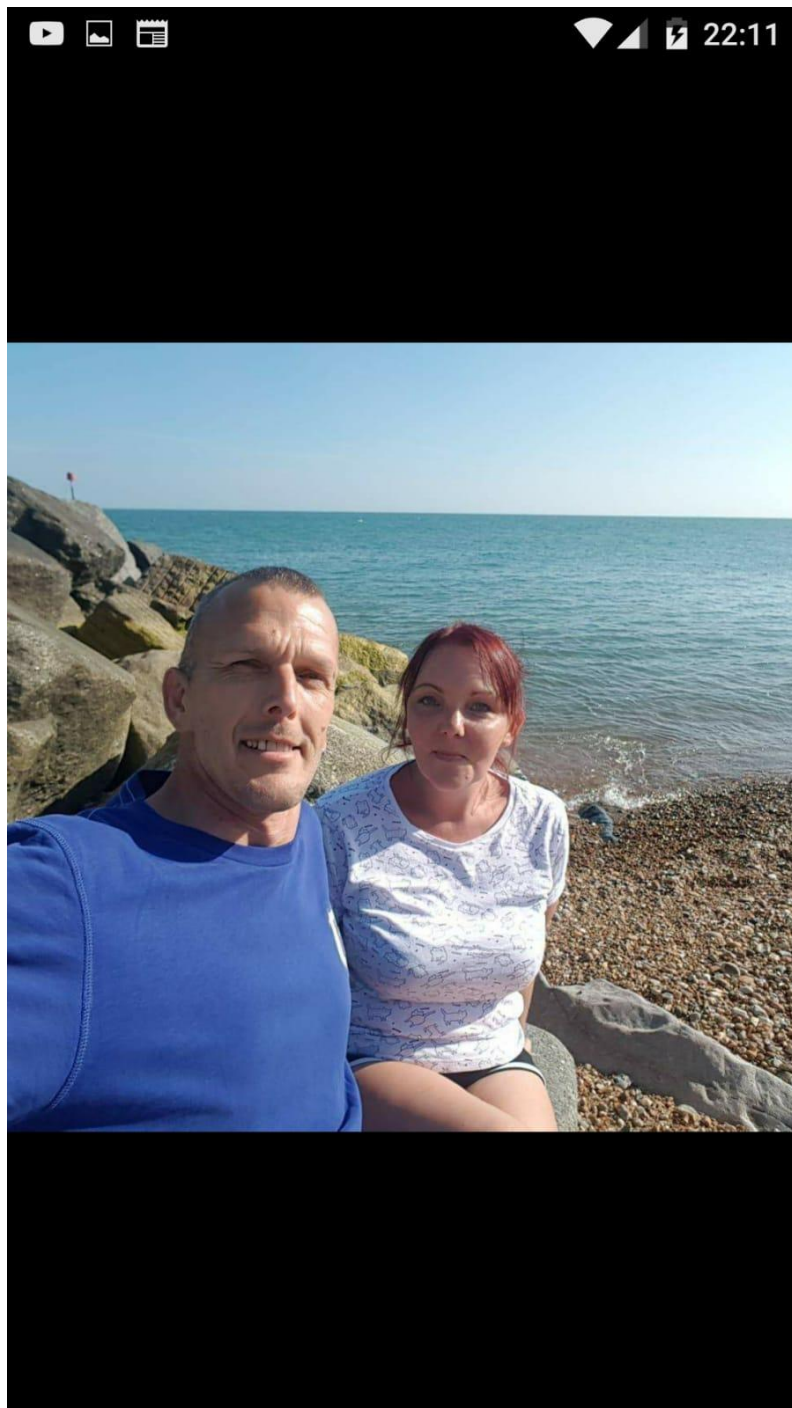
How 'Digitally Ready' am I? At home I can manage my own health needs online and advise my family and friends how they can too.

At work I know how best to use existing digital systems in my job and how they can improve the quality of our service and reduce any waste. In my moments of inspiration or frustration I know where I can get support to take my ideas forward and/or other organizations where they've already made such improvements.

My experiences using patient access

Cheryl Ashton

My name is Cheryl Ashton and I am 42 years old. I first started using patient access in 2014 shortly after I had a complete hysterectomy with conservation of ovaries. I was experiencing a lot of post-operative problems and having lots of tests and the receptionists at my GP surgery suggested patient access to me as a way of accessing the results.



Installing this made a huge difference to my life and eased lots of stress and anxiety, for example I could have one test (maybe an ultra-sound) but it could be several months before the appointment in which I saw the consultant for the results. The results would come through on patient access in around 7-10 days and anything I didn't understand

I could go and discuss with my GP It also allowed me to prepare for the appointment with the consultant by researching different options and by giving me enough time to think of questions I wanted to ask rather than trying to take everything in there and then.

I have used patient access at many consultations because being under several different consultants many times my medical information or results have not been in my medical file meaning the Doctors did not have access to it so they often wanted to repeat MRI scans or other tests. Once I showed them the results on-line (I have it downloaded onto my phone) it then meant that no tests had to be repeated and we could move forward in finding answers to the issues I was having.



The most important time patient access was used probably saved my life, it was a couple of weeks after abdominal surgery and I was in a lot of pain and very sick, my GP sent me for an emergency scan at another practice and the results were immediately sent to my Consultant marked Urgent....this was missed and after myself phoning the hospital and insisting I was seen immediately and not in two months as they suggested I got an emergency appointment as an outpatient that day. When I arrived they looked at the scan but lost my notes which again I was able to show them on my phone it turned out I had Urosepsis and I was kept in hospital on antibiotics for 3 days and was on them for a further 10 days when I returned home.

Having problems with low vitamin B12 and Vitamin D meant I had to have regular blood tests and regular vitamin supplements, before patient access I would phone the practice two days after bloods were taken and daily until I got the results, that would then often lead to a doctor appointment to discuss the results and get the necessary prescription.



21:41



21:47



Serum vitamin B12



Results history

249 ng/L • Normal
Normal range: 145 - 910 ng/L
10 Sep 2019



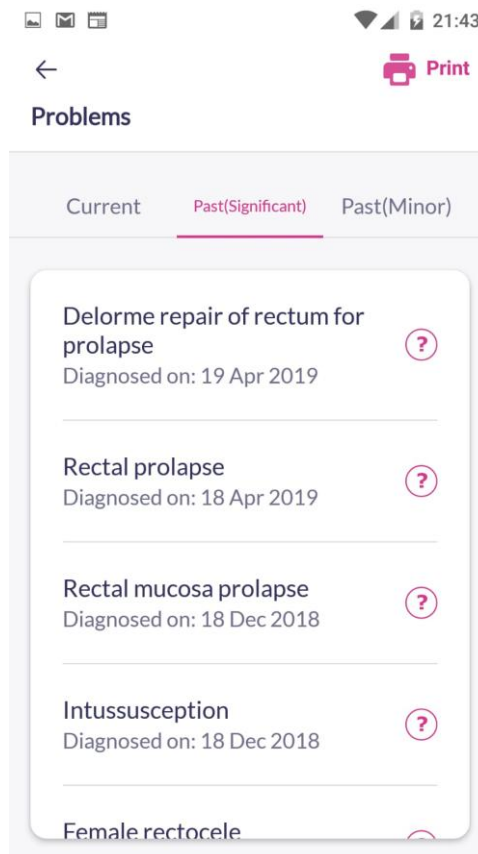
Serum total 25-OH vit D level



Results history

56.9 nmol/L • Normal
Normal range: 50.0 - 250.0 nmol/L
10 Sep 2019

Now the results come up usually within 24 hours, if there is a problem it is marked with a red star and I know that either my GP or the surgery will be in touch with me in the next couple of days to inform me of the next step.



Having a lot of medical issues, I do have problems with pain and take pain relief daily. Rather than phone the surgery every 7 days for repeat prescriptions I just order it as and when I need it on line, same with appointments, I can now book a appointment at a time and date that suits me and I'm no longer taking up the receptionists time. I've used patient access when I've been abroad, both to access my medical record and to order prescriptions so they have been ready and available upon my return.

Patient access as given me back some control, when your ill and in pain you put all your faith and hope into other people, you don't really have much say in what happens to you nor do you have any knowledge of what is happening to you either. Now I can see for myself I can research my

problems and educate myself, I can discuss various options with my consultants and have a say what happens to me, I trust them whole heartedly(most of the time) after all they are the expert but it is nice to have a input in what happens to me.

Its also given me the confidence to stand up for myself a perfect example was when one consultant informed me he was up to speed and knew my medical history then proceeded to ask me if I wanted children (as I stated earlier I had a hysterectomy 2 years prior to seeing this guy). We then had a disagreement who did a camera test a few weeks prior. He obviously didn't read my medical record very well. He wanted to discharge me, and I wasn't having any of it, I asked to see my original consultant and it turned out I had a rectocele, enterocele and inter-rectal insusseption...another operation later and I'm much better than I was. If I didn't have patient access, I wouldn't have the knowledge or the confidence to stand up for myself and I would still be in lots of pain with lots of medical problems and very miserable.

I would highly recommend patient access to everyone, everyone deserves a say in what happens to them, and everyone should have the access to their medical record.

C.Ashton

Edna and Abigail



Edna Davies Mother of Abigail Davies is a member of the patient participation group at Simmondley practice in Glossop and was one of the first of six patients to trial on line access to their contemporary GP record. Edna decided to register her daughter, Abigail, for on line access of her General Practice record in Glossop, England. Edna found a number of discrepancies and inaccuracies in her daughter's record which she wished to correct – not least because her daughter might be shown to other professionals (a feature of the EMIS access system of patient access to records).

Abigail – has many professionals involved in her care who could benefit from a shared record: Abigail is under School SENCO special educational needs coordinator, community paediatrician, physiotherapist, occupational therapist, orthotics, wheel chair service, upper limbs specialist, specialist hand occupational therapist, lower limb specialist, specialist teacher for children with physical needs, moving and handling advisor, inclusions officer and social worker.



Using the on line access view of the primary care GP record from home, a paper print out, and a shared view with the GP at the surgery/office Edna checked the accuracy and completeness of her daughter's GP medical record. A more accurate and complete record was achieved.

Abigail's premature birth and perinatal problems: Abigail was a twin birth but this was not placed in her records. Mum wanted it placed there. (Her twin sister, Faith, suffered a complication of ruptured intestine from which she died.)

On the sixth and seventh day of her life, Abigail suffered intracerebral haemorrhages which led to neurological disabilities. This was misrepresented in Abigail's notes which had coded Abigail's condition as congenital cerebral palsy (which meant from birth)

One entry stated that Abigail has learning difficulties which she does not. We corrected this entry.

Abigail's most influential summary entry is "Cerebral Palsy Spastic Quadriplegia" – presenting high tone in all four limbs and low tone in the torso.



However she has many other specific impairments:

Severe mobility issues and is a wheelchair user. Abigail crawls as a mode of mobility . Around the house, Abigail can high kneel but not sustain for long periods of time, unless at a low table. Abigail can pull herself up to standing and remain stood for short periods of time if holding on or leaning onto something to support herself.

Abigail can self-transfer into seating if the seat is low enough to allow sitting from standing.

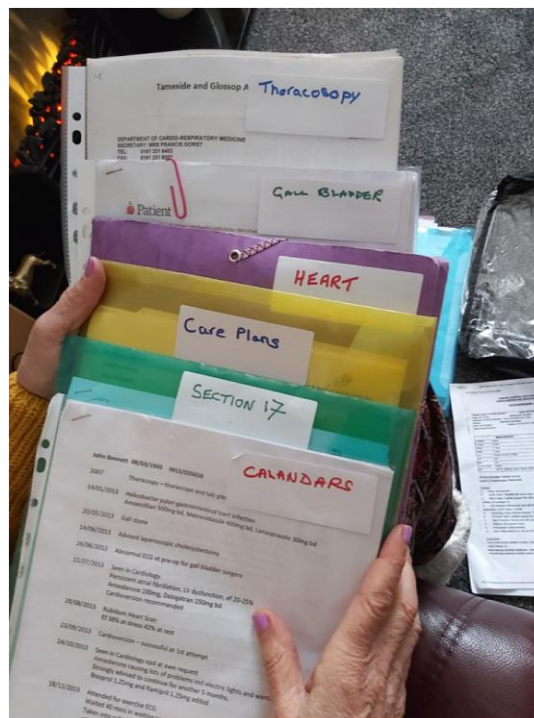
Conclusion: On line access to contemporary records is a new disruptive technology which may improve the lives of patients with disabilities. It allows patients and carers to check and if necessary request modifications and updates to on line primary care records. It allows them to share a professional record with whoever they wish.

Another Patient – A -that Yvonne helped

“7 years ago the patient had basal cell carcinomas (Small skin cancers), which were excised (cut out). Suspecting that one of the skin cancers had started growing again, the patient saw their GP who referred the patient back to the Consultant Dermatologist. For one reason or another the GP

was unable to send the patient to the original hospital and so the patient was referred to a different hospital.

At the initial consultation at the next hospital questions were asked about the previous basal cell carcinomas (skin cancers) including questions about the past findings and results. (Results from hospitals are not currently available to each other unless the patient has a copy).



With her permission I had printed off letters from the 1st hospital and had taken them with us. I offered these letters to the Consultant and told him they could be kept for the patient's records. The Consultant was both pleased and grateful - especially as he was able to keep them for file. Result – the patient referred for surgery, successfully treated and has now been discharged.

Another Patient – B -that Yvonne helped

Patient B was seen at hospital for possible removal of gallbladder due to the presence of gall stones. The consultant at the hospital did not have the scan that had been arranged by the GP Practice and explained to the patient that he would need to arrange another scan. The patient, however, had printed a copy of the scan before attending the outpatient appointment.

The patient the scan result for file to the consultant which the Consultant was pleased to accept. It was not an issue of complaint for the patient whether the scan was not included by Practice or lost at the hospital. Actually, the expense of saving another scan came second to saving the patient time and preventing the need for two more visits to hospitals.

**Created patient story at the presentation of
Microsoft's "Healthvault" in London in 2007**

"I am a working mum looking after a small child, a part-time job, a husband, a house... I also have Diabetes, an under-active Thyroid, fertility problems, depression, asthma and recently started medication to protect my kidneys!

"I don't have time to be ill!

"I now order my prescriptions, book my appointments to see the doctor, check my test results and sometimes I even go

over the conversation I had in my consultation with the Doctor when I feel I need to clarify issues.

“I shop online, I communicate online, I educate myself online, I control my finances online. In 2007 it’s only right that I look after myself ONLINE



The Story of lifelong medical records in England since 1928

Digital versus paper data

The General Practice records in the United Kingdom were traditionally paper-based and, importantly, retained cradle to grave. The standard GP record for 80 years or so was a system of cards placed in a buff-coloured, stiff card, 5 by 7 inch wallet known as a Lloyd-George Envelope. These records were linked to a national register of British citizens held by Somerset House and managed at Exeter. The records were held in the house of the doctor who provided care for the patient. (doctors worked from their own homes in the early decades of the 20th century.



Each record was lifelong, beginning at the birth of each patient or at their registration with Somerset House or at patient's inclusion in the health insurance scheme. All correspondence and events relating to the patient's health care under the health insurance and later to their NHS care were to be copied to the record in paper hard copy making it a life long record of the patient's medical and preventative history(including for example, events relating to birth, maternity, contraception, vaccinations, infancy, breast and bowel and cervix screening, disease, death and dying).

At that time most practices only recorded incident by incident notes. There was no summary of problems and the notes were in handwriting and mnemonics that could often only be interpreted by the author. Handwritten notes were often illegible except to the writer of the note whereas digital text is legible to all.

In the 60's, Card indexes were used to form registers of patients with specific diseases and services.



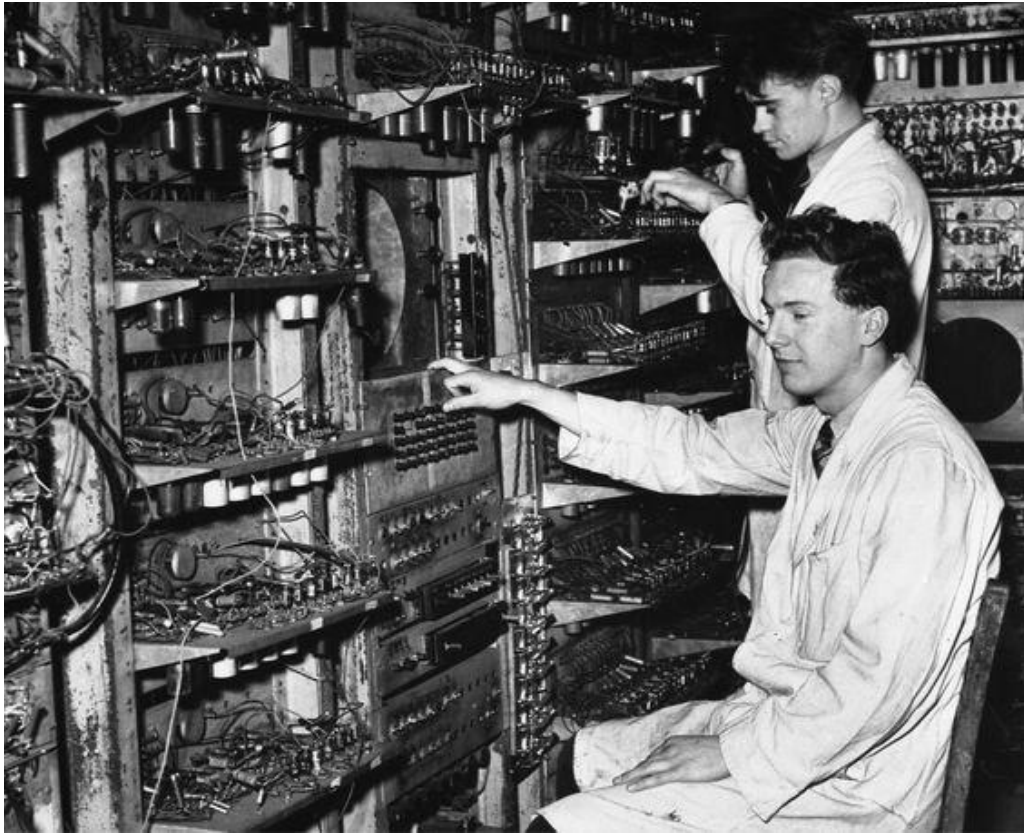
The eight week turn around for records from one GP to another.

In the past when a patient registered with a new doctor, the new doctor notified the FHSA at the end of the week. It took eight weeks for the old notes to arrive at the surgery. Today the electronic GP record sits in a central site and the access to the record can be activated on the day that the patient registers with the GP.

Digital records were kept alongside paper records. It was not until there was an adequate audit trail to record deletions and alterations in 2001 that doctors could legally maintain digital records alone. Paper records for patients still exist and are still transferred from one doctor to another but are not often used in practice.

Digital data

The Manchester Small-Scale Experimental Machine, nicknamed Baby, was the world's first stored-program computer. It was built at the Victoria University of Manchester by Frederic C. Williams, Tom Kilburn and Geoff Tootill, and ran its first program on 21 June 1948.^[78] The potential to record and share data digitally was born.



Data Banks

“In telecommunications, a data bank is a repository of information on one or more subjects that is organized in a way that facilitates local or remote information retrieval. A data bank may be either centralized or decentralized. In computers the data bank is the same as in telecommunication (i.e. it is the repository of data. The data in the data bank can be things such as credit card transactions or it can be any data base of a company where large quantities of queries are being processed on daily bases).”



Patient engagement, education and culture change

GPs began to give patients their own blood pressure cards (supplied by ICI the maker of propranolol) with the blood pressures, lipids and glucose levels marked on. Patients were encouraged to understand their results and to measure their own weights, heights and blood pressures and to add these readings to their paper records. “internally controlled patients” wanted to be involved with their disease and to help manage their disease. Externally controlled patients wanted someone else to manage their disease. “Originally the screen was turned away from the patient but increasingly it was being shared with the patient.”



Many patients with complicated diseases, or diseases which were developing or changing rapidly, did not travel abroad as they knew that professionals would not know the full extent of their history, investigations and treatment. Having access to their full digital record made travel for patients with complicated health problems less risky.

Patients wanted to enter their own clinical data. Diabetics wanted to enter their glucose levels, epileptics wanted to enter the number of fits, hypertensives wanted to enter their BP readings, etc, etc. They also wanted to enter their own text about how they feel.

Patient training, education and conversations and Press:

The patient participation group (PPG) was formed and ran until 2006. A multiplicity of training techniques was used to help the patients gain confidence and understanding. Medical terminology was explained pictorially and made available to the patients. Patients were trained to do their own weights and blood pressures whilst in the waiting room. The medical press was informed, too, as

local practitioners questioned the practices of patient centred care. Patients learned to manage and understand their own blood pressure readings through the formation of “HeartBeat” self-help group.

Handling bad news – is it harmful to patients to know everything?

Should we upset patients by telling them that they might have another heart attack when they have just had the first or should we say “there there, you have nothing to worry about”? Should we let patients know their prognosis? What should we tell the family? What does the law and ethics allow? Discussions at the GMC 20 years later, at UNESCO 22 years later and also at the MDU, ICO and National Care Record Board helped us to decide that patients should be able to see everything immediately if they wished to do so and if they demonstrate that they understood that they might be upset.

Patient Participation Groups

PPGs helped to provide a patient voice. Patients wanted to promote online access to records as a way of maintaining trust in General Practice.



Practice-Based Web Portal and public engagement

Haughton Thornley Medical Centres launches the practice-based web portal www.htmc.co.uk with Glen Griffiths and the patients and staff at the practice to support the Partnership of Trust. It signposts patients to trusted information to support their care generated by patients and staff (particularly the clinicians) alongside local, regional, national and international sources of information.

References

- 1. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995. Official Journal of the European Communities, L 281/31-50, dated 23/11/1995
European Commission COM(2012) 11 final 2012/0011 (COD). Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation)***
- 2. United Nations Convention on the Rights of Persons with Disabilities***
- 3. Informatics in Primary care 2006 14:55-7 PHCSG British Computer Society “Sharing electronic records – the patient’s view” John Powell, Richard Fitton, Caroline Fitton***

- 4. Lond. J. Prim. Care 6 (2014) 8–15C. Fitton, R. Fitton, A. Hannan, B. Fisher, L. Morgan, The impact of patient record access on appointments and telephone calls in two English general practices. A population based study,**
- 5. International Journal of medical informatics –Syed Ghulam Sarwar Shah, Richard Fitton, Amir Hannan, Brian Fisher, Terry Young, Julie Barnett “Accessing personal medical records online: A means to what ends?”**
- 6. Medical and Care Compunetics 4 L. Bos and B. Blobel (Eds.) “Towards a Partnership of Trust” Dr Amir Hannan, B.Sc., M.B. Ch.B, M.R.C.G.P. General Practitioner & Fred Webber, B.Sc., Ph.D. patient**
- 7. Culture and Change at The Hadfield Medical Centre, Samina Munir Salford Health Informatics Research Environment (Shire) University of Salford & Dr. Ruth Boaden Manchester School of Management University of Manchester Institute of Science and Technology (UMIST)**
- 8. C. Pagliari, T. Shand, B. Fisher, Embedding online patient record access in UK primary care: a survey of stakeholder experiences, J. R. Soc. Med. Short Rep. 3 (5) (2012) 34.**
- 9. European Union, Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the Application of Patients’ Rights in Cross-border Healthcare, OJEU, L 88/45 (4.4.2011).**
- 10. Department of Health, The NHS Constitution for England, London, 2013.**
- 11. H.M. Treasury, Autumn statement 2011, in: Presented to Parliament by the Chancellor of the Exchequer by Command of Her Majesty, The Stationery Office Limited, Norwich, UK, 2011.**
- 12. Department of Health, The Power of Information: Putting all of us in Control of the Health and Care Information We Need, 2012, London.**
- 13. Royal College of General Practitioners, Enabling Patients to Access Electronic Health Records. Guidance for Health Professionals, 2010, London.**
- 14. Royal College of General Practitioners, Patients Access to Records, 2012, London, <http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/patient-access-to-records.aspx> (accessed 22.04.13).**
- 15. T. Greenhalgh, G.W. Wood, T. Bratan, K. Stramer, S. Hinder, Patients’ attitudes to the summary care record and HealthSpace: qualitative study, BMJ 336 (7656) (2008) 1290–1295.**

- 16. C. Pyper, J. Amery, M. Watson, C. Crook, Patients' experiences when accessing their on-line electronic patient records in primary care, Br. J. Gen. Pract. 54 (498) (2004) 38–43.**
- [17. B. Fisher, V. Bhavnani, M. Winfield, How patients use access to their full health records: a qualitative study of patients in general practice, J. R. Soc. Med. 102 (12) (2009) 539–544.**
- [18. V. Bhavnani, B. Fisher, M. Winfield, P. Seed, How patients use access to their electronic GP record—a quantitative study, Fam. Pract. 28 (2) (2011) 188–194.**
- 19. C. Fitton, R. Fitton, A. Hannan, B. Fisher, L. Morgan, The impact of patient record access on appointments and telephone calls in two English general practices. A population based study, Lond. J. Prim. Care 6 (2014) 8–15**
- [20. Syed Ghulam Sarwar Shah, Richard Fitton, Amir Hannan, Brian Fisher, Terry Young, Julie Barnett Accessing personal medical records online: A means to what ends?**