

# Building Trust Patient Access to Records

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Please see NOTES that accompany the slides

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# Let's go on a journey...



We are going on a long journey. Not sure where it is heading at the moment...



## October 1<sup>st</sup> 2000

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- Day 1 Market st surgery
- No computer system
- Health care did not stop
- Remained safe and secure

I started as a GP on October 1<sup>st</sup> 2000 at Market St surgery where Dr Harold Shipman used to work. His wife the night before had come in and took her property away (including the computer system). The hard-drive with patient data on had been removed and was with the Heath Authority. So I started with no computer system. But that did not stop delivery of health-care



## My priorities

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1. Build **trust** amongst my patients and staff that I was "safe"
2. Put the PATIENT at the centre of what I do and not do
3. Identify who / what could help me
4. Health authority, Partners, Staff, PATIENTS

Here were the priorities I had set myself with . In many ways these are the founding principles upon which I still work from, although their nature has changed. The last one is in order of importance with lowest first!



## “Doctor-Patient relationship”

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- Not about information, gizmos, the latest treatments or protocols, guidelines etc *per se*
- About the **doctor**, the **patient** and the **notes**
- Mystique surrounding notes started to break down as people became interested in knowing what had been recorded about them

What I realised very quickly and then started to work through. This will b very important today because people sometimes get confused about technology and its place and some of these more basic issues. Many others know much more about this than I do but this is what I came to realise



- Initially to see if any crime had been committed....
- Then I realised notes could be a way of bringing trust back to the patient whilst ensuring I have a healthy relationship with my patients
- *"My management is so and so and I am happy for you to see anybody in the world to see whether you are being managed well or not based on the constraints I am working within"*

Why did people want to see their records and get copies of them?

I had no problem with patients wanting records and reasons behind it because of the basic principle for working



- *"People in Hyde are good people and yet all the rest of the world hears is about Shipman and Myra Hindley. A terrible calamity came to Hyde but from here I am determined for something positive to come out which could one day show the rest of the world how to move forwards and progress"*
- Raising trust by showing I had nothing to hide
- Hence met Dr Richard Fitton and embarked on a process of identifying a process of enabling patients to have copies of their records

Why did I stay in Hyde despite the fantastic pressure from the media, the patients and the "high risk" environment I was working in. One patient complained to the GMC because I would not prescribe valsartan for them. Fortunately that was passed back to the PCT who in turn passed it back to the practice! But it indicated to me that my patients had a direct link to the GMC! And the GMC were under pressure and hence would have to act on anything suspicious. Nothing like focusing your mind on the job at hand! But of course we all operate under the same pressures – I was simply more aware of it! Being more sensitive to this meant I was more sensitive to any solutions around!



## Started Research

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- To get through ethics committee approval, 3 main exclusions were applied
  - no children,
  - no patients with mental health problems
  - no patients who did not speak English

We started the research with Claire Harris from the University of Manchester Institute of Science and Technology (UMIST). 50 patients were identified in the practice and given copies of their electronic records. But there were 3 significant exclusion criteria





## Research experience

- Some patients are very positive
- "Yes please! I think it's great that I can have a copy of my own record"
- Others – no way – I would not know what to do with the disk even if you gave it to me
- Staff felt it was some superfluous thing that I was doing
- Partners happy with what I was doing but not necessarily wanting to get involved
- Very challenging time – 2 doctors down, 2 surgeries needing to be brought together, Shipman Enquiry in full swing and staff under fantastic pressure
- Under pressure, pushed forwards to identify 50 patients for the study



## Change from Research

- 2 years went by and a lot of interest generated locally, nationally and internationally
- Tameside & Glossop PCT decided to make it a policy that all patients should be enabled to have their own Electronic Health Records
- We talked about a Patient-Led NHS at PEC and Board
- My answer was that patients needed to have knowledge of their own health condition to understand it better and to help develop better services locally responding to their needs

After the research lots of interest in what we had achieved to date. It also linked more closely with national policy suggesting that we were heading in the right direction in our thinking. This was confirmed independently at PEC, Board (and LMC!)



## Electronic Health Records for All!

- Following much discussion including a workshop hosted by Tameside & Glossop PCT on behalf of NHS Connecting for Health, we decided to have an open policy for anyone to be able to get copies of their records
- Patients are often surprised...
- ...expecting this to be standard practice
- "*Our Health, Our Care, Our Say*" talks about "a new era where the service is designed around the patient"

The workshop (which was a Joint venture between T & G PCT and NHS CfH), we had the confidence to produce a policy that said all residents of T& G were entitled to have copies of their electronic records. This was a small symbolic gesture but has very significant implications for the direction that we were taking and what we stood for. It seemed very natural but yet patients started to realise when they went away from the area that this was not standard across the NHS



## What problems have I NOT had!

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- Litigation
- Large number of patients coming back to ask about the record
- Sexually transmitted diseases
- 3<sup>rd</sup> party information
- Foreign speaking patients asking for records
- Children / Guardians requesting records

Everyone I speak to worries about these aspects – the world we live in today. It suggests that these are not the “real” issues that matter and possibly distractions although there is not enough experience for me to say this with any certainty. We all must be careful of anecdotal, personal experience and so I must not get complacent. I have personally not been sued but that does not mean it does not happen!



## What problems *have* I had

- Mental health problems
- Termination of pregnancy
- Patient who has died following request for notes
- Numbers of patients signing up for their Electronic Health Records
- A perception by staff that this will create more work for them and that they are ill-prepared for it

These are common problems I have had over the last 2 years. Dealing with “termination of pregnancy” has come up time and time again. Patients have often forgotten about this because it happened 30-40 years ago in a “previous life”. Now they are perhaps happily married with grand-children. Suddenly they are confronted with a distant truth that maybe nobody knows about. This reignites very powerful emotions and worries that need to be worked through and a sympathetic doctor! Similarly mental health problems – more for me than the patient. What will happen if a patient finds out the circumstances around a time when a patient was psychotic or perhaps had a diagnosis of “pathological liar” – a term I am not familiar with. Is that the same as Munchausen’s syndrome? What if the patient thought this was wrong and yet it had been in their notes for 40 years without them realising it. Again very powerful emotions start to filter through and perhaps a “bereavement process” of sorts that again needs careful management. I had an interesting problem with the patient who died after requesting his records. He had paid the money but had not received his records yet. His spouse then came to the requesting a copy of her husband’s records which she felt she had a right to have!

We have charged £10 for a copy of the records on disk. This seems reasonable considering it can take 3-4 hours to summarise and enter the information on to the computer per patient. (Most requests came from people with long histories!) Despite this the number of patients taking up the offer were small – in the 10s rather than 100s or 1000s. We have a practice of 12,000 patients and have plasma screens in the waiting room telling patients that they can have access to their records.

The staff were relatively resistant to the idea of patients having records (though not the partners who were more neutral as long as they had not much to do with it!). The staff did not feel this was a core part of the NHS business or their job. Keeping them on side and winning hearts and minds amongst staff has been difficult



[www.patient.co.uk/surgery.asp](http://www.patient.co.uk/surgery.asp)

On 16<sup>th</sup> March 2006, internet access real-time of patient's GP-held electronic health record demonstrated for the first time to a live audience

- Latest consultations
- Results
- Medication
- Letters / Pictures / Other scanned documents

all became available for patients to see and share with whom they please

We launched internet access to medical records

Address [https://access.e-mis.co.uk/PAERS/summary\\_rec.asp](https://access.e-mis.co.uk/PAERS/summary_rec.asp)

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 [ ■ ] [ A A A A A ]  
 22 May 2006

<b>Summary Record</b>	<b>Allergies</b>
<b>Consultations</b>	15/07/2005 Adverse reaction to Penicillin V
<b>Results</b>	21/07/2005 Adverse reaction to Ciprofloxacin
<b>Letters</b>	16/09/2005 Adverse reaction to Penicillin V
<b>Medication</b>	<b>Current Medication</b>
<b>Record by Date</b>	14/01/2005 Asprin Dispersible Tablets 75 mg ONE TO BE TAKEN DAILY
<b>Record by System</b>	20/01/2005 Glyceryl Trinitrate Cfc-Free Pump Spray 400 micrograms/dose AS REQUIRED
<b>Links</b>	Paracetamol Tablets 500 mg ONE TO BE TAKEN THREE TIMES A DAY
<b>Sign Out</b>	03/06/2005 Tretinoin Cream 0.025 % MDU
	15/07/2005 Asprin E/C Tablets 75 mg ONE TO BE TAKEN DAILY
	18/07/2005 Ramipril Capsules 2.5 mg ONE TO BE TAKEN DAILY
	12/12/2005 Tramadol Hydrochloride Capsules 50 mg TWO THREE TIMES A DAY
	13/01/2006 Fentanyl Transdermal Patches 25 micrograms/hour ONCE
	24/04/2006 Paracetamol Tablets 500 mg 1 -2 FOUR TIMES A DAY AS REQUIRED
	01/05/2006 Asprin Dispersible Tablets 75 mg ONE TO BE TAKEN DAILY
	01/05/2006 Procoralan Tablets 5 mg ONE TO BE TAKEN TWICE A DAY
	02/05/2006 Ibuprofen Sugar-Free Suspension 100 mg/5 ml TAKE ONE 5 ML SPOONFUL THREE TIMES A DAY
	03/05/2006 Epaderm Ointment APPLY THREE TIMES DAILY
	18/05/2006 Morphine Sulphate MR Tablets 30 mg ONE TO BE TAKEN DAILY
	<b>Active Clinical Problems in date order</b>
	03/05/2006 Blood glucose abnormal

Screen shot of what patients can see from our test patient





Address <https://access.e-nis.co.uk/PAERS/results.asp>

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Summary Record	Test Results (within 1 year) in Date Order			
Consultations	Date	Test name	Test Result	Normal Range
Results	03/05/2006	Systolic blood pressure	112mm Hg	0-350
Letters		Normal		
Medication	03/05/2006	Diastolic blood pressure	66mm Hg	0-250
Record by Date		Normal		
Record by System	03/05/2006	Cigarette smoker	5Per Day	1-200
Links		Normal		
Sign Out	03/05/2006	O/E - weight	80Kg	0-400
		Normal		
	03/05/2006	Body Mass Index	32.9	22.5-30
		Normal		
	03/05/2006	Ideal Weight	56Kg	0-0
		Normal		
	03/05/2006	Alcohol Intake	25units/week	0-20
		Abnormal		
	03/05/2006	Waist Measurement	92cm	0-100
		Normal		
	03/05/2006	10 yr CHD risk (Framingham)	16%	0-100
		Normal		
	02/05/2006	Serum potassium	3.6mmol/l	3.5-5.5
		Normal		
	02/05/2006	Serum sodium	132mmol/l	132-144
		Normal		
	02/05/2006	Serum creatinine	64umol/l	44-80
		Normal		
	02/05/2006	Serum urea level	5.6	3.5-7.4
		Normal		
	02/05/2006	Blood glucose result	6.4mmol/l	3-6
		Abnormal		
	01/05/2006	Case management risk assessment score		-
		Normal		
	01/05/2006	O/E - pulse rate	72/minute	0-80
		Normal		

Results view. Note how abnormal results are flagged for the patient to see eg abnormal glucose or abnormal alcohol. Positive feedback for the patient or someone else who the patient let's the person see





I often take pictures of lesions and attach them to the medical record. Now the patient can see the picture too wherever they are! The only “catch” is that documents can only be viewed that are less than 100KB long. Most pictures I take are about 1MB long. This is one I highly compressed to make it fit under 100KB showing the technology works (sort of!)

Address https://access.e-nis.co.uk/PAERS/attach\_view.asp?AttachmentID=49E22B0C-D6A0-4AA2-9B8B-827194B35005\_EMS9096\_31862.rtf

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18 May 2006

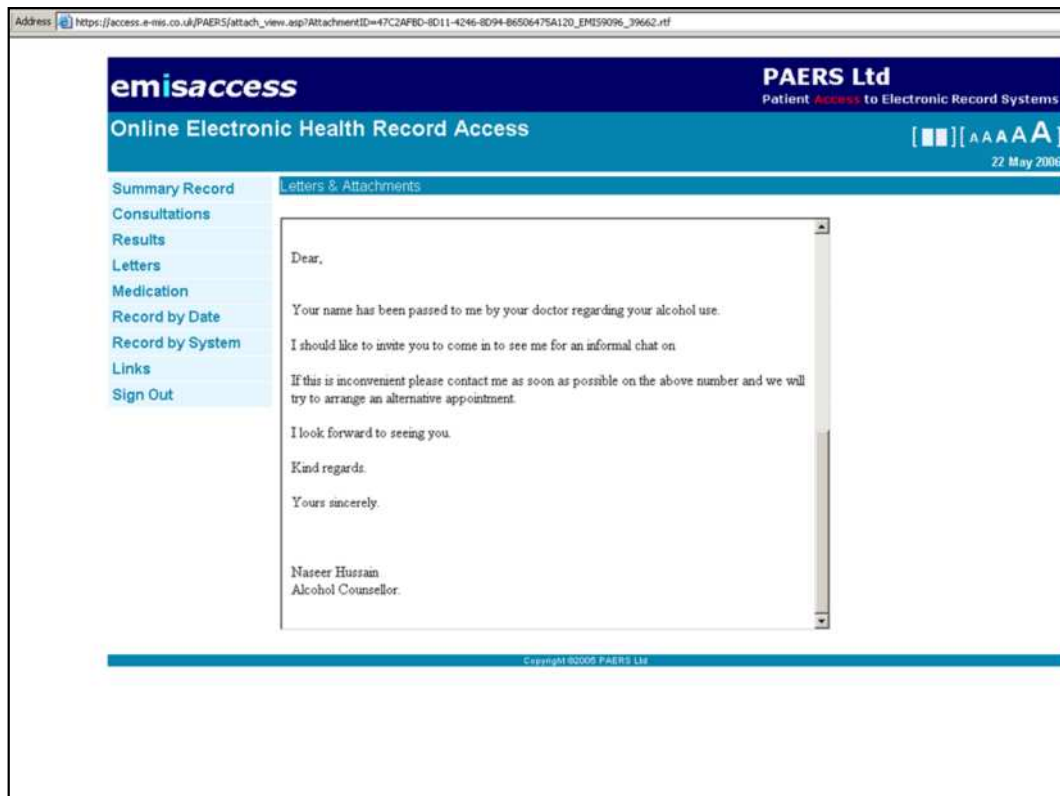
Summary Record  
Consultations  
Results  
Letters  
Medication  
Record by Date  
Record by System  
Links  
Sign Out

Letters & Attachments

**Houghton Thornley  
Medical Centres**  
  
**Tatton Road, Houghton Green  
Denton, Manchester M34 7PL**  
Tel 0161 336 3005 Fax 0161 320 3884  
  
**Thornley Street, Hyde  
Cheshire SK14 1JY**  
Tel 0161 367 7910 Fax 0161 367 1799  
  
Date seen in surgery  
  
11.11.2005  
  
FOR THE ATTENTION OF  
  
Surname:      Testtransfer

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Here is a letter we sent out...



... to the alcohol counsellor as our patient has an alcohol problem! Again further positive feedback for the patient to see


Address <https://access.e-em.co.uk/PAERS/meds.asp>

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 Online Electronic Health Record Access

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 [■■][AAAAA]  
 22 May 2006

Summary Record	Current Medication
Consultations	18/05/2006 Morphine Sulphate MR Tablets 30 mg ONE TO BE TAKEN DAILY
Results	03/05/2006 Epaderm Ointment APPLY THREE TIMES DAILY
Letters	02/05/2006 Ibuprofen Sugar-Free Suspension 100 mg/5 ml TAKE ONE 5 ML SPOONFUL THREE TIMES A DAY
Medication	01/05/2006 Aspirin Dispersible Tablets 75 mg ONE TO BE TAKEN DAILY
Record by Date	01/05/2006 Procoralan Tablets 5 mg ONE TO BE TAKEN TWICE A DAY
Record by System	24/04/2006 Paracetamol Tablets 500 mg 1-2 FOUR TIMES A DAY AS REQUIRED
Links	13/01/2006 Fentanyl Transdermal Patches 25 micrograms/hour ONCE
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	18/07/2005 Ramipril Capsules 2.5 mg ONE TO BE TAKEN DAILY
	15/07/2005 Aspirin E/C Tablets 75 mg ONE TO BE TAKEN DAILY
	03/06/2005 Paracetamol Tablets 500 mg ONE TO BE TAKEN THREE TIMES A DAY
	03/06/2005 Tretinoin Cream 0.025 % MDU
	20/01/2005 Glyceryl Trinitrate Cfc-Free Pump Spray 400 micrograms/dose AS REQUIRED
	14/01/2005 Aspirin Dispersible Tablets 75 mg ONE TO BE TAKEN DAILY
	Past Medication
	05/05/2006 Paracetamol Sugar Free Suspension 120 mg/5 ml 5 MLS 6 HRLY AS REQUIRED
	21/03/2006 Amoxicillin Capsules 250 mg ONE TO BE TAKEN THREE TIMES A DAY
	23/02/2006 Thyroxine Tablets 25 micrograms ONE TO BE TAKEN DAILY

The medication screen. Do you remember going to the out of hours doctor and saying my doctor gave me an antibiotic last week and I feel no better. Well now you can show the doctor what antibiotic it was that I gave last week! Past medication would be so useful and an instant benefit in so many consultations that take place away from the surgery setting.



## Local Care Record Development Board

**Objectives – Chaired by Vice Chair of Board – Lay member**

- Identify and promote the values and principles which should govern the development and implementation of the NHS Care Record
- Advise (Tameside & Glossop) PCT Board and PEC on the development of the NHS Care Record
- Ensure that ethical and policy issues including those concerning security and confidentiality are adequately addressed
- Represent users of the NHS Care Record including patients, the public and staff in health and social care and reflect their views and interests
- Enable users of the NHS Care Record to be included and engaged in its development and implementation
- Support an inclusive communications strategy that keeps all stakeholder groups engaged in the development of the NHS Care Record
- Identify the risks and issues arising from the development and implementation of the NHS Care Record and to propose solutions to those risks and issues

What else have we done to support the venture. Clearly there are significant implications for a large number of stakeholders locally. What happens if a patient wants to know from someone independently what the risks and benefits of sharing information are? What if a local GP is being “difficult” and does not allow their patients to have this access, who can the patients turn to. What about a consultant at the local hospital who has problems and wants to know what his “rights” are and wishes to share his views with the wider local health community. What about social services or the local mental health trust? What if a fundamental problem is uncovered and the project needs to be “stopped”. Here is the expert local group who oversee the implementation, trying to ensure there are local benefits for the local health eco-system but which can have a direct link with the national Care Record Development Board when there are issues that are proving difficult to resolve locally. My experience over the last 2 years is that there will be many ethical dilemmas that will need to be resolved. For example 14 year old girl who asks for contraception – who should have the password to her record. What if her legal guardians ask for the password. What should I do as her GP?



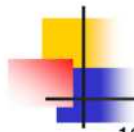
## Local Care Record Development Board

It will include the following stakeholders:

- Patients
- Public
- Tameside & Glossop Primary Care Trust
- General Medical Practitioners
- Tameside & Glossop Acute Trust
- Pennine Care Trust (mental health)
- Tameside MBE (social services)
- Other stakeholders eg the voluntary sector and independent sector may be brought in... at a (later) date

Start to see how the independent sector can be brought into the fold of the new NHS!





## Ten Cutting Edge Meetings

16 <sup>th</sup> March 2006	Internet Access to GP record demonstrated for the first time
2 <sup>nd</sup> May 2006	<i>After Shipman – Trust between Patients and Doctors</i> Royal Society of Medicine
4 <sup>th</sup> May 2006	Inaugural Local Care Record Development Board meeting, Tameside & Glossop PCT
14 <sup>th</sup> May 2006	Meeting with surgeons at Tameside General Hospital
23 <sup>rd</sup> May 2006	<i>Building Trust - Patient Access to Records</i> Meeting at Primary Health Care Specialist Group, BCS
1 <sup>st</sup> June 2006	Meeting with Sir Graeme Catto – President of GMC and Professor Richard Baker University of Leicester
8 <sup>th</sup> June 2006	<i>Patient Record Access - The Time Has Come</i> The International Council on Medical & Care Compunetics The Hague, The Netherlands
12 <sup>th</sup> June 2006	Meeting with Geriatricians and Professor Martin Severs Chair of NHS Standards Board, University of Portsmouth
19 <sup>th</sup> June 2006	Meeting with Royal College of Surgeons (Edinburgh)
Autumn 2006	Meeting with Professor Denis Protti (Canada), David de Bhal (Australia) and Phil Marshall (USA) (To be confirmed)

The meetings that have changed my world and put this on the map



## "Problems" We Are Dealing With

- Minor with terminal cancer
- Letter scanned into wrong notes
- Children, people with mental health problems and foreign speaking patients
- Explaining to staff benefits of sharing records with patients
- Understanding how we can help patients to use records access to improve health outcomes

I had a child with terminal cancer and offered him access to his medical records. At the time he chose to think about it. Did I do right? I don't know but this is my world now. I believe all patients have a right to see their medical records, even children!

Letters scanned into the wrong records are a real problem. Completely breaks patient confidentiality. Could be a show-stopper. We need to understand how to manage this problem / risk without having to resolve to the courts.

The exclusions... most of the patients I actually see in my routine work.... We have to now get on and work in the real world instead of a make-believe research world. The local CRDB will prove very useful in all this helping to keep everything "real"

## The ERA of RECORD ACCESS has come



- And with it the opportunity to re-build the trust in the medical profession
- Let's join together and take this message to the World
- Any questions?



Rolling back the path, one step at a time!