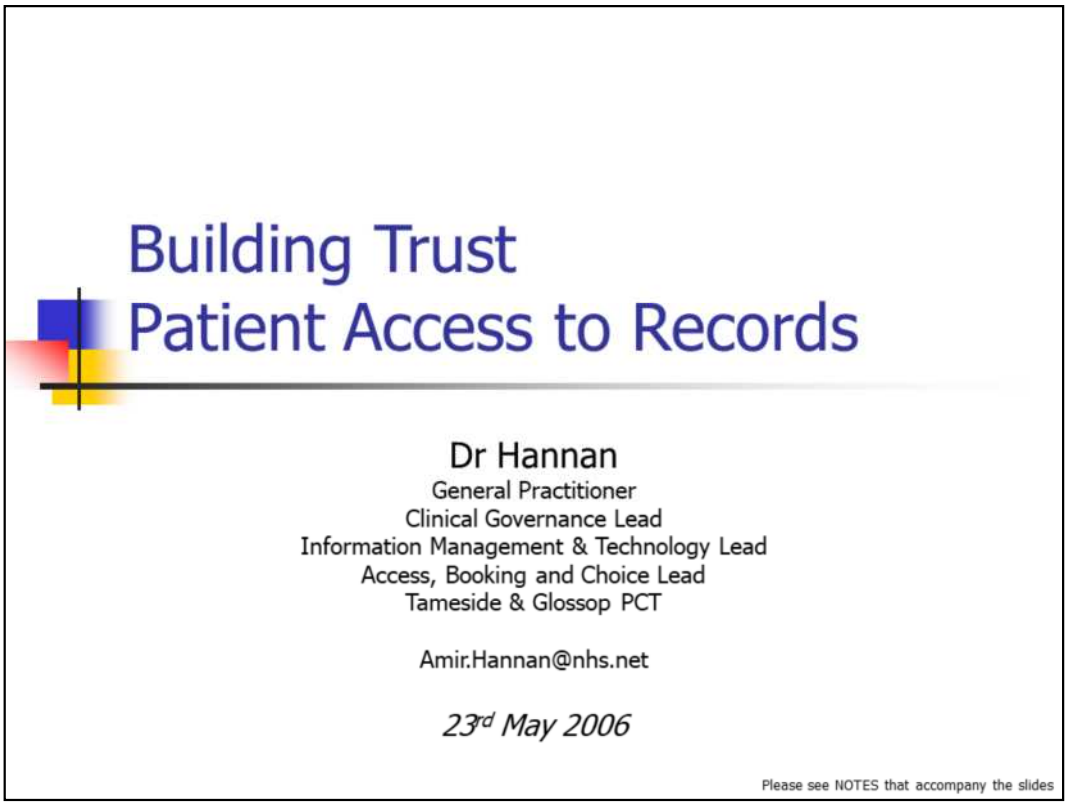
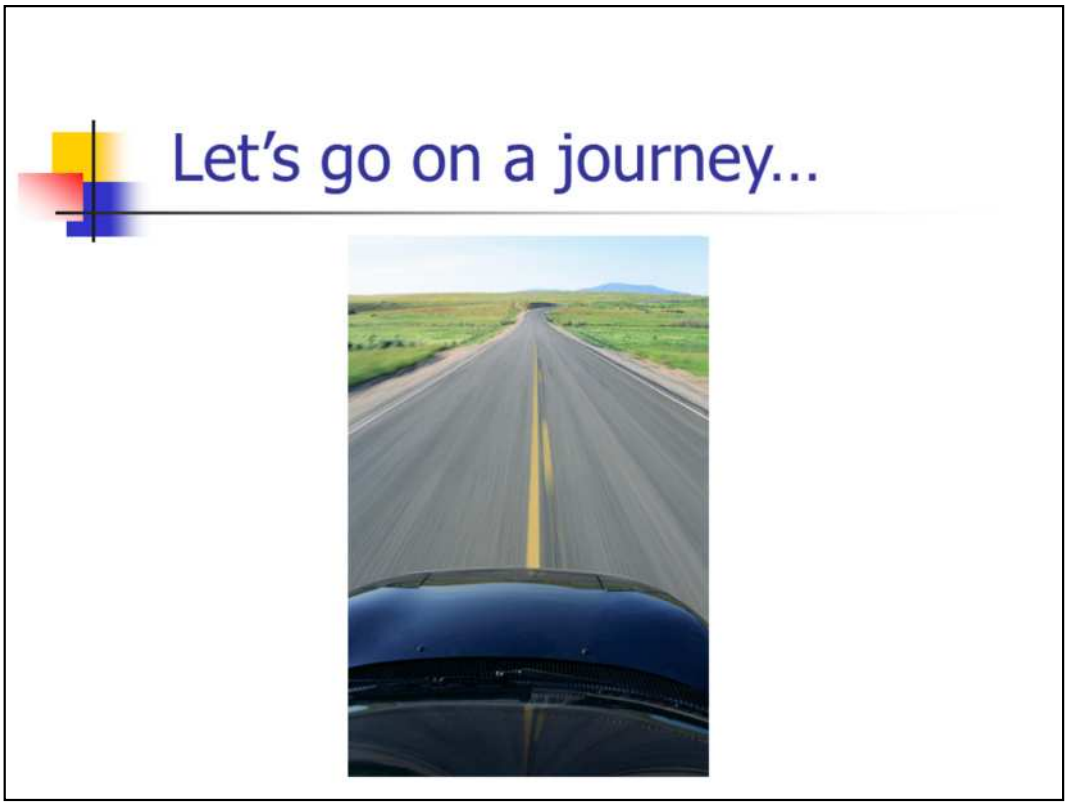
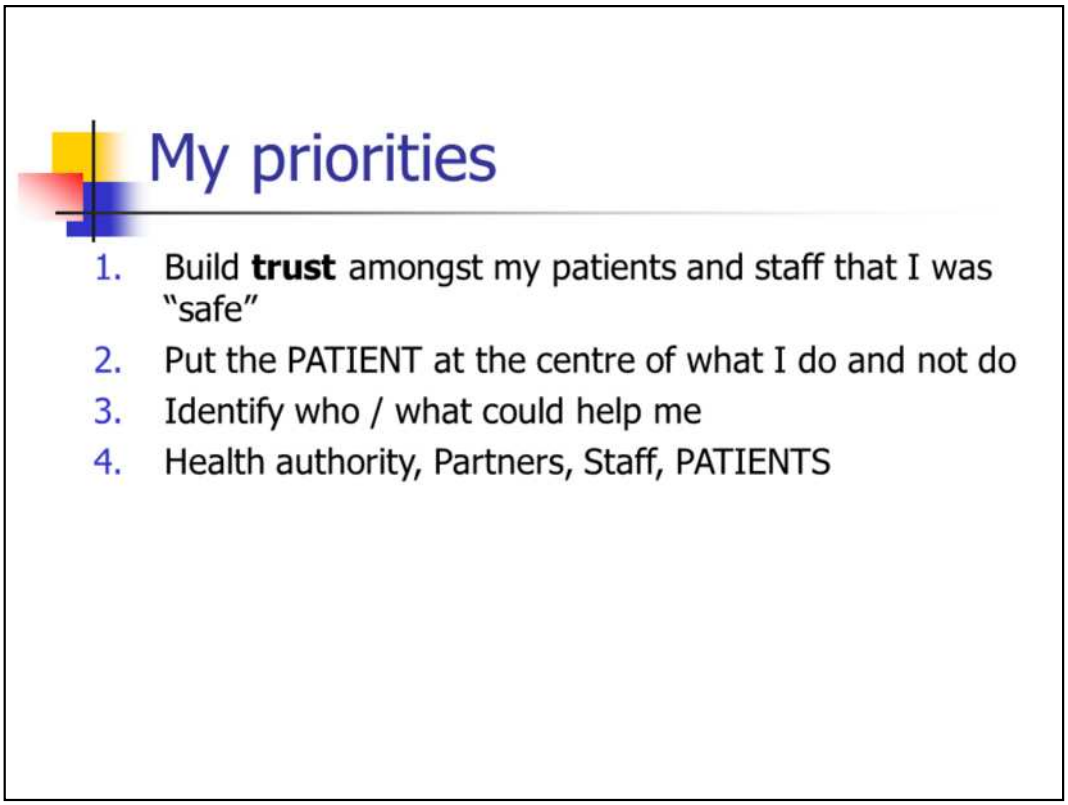


Please see NOTES that accompany the slides

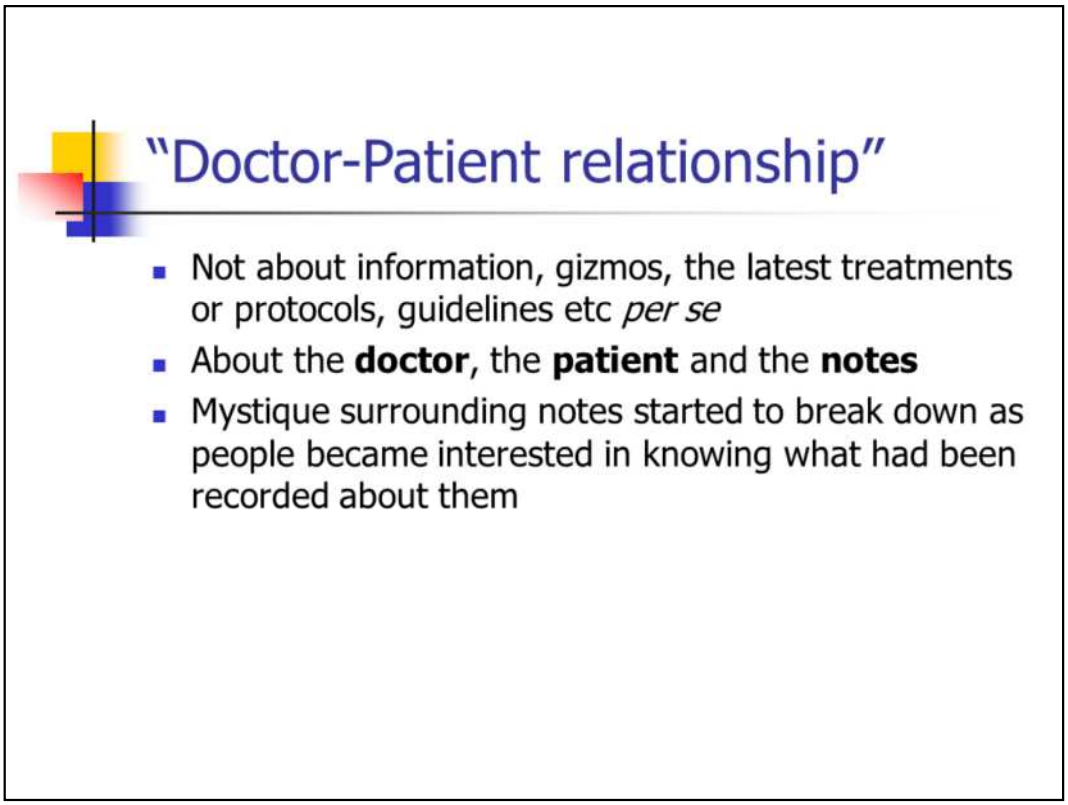


We are going on a long journey. Not sure where it is heading at the moment…

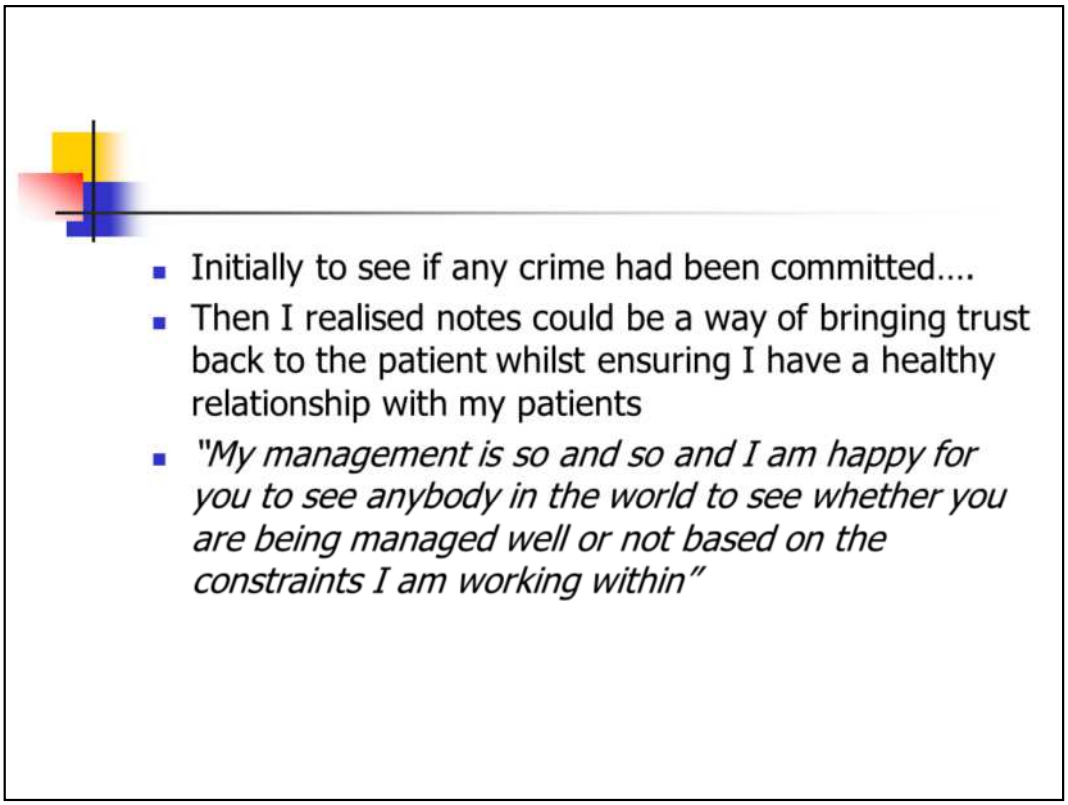
I started as a GP on October 1st 2000 at Market St surgery where Dr Harold Shipman used to work. His wife the night before had come in and took her property away (inclduing the computer system). The hard-drive with patient data on had been removed and was with the Heath Authority. So I started with no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



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!

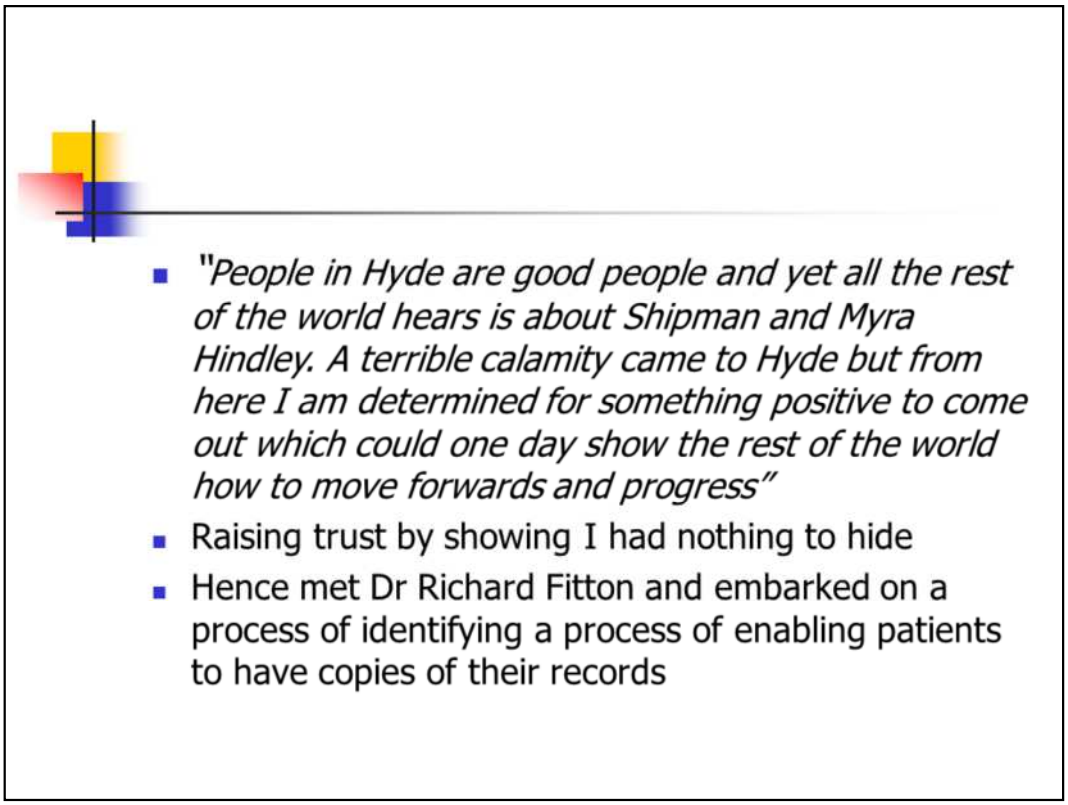


What I realised very quickly and then started to work through. This will b very important today because people sometimes get confused about technology and its place and some of these more basic issues. Many others know much more about this than I do but this is what I came to realise



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

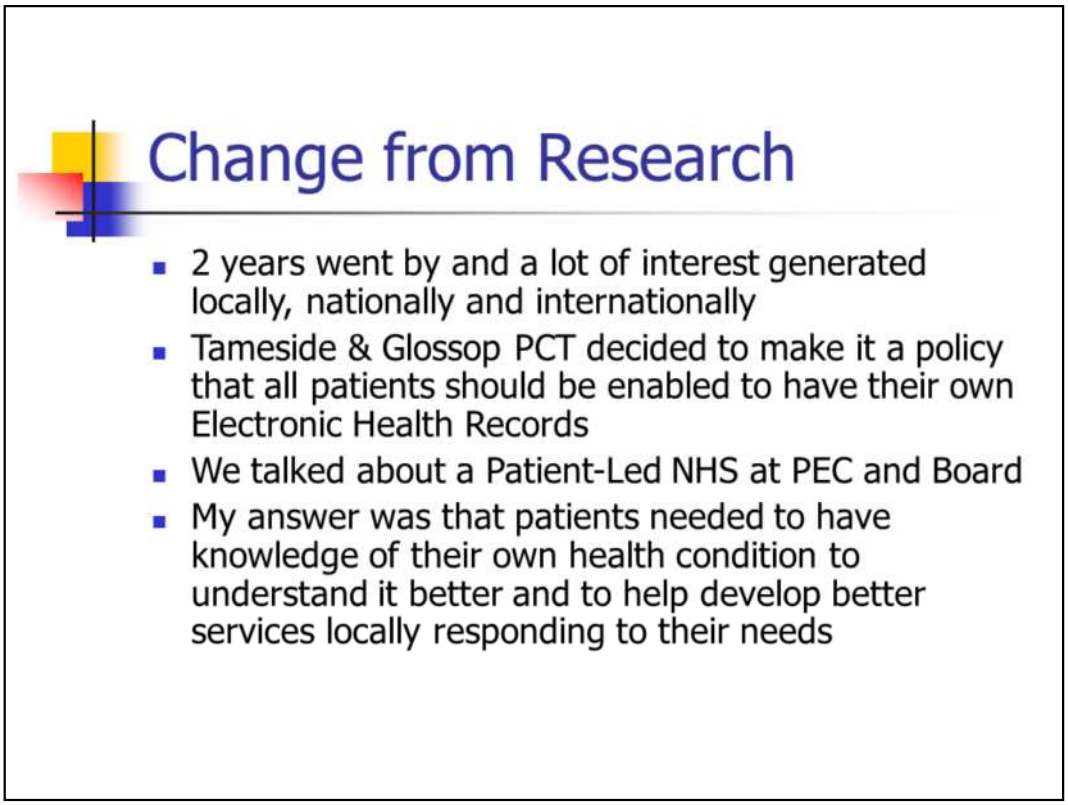


Why did I stay in Hyde despite the fantastic pressure from the media, the patients and the “high risk” environment I was working in. One patient complained to the GMC because I would not prescribe valsartan for them. Fortunately that was passed back to the PCT who in turn passed it back to the practice! 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!

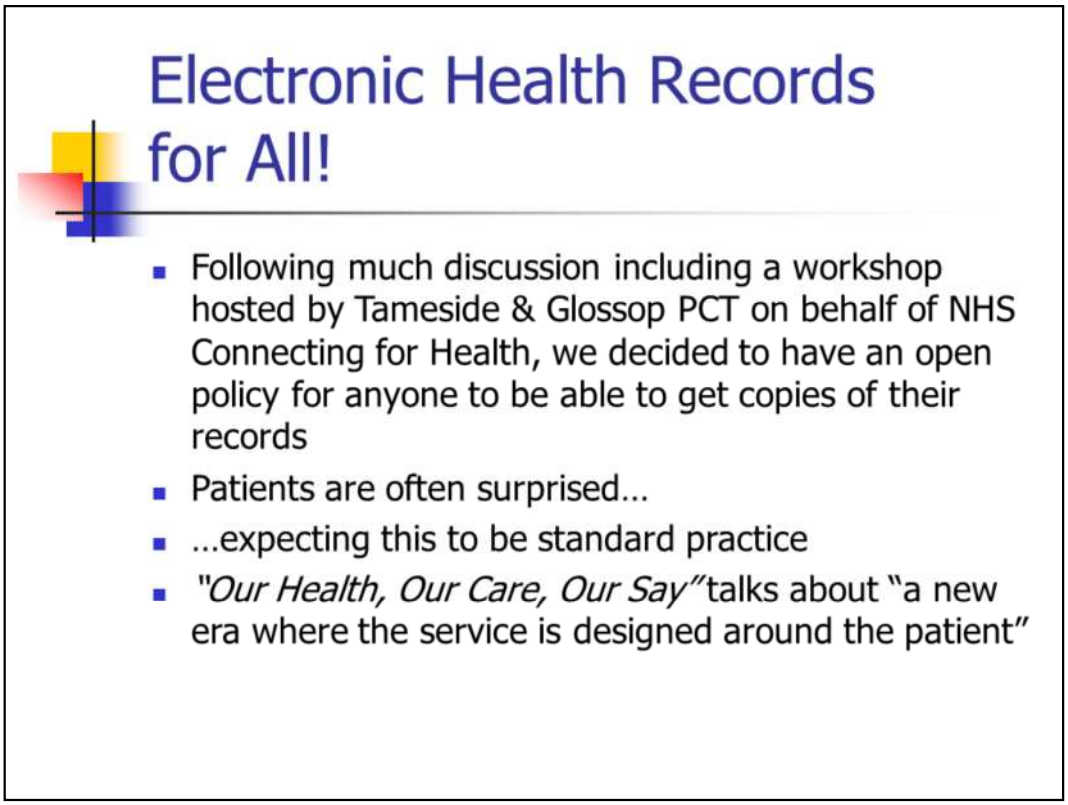
We started the research with Claire Harris from the University of Manchester Institute of Science and Technology (UMIST). 50 patients were identified in the practice and given copies of their electronic records. But there were 3 significant exclusion criteria

Research experience

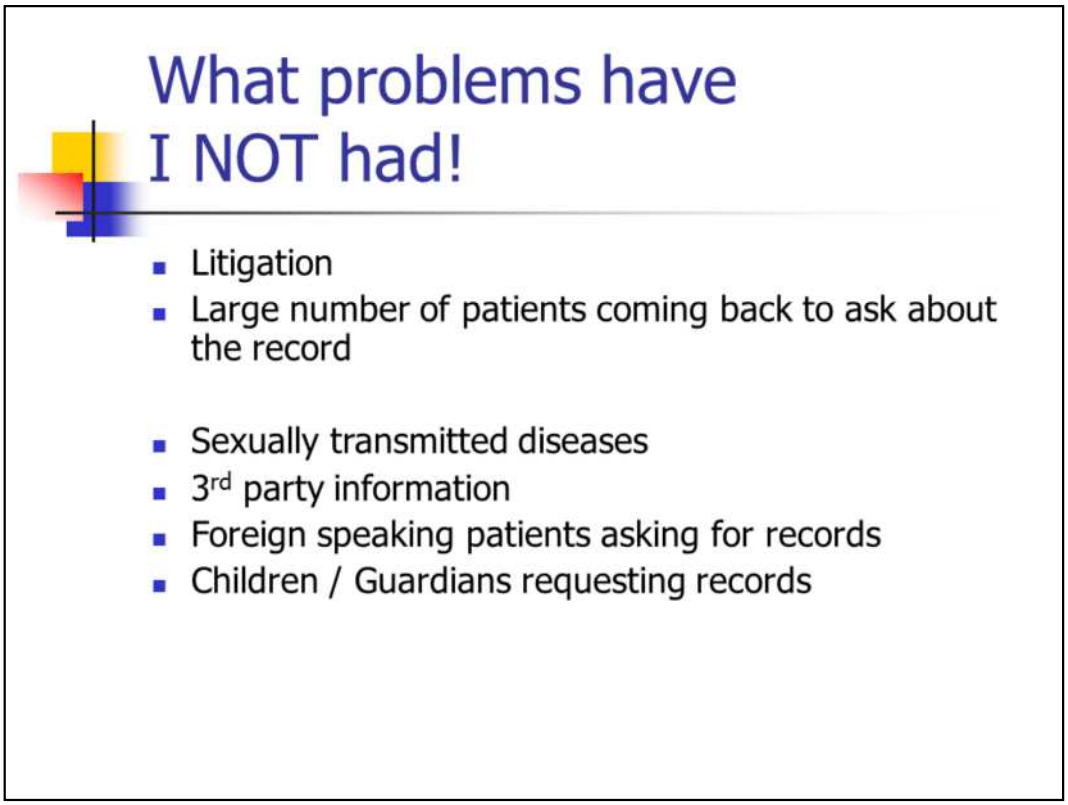
- Some patients are very positive
- "Yes please! I think it's great that I can have a copy of my own record"
- Others – no way – I would not know what to do with the disk even if you gave it to me
- Staff felt it was some superfluous thing that I was doing
- Partners happy with what I was doing but not 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



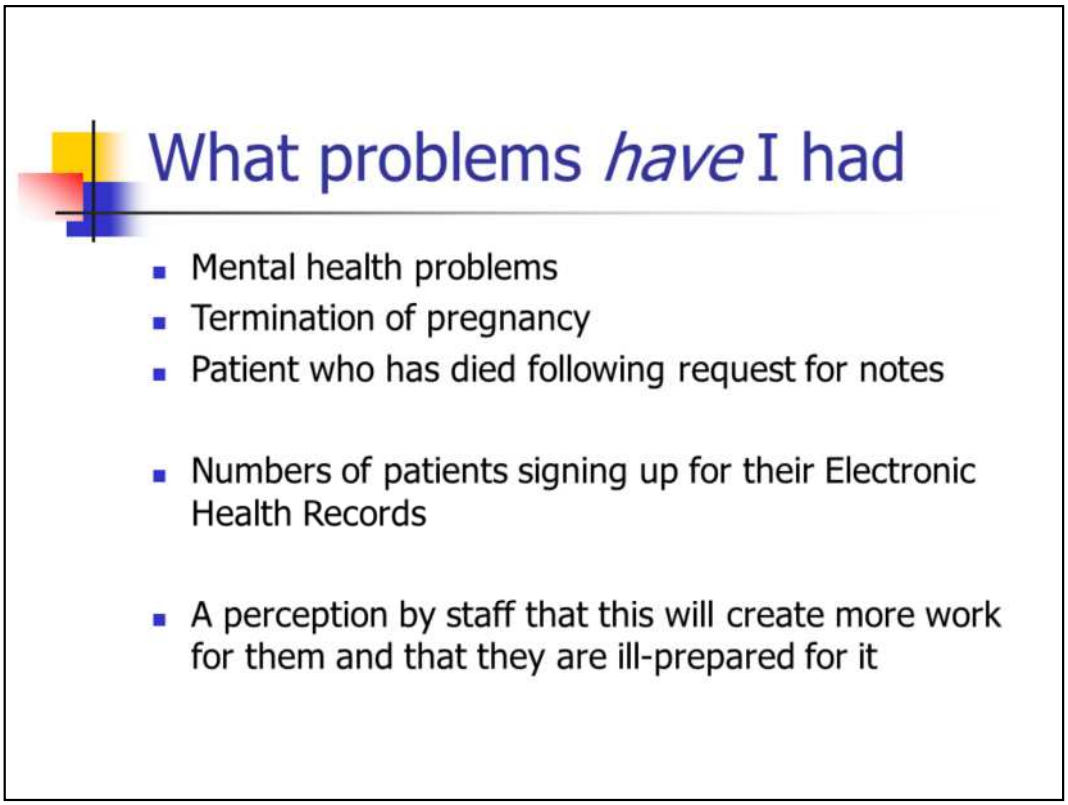
After the research lots of interest in what we had achieved to date. It also linked more closely with national policy suggesting that we were heading in the right direction in our thinking. This was confirmed independently at PEC, Board (and LMC!)



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



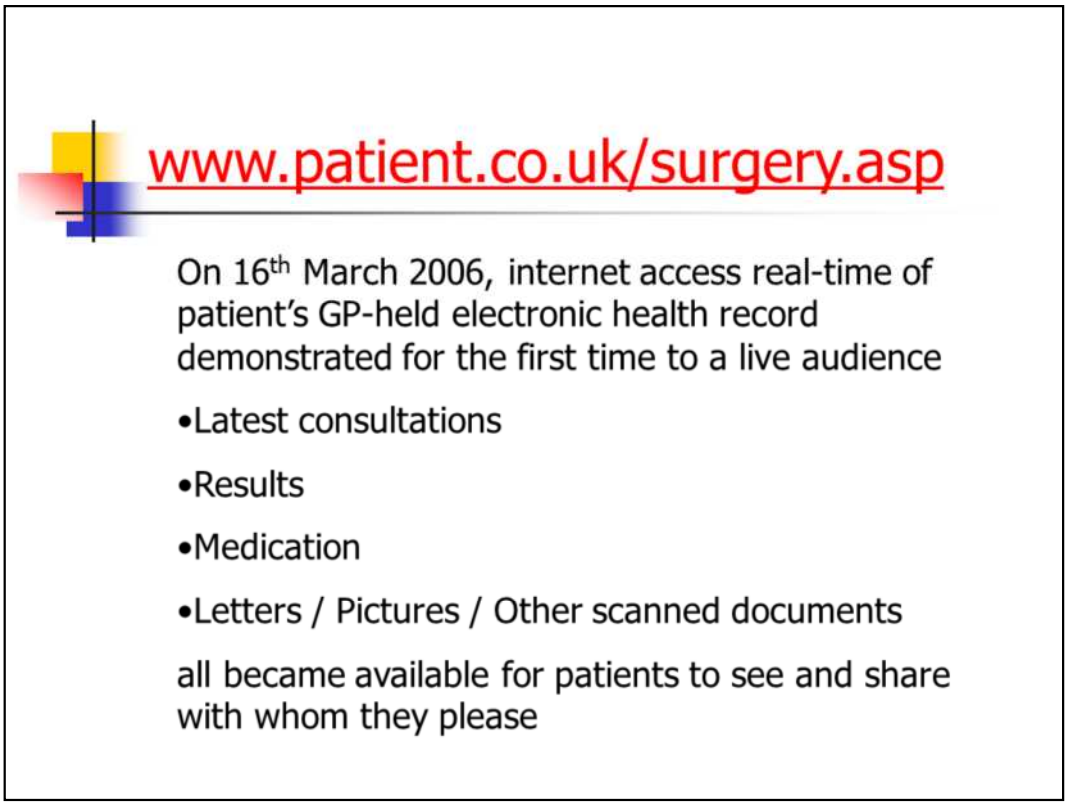
Everyone I speak to worries about these aspects – the world we live in today. It suggests that these are not the “real” issues that matter and possibly distractions although there is not enough experience for me to say this with any certainty. We all must be careful of anecdotal, personal experience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



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!

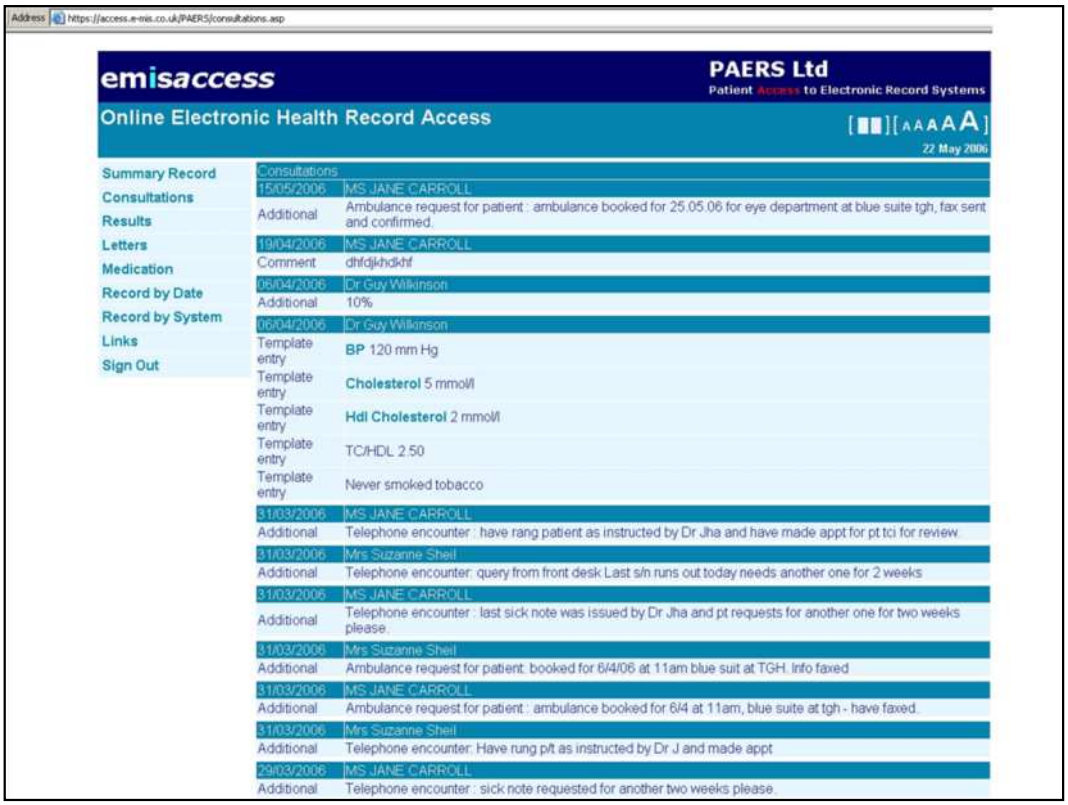
We have charged £10 for a copy of the records on disk. This seems reasonable considering it can take 3-4 hours to summarise and enter the information on to the computer per patient. (Most requests came from people with long histories!) Despite this the number of patients taking up the offer were small – 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



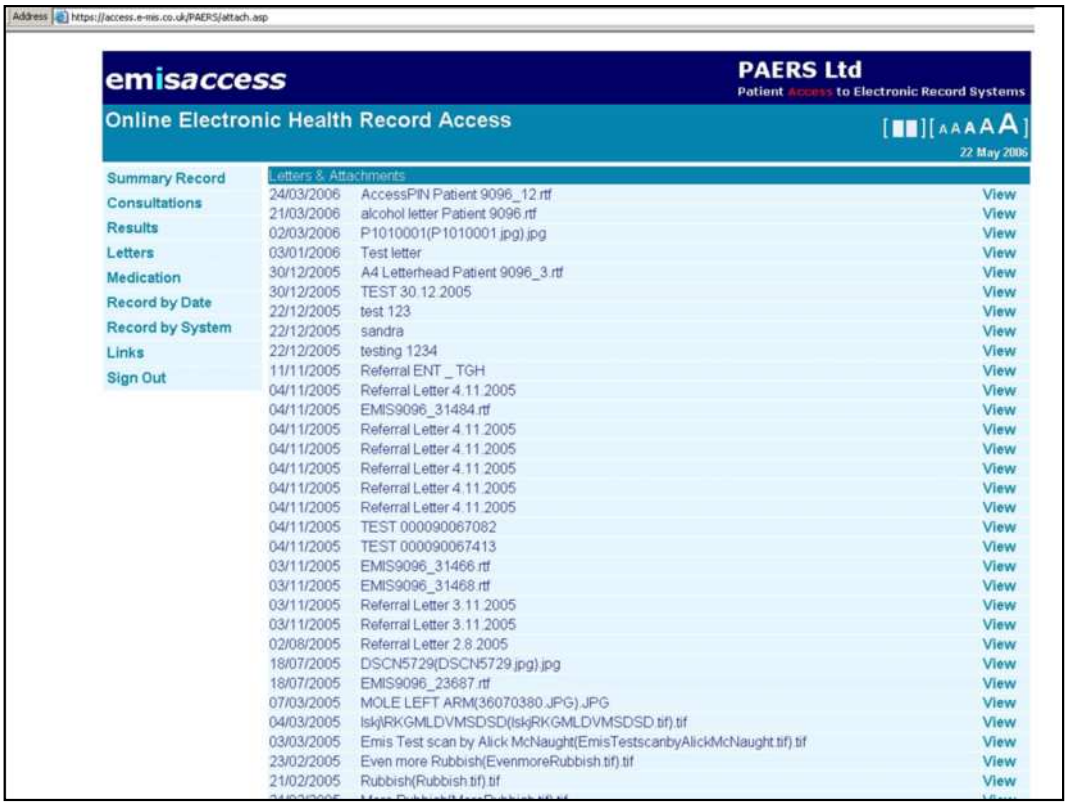
We launched internet access to medical records

Screen shot of what patients can see from our test patient



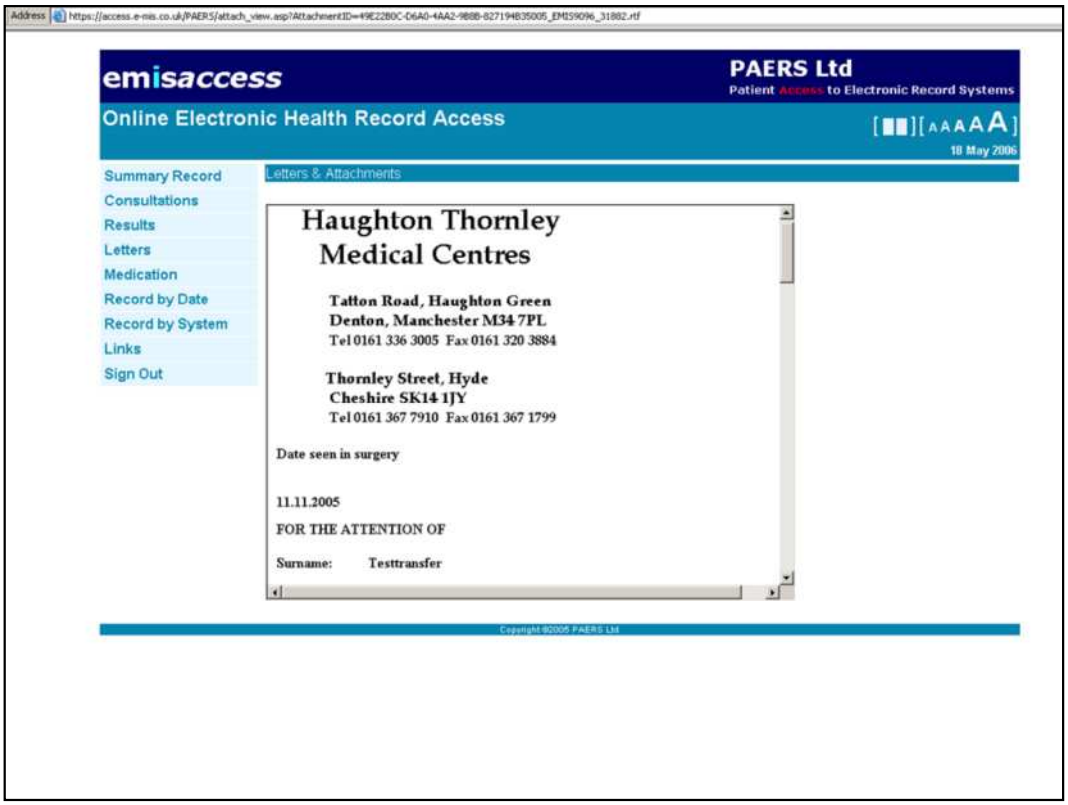
AN example consultation screen

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

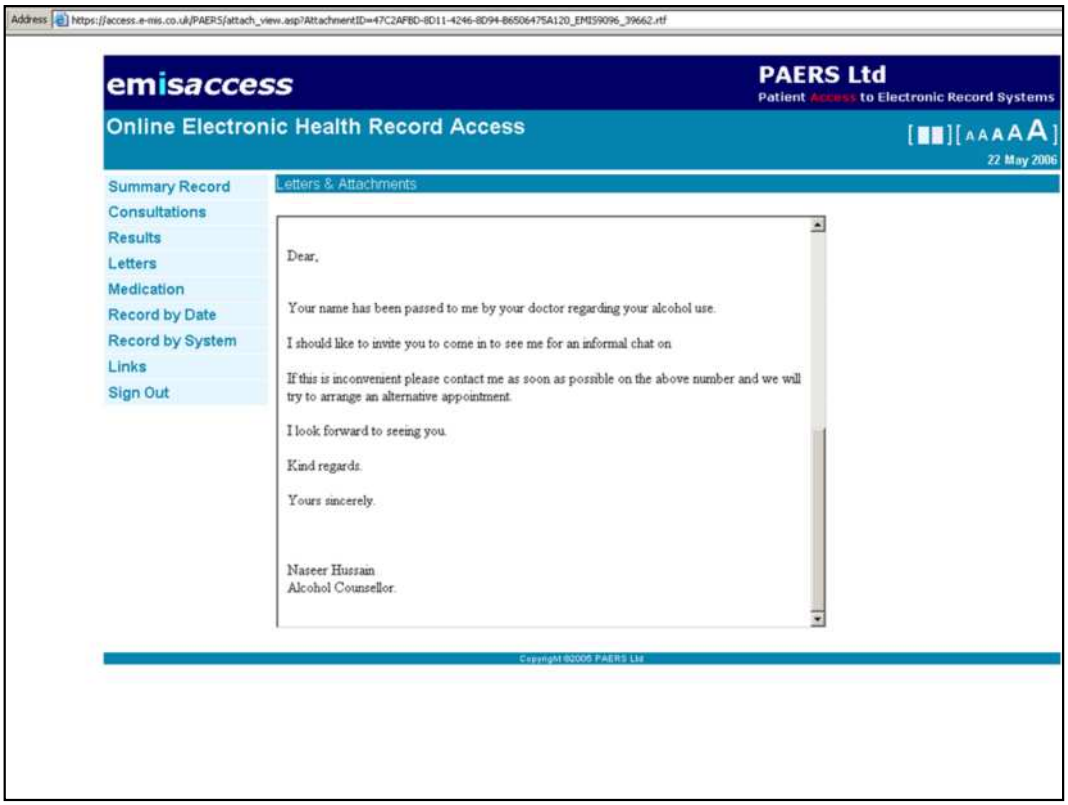


All letters and other paper documentation are scanned in to the computer record as soon as they arrive in the practice. The patient can now see all these documents too. This would include CT scans, ultrasound scans, Xrays, letters from the hospital and also our referral letters etc too so they know we have done what we said we would do!

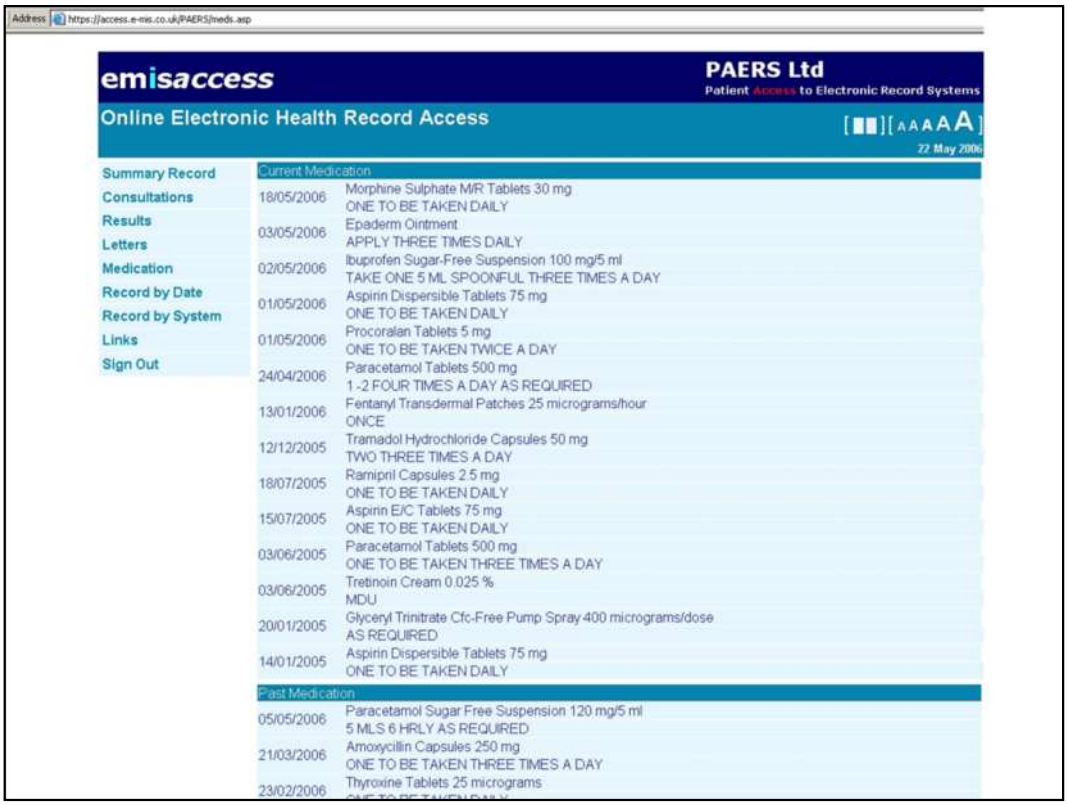
I often take pictures of lesions and attach them to the medical record. Now the patient can see the picture too whereever they are! The only “catch” is that documents can only be viewed that are less than 100KB long. Most pictures I take are about 1MB long. This is one I highly compressed to make it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



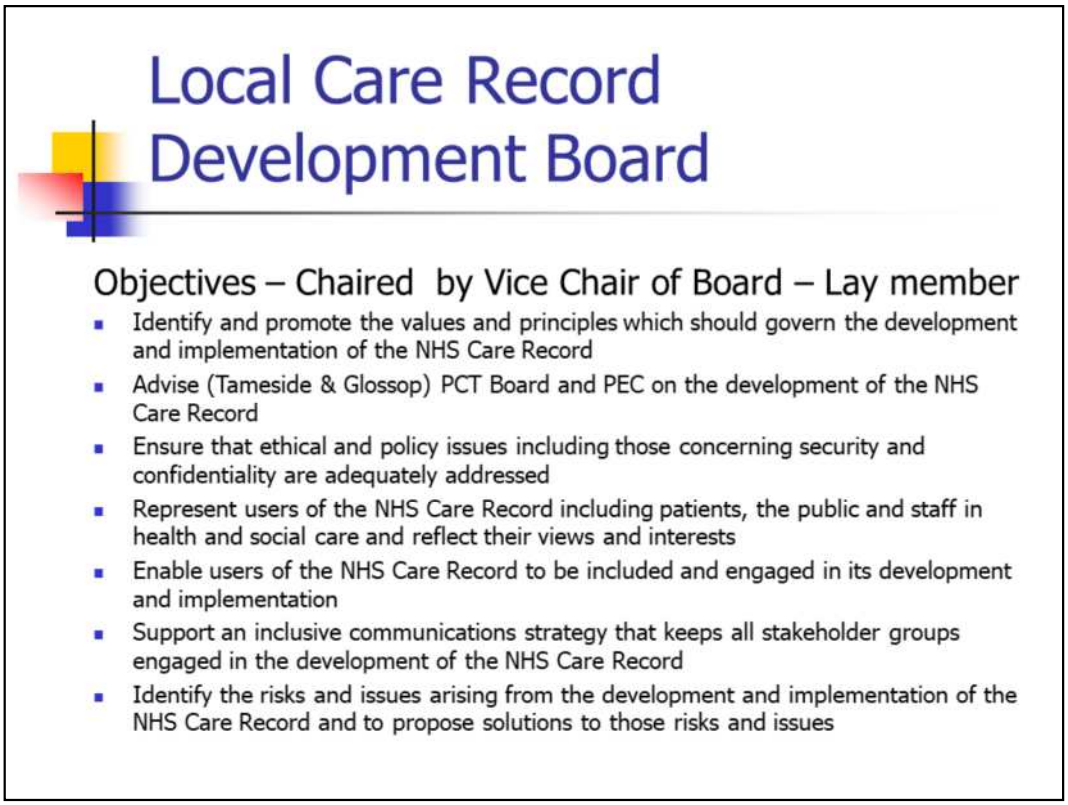
Here is a letter we sent out…



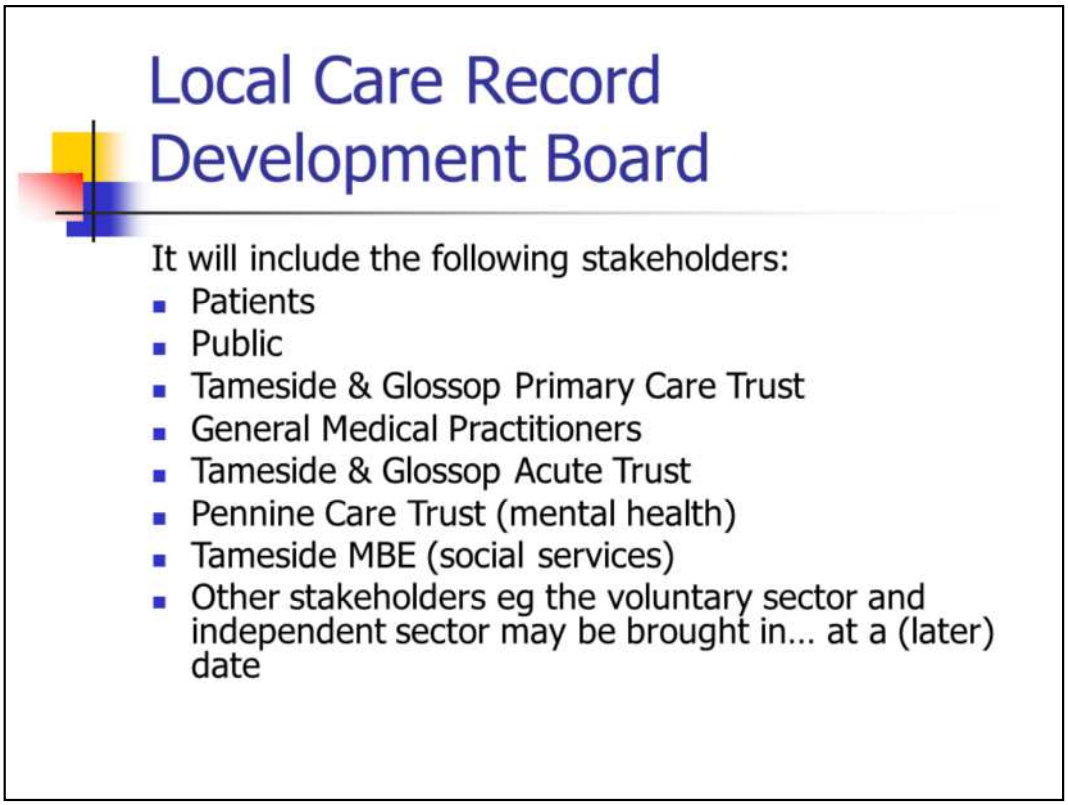
… to the alcohol counsellor as our patient has an alcohol problem! Again further positive feedback for the patient to see



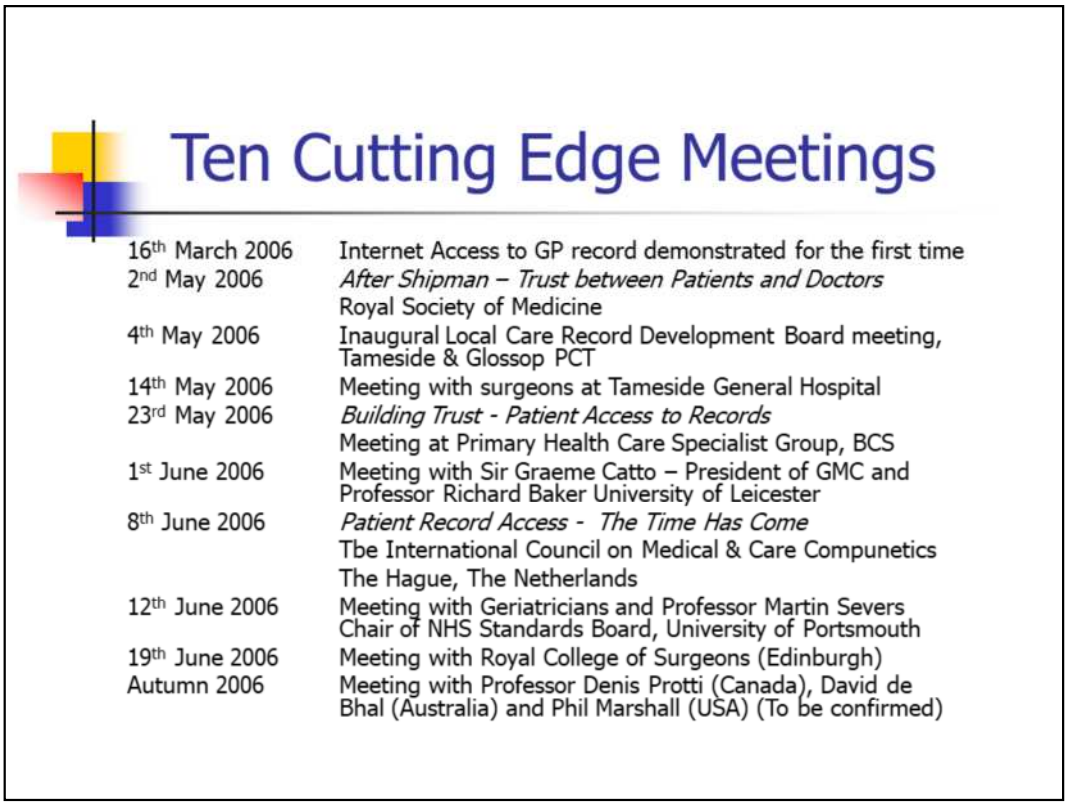
The medication screen. Do you remember going to the out of hours doctor and saying my doctor gave me an antibiotic last week and I feel no better. Well now you can show the doctor what antibiotic it was that I gave last week! Past medication would be so useful and an instant benefit in so many consultations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



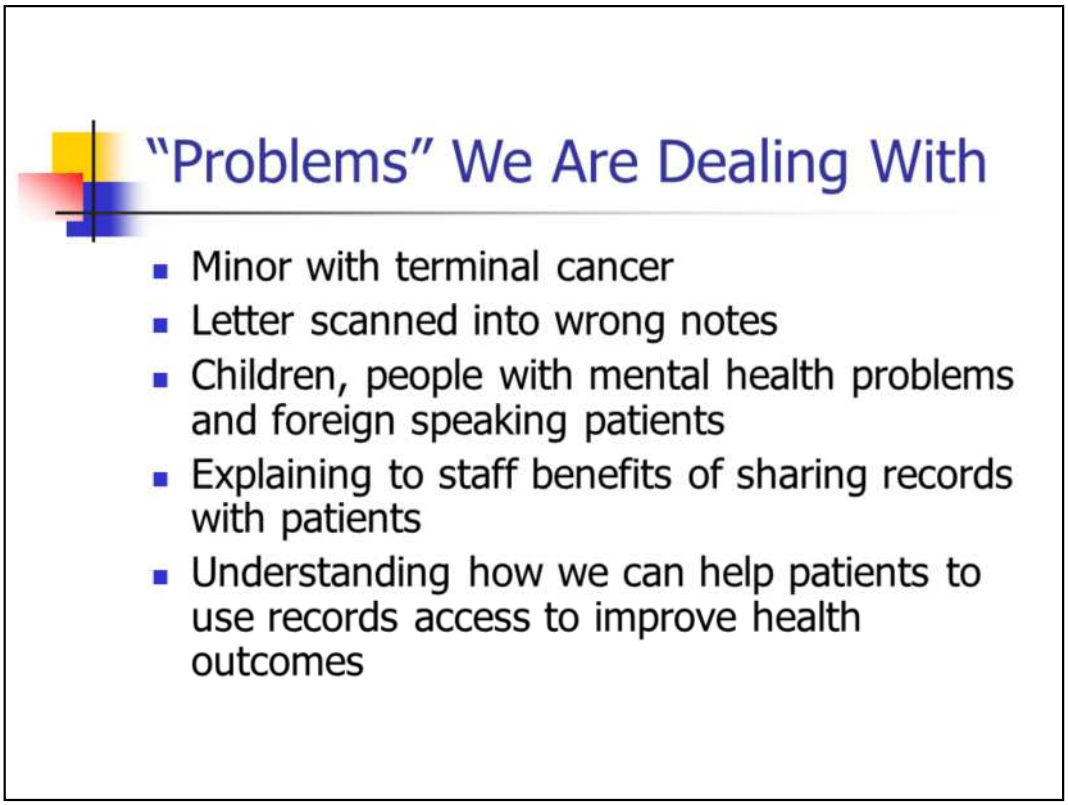
What else have we done to support the venture. Clearly there are significant implications for a large number of stakeholders locally. What happens if a patient wants to know from someone independently what the risks and benefits of sharing information are? What if a local GP is being “difficult” and 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 Devlopment 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 dillemnas 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 pasword. What should I do as her GP?



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



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



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 al 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!