Perceptions on the Access to Electronic Health Records

Prof Bill Buchanan and Adrian Smales

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NHS told to abandon delayed IT project

£12.7bn computer scheme to create patient record system is to be scrapped after years of delays

Denis Campbell, health correspondent
The Guardian, Thursday 22 September 2011
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The NHS has spent billions of pounds on a computerised patient record and booking system, which has never worked properly. Photograph: Martin Godwin

The Telegraph

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Patients will view their NHS records online in three years

NHS patients will be given online access to their health records in the next three years under plans to be announced by the Government today.

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EDITOR'S CHOICE »

Rowan Atkinson: Goodbye, Mr Bean?

The move for online health records comes despite the decision by Andrew Lansley, the previous health secretary, to cancel a massive NHS national database Photo: ALAMY

By Robert Winnett, Political Editor
7:00AM GMT 13 Nov 2012

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Doctors' surgeries will have to set up services to allow anyone to see their health files, book appointments and order repeat prescriptions on the Internet.

The new campaign is being spearheaded by Jeremy Hunt, the Health Secretary.

"Looking after their own health, and the health of their families needs to be as straightforward as possible.

"Looking after our health should be easy — in an age where people can do their banking or shopping online, it should be just as simple to view your health records, order a repeat prescription or book a GP

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dreich27

11/13/2012 06:02 PM

1) is this in the **interest of people whose hypochondriac and worrying tendencies** are made worse by all the medical information on the internet?

2) how much will it **cost?**

3) what's wrong with the current system where you can **request your records from the surgery?**

4) how will it be **secured a) from hackers b) from your boss c) from your intimidating other half or family member** who is standing next to you at the computer and demanding that you log in?

The Telegraph

Patients will view their NHS records online in three years

5) is this going to cause doctors to have to go through your records with a **fine-toothed comb to weed out an ill-advised comment made in 19-whenever** when the idea that patients could sue or access their records online was very remote.

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Thierrytt

11/13/2012 04:00 AM

My partner's doctor here in France hands over the hard copy of any documents to her. This includes notes and letters passed between doctors and other specialists. **He keeps an electronic copy. This means we have all the x-rays, DVDs of MRI scans etc.** He gives a regular print out of any notes made.

The notes are released on the processing of the Carte Vitale which has a photo of the patient.

Other doctors can have accss to her records through the Carte Vitale system.

It puts the patient at the forefront of treatment.

When I **moved to France** from the UK some years ago I obtained a photocopy of my medical records. It contained notes in code which **made no sense to me whatsoever.** I could find nothing regarding hospital treatments ,the fact I had broken my leg when 11 yrs old , had my tonsils out etc. No vaccines as a child or adult were noted. **The french doctor said the notes were worse than useless.**

Why is the **NHS so out of date**?

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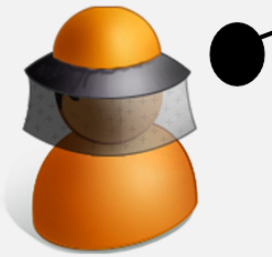

ivan_opinion

11/13/2012 06:26 AM

NFN – Normal for Norfolk.
FLK – Funny Looking Kid.
GLM – Good Looking Mom.

Who, other than **hypochondriacs, narcissists, neurotics, ME 'sufferers', DLA scroungers and the mentally ill, wants this?** And, for all the groups mentioned, this will only make them feel worse, do no good at all and increase costs. How much will it cost, how secure will it be and how late will it be? **If doctors cannot be frank in the notes, they will end up being defensive and guarded**, which will be bad for everyone. Sadly, **NFN**, **FLK** and **GLM** have largely disappeared but this is the death knell.

The truth is, however, that a patient-accessible record system **is essential for the dismantling and selling-off of the NHS**. Alternative providers, doctors and Prince Charles' quacks and businesses run by Hunt and Lansley's mates **will be able to read them, print them, import them and invoice services accordingly**. "Oh, I see you've never had any of my very special water, never tried accupuncture, had this scan." That is what this is about, whether you agree with it or not.

Thierrytt

11/13/2012 05:13 AM

The problem is that the doctors may not be telling the "truth". My partner was **diagnosed as a psychiatric case when she lost use of her legs**. A letter from the neurologist who examined her said she had had an **MRI scan. That had never taken place. All doctors treating her afterwards took that as gospel.**
I reviewed her case and discovered that and **other serious errors by other neurologists, rheumatologist and opthalmologists.**

In the end I requested the MRI scan and all accompanying tests for **Multiple Schlerosis and every one proved positive**. A review of all previous tests including one when she had lost vision in one eye had pointed to MS.
Maybe **knowing the patients can see all the results of tests etc may lead doctors to be more careful.**
My partner is french and medical records rest with the patient. The doctor keeps an electronic copy.

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The Survey …

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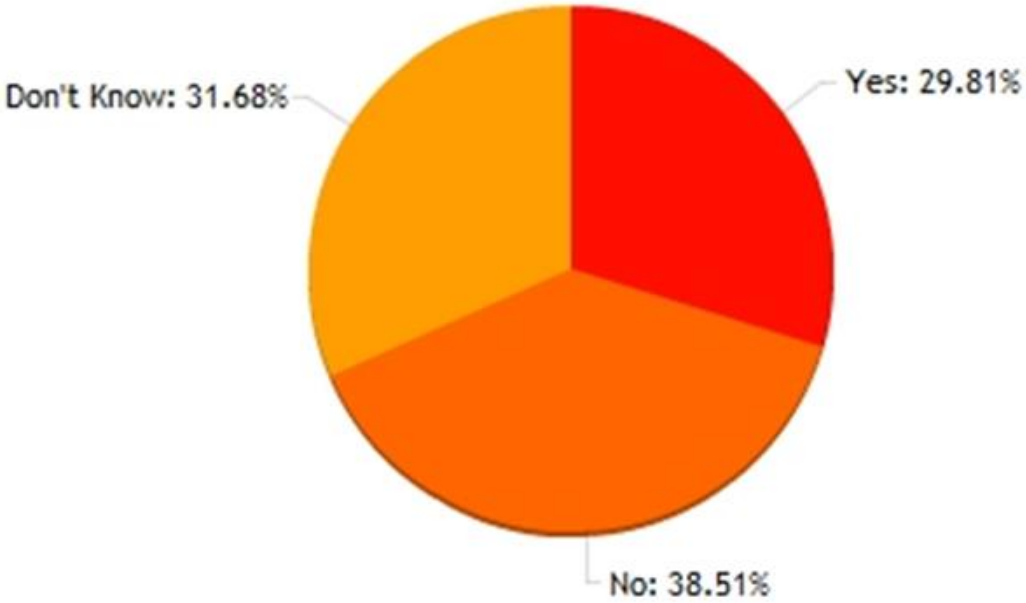
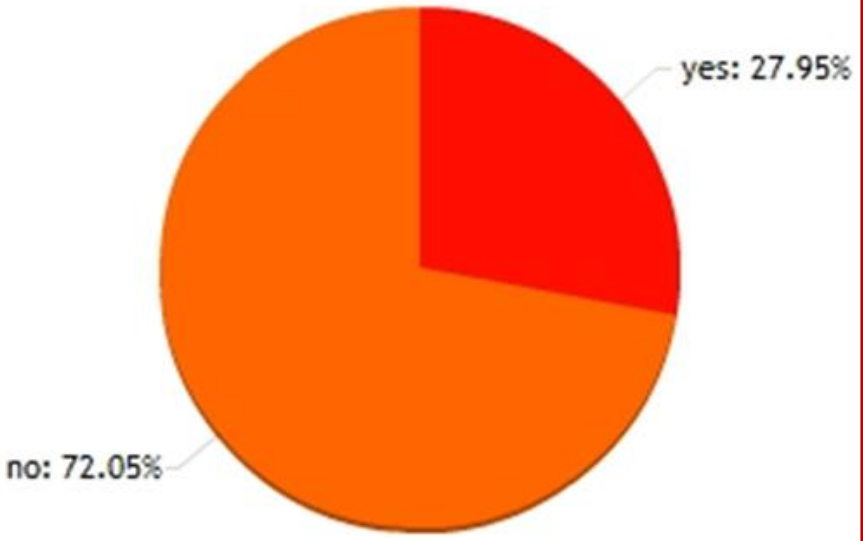
Within three years will health records be on-line?

1. Yes.
2. No
3. Don’t know

Within three years do you think you will be able to get access to your Electronic Health Record (EHR) ?



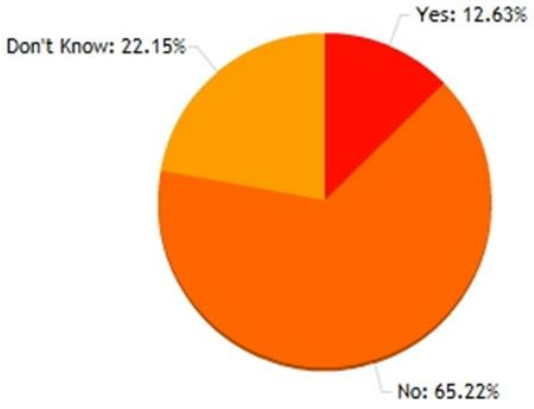
As a citizen/patient, do you have any Internet based or electronic communication with the health/social sector?



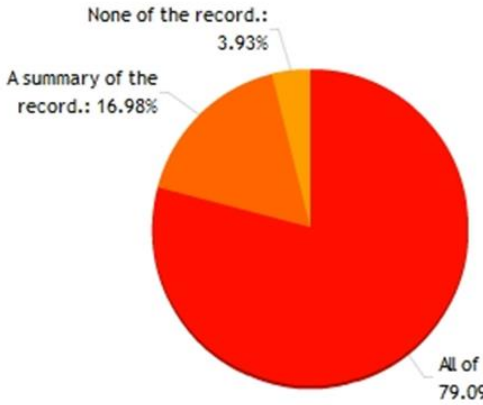
Which service would you most like to get access to?

1. View health record.
2. Book appointments.
3. Email with clinical staff.
4. Video conference with clinical staff.
5. Order repeat prescriptions.
6. Manage my child's health record.

Can you book appointments with your GP on-line?



If you had access to your EHR, what would you want access to?



As a citizen, which Digital Health Service would you like most?

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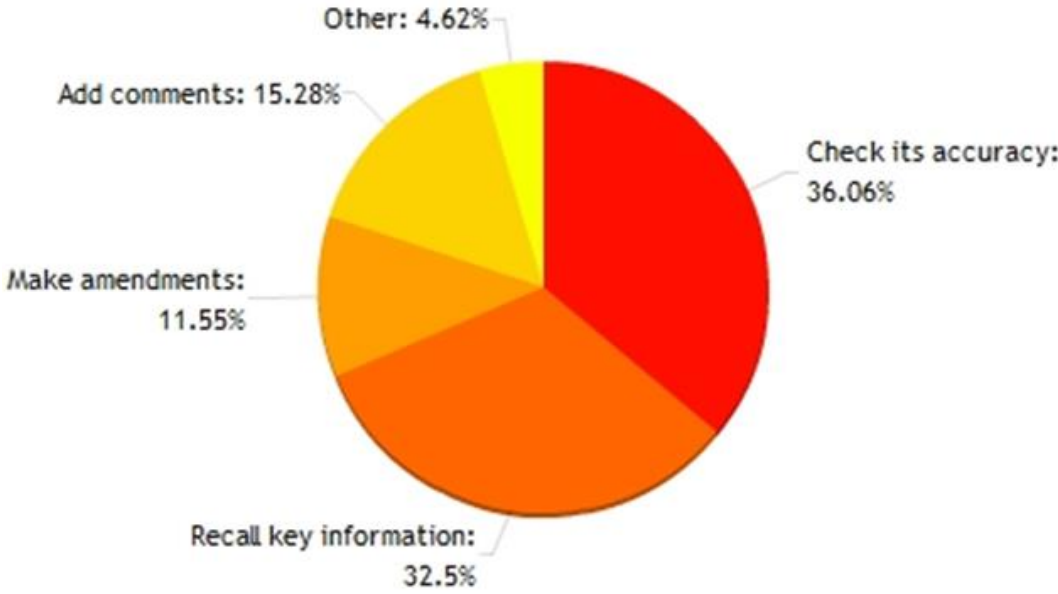
If you had access, what would you like to do with your data?

1. Check its accuracy
2. Recall key information
3. Make amendments
4. Add comments

What would you do with the data?



"Review lab results and medication"

"Research treatments and developments"

"Ascertain what actions to take in life"

"**Review doctors opinions on myself**"

"Track my progress/history."

"Order repeat prescriptions"

"Request deletion irrelevant information"

"Understand what's on file"

"Have access in order if laboratory results (others) need to be provided to private clinic or foreign GP."

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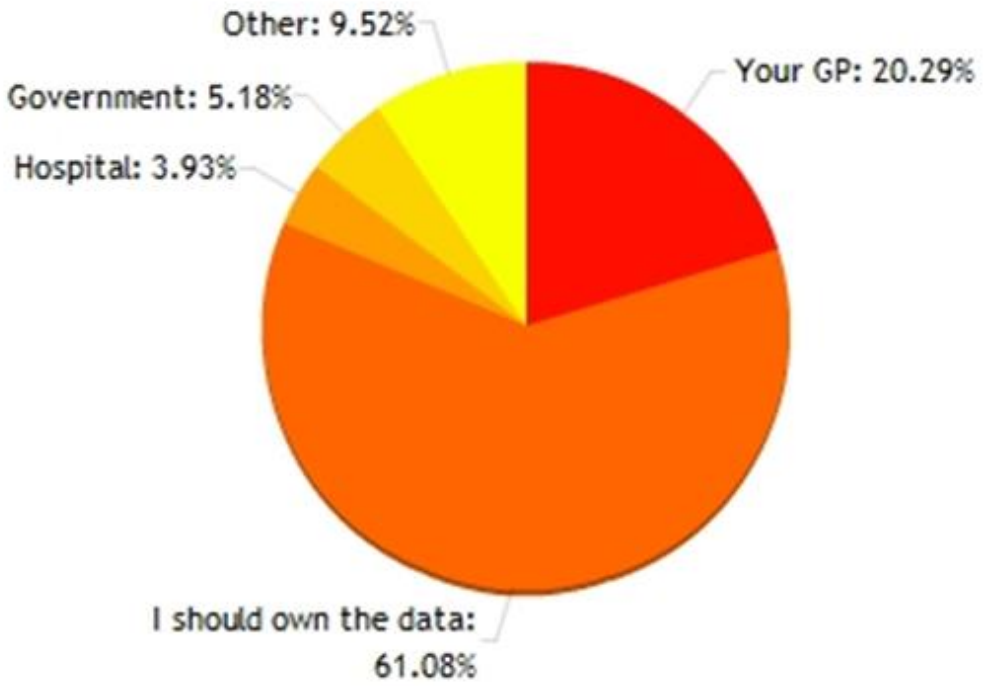
Who should own the data?

1. Your GP
2. I should own the data
3. Hospital
4. Government

Who should own the data in your health record?



"Joint between me and my GP"

"Myself and the hospital (if they need to access it)"

"I should own it, GP and Hospital should have right to access, amend."

"Joint Ownership"

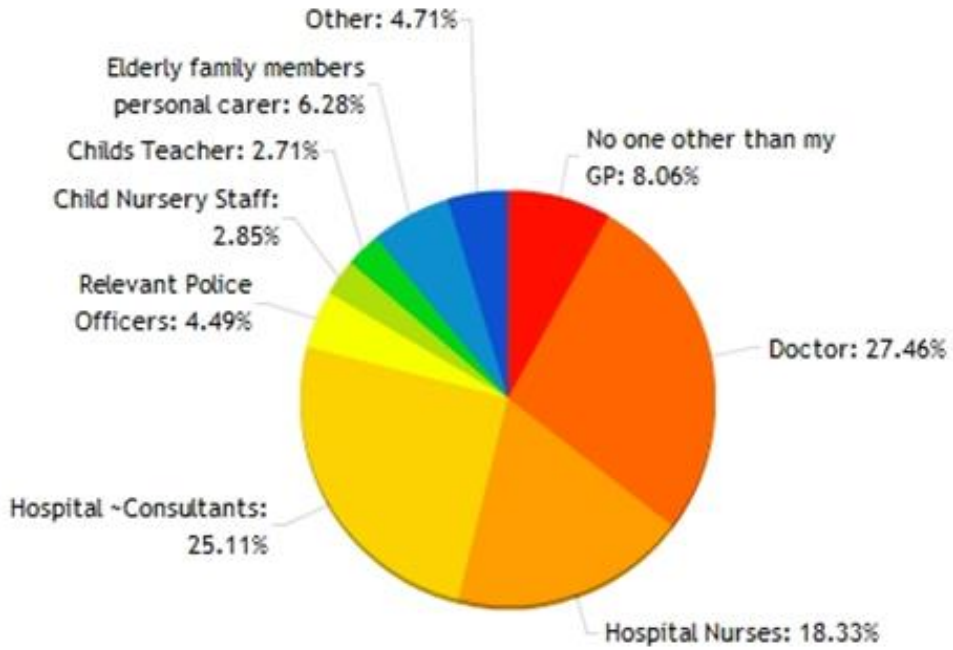
"GP and patient in partnership"

"Joint ownership - myself and whoever assessed/treated me for a recordable event."

"Independent regulator on my behalf"

"Although I should own the data, permission should be provided to healthcare professionals with my approval, similar to US HIPAA"

Who would you want your EHR to be shareable with in a responsible manner?



"Emergency Responders (Ambulance Staff)"

"only those I specify"

"Depends on the level of data exposed"

"Power of Attorney"

"Ambulance service"

"My grown up children"

"Temporarily permission"

"Any relevant staff member should have access but only with my permission"

"Next of kin"

"People I specifically allow access at particular times"

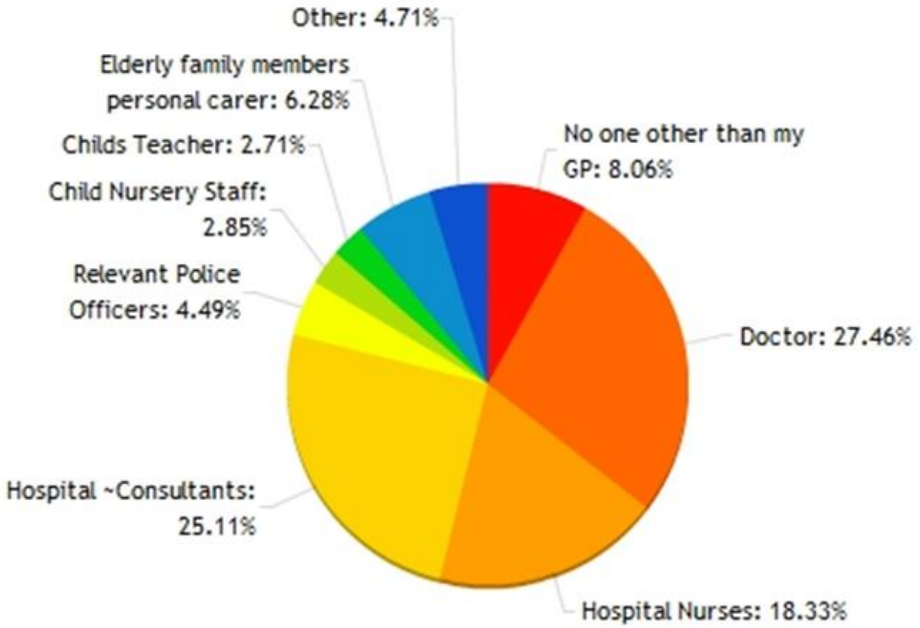
Greatest barrier to Citizen Access

1. Poor security within the health care system.
2. Resistance from health and social care professional
3. Lack of understanding of the usage of the Internet from citizens.
4. Difficult to change existing systems to allow access
5. Poor access to the Internet.
6. Cost of building an IT system to provide access.

Please indicate the severity of the barriers to providing citizen access to EHR?

	Major Barrier %	Some what of a Barrier %	Not a Barrier %	Don't know %
Poor security within the health care system.	54.79	30.83	6.67	8.96
Resistance from health and social care professionals.	31.67	43.33	9.58	16.46
Lack of understanding of the usage of the Internet from citizens.	22.71	51.88	21.25	5.21
Difficult to change existing systems to allow access.	46.46	33.13	11.46	10.00
Poor access to the Internet.	7.08	37.29	52.71	4.38
Cost of building an IT system to provide access.	45.00	36.88	14.17	5.00

Who wound you want your EHR to be shareable in a responsible manner?



"Health consultants"

"Next of kin"

"Emergency Responders (Ambulance Staff)"

"My grown up children"

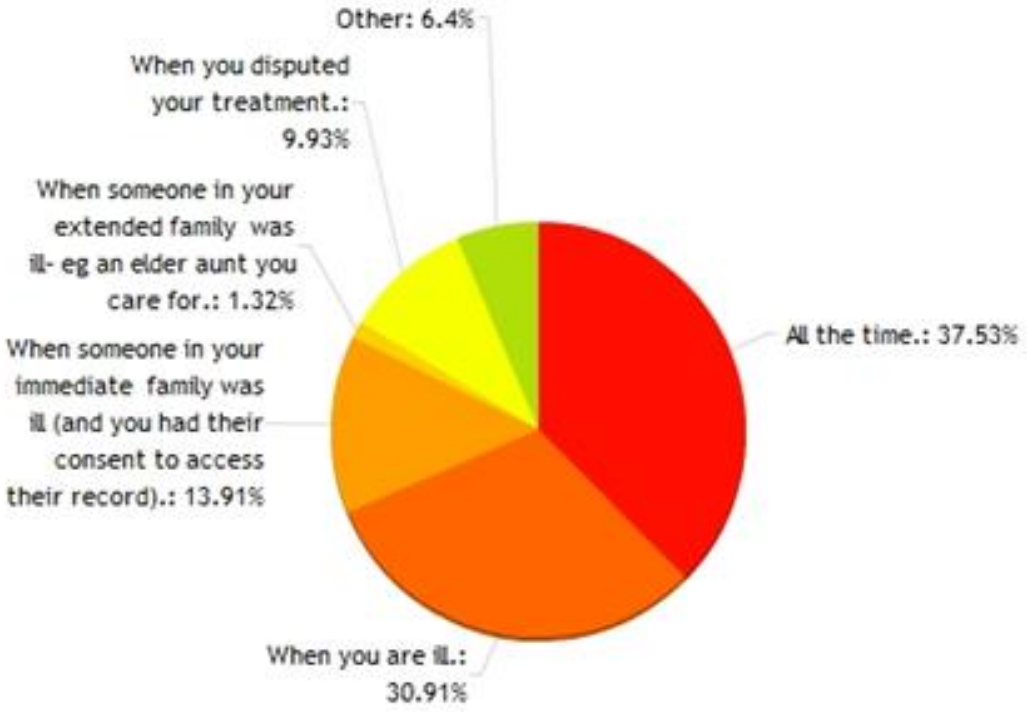
"ambulance service"

"With people who are in need of data, have a reasonable requests, due to illness or crime etc."

"Only those I specify"

"Emergency staff - ambulance, paramedics, similar"

When would you want access to your EHR?



"Ordering repeat prescriptions"

"Providing medical info for insurance purposes"

"Occasionally to check what has been said"

"General Interest and knowledge."

"When completing applications for health/travel insurance"

"As part of personal life change/ management plan"

"To check inoculations are up to date"

"managing chronic conditions"

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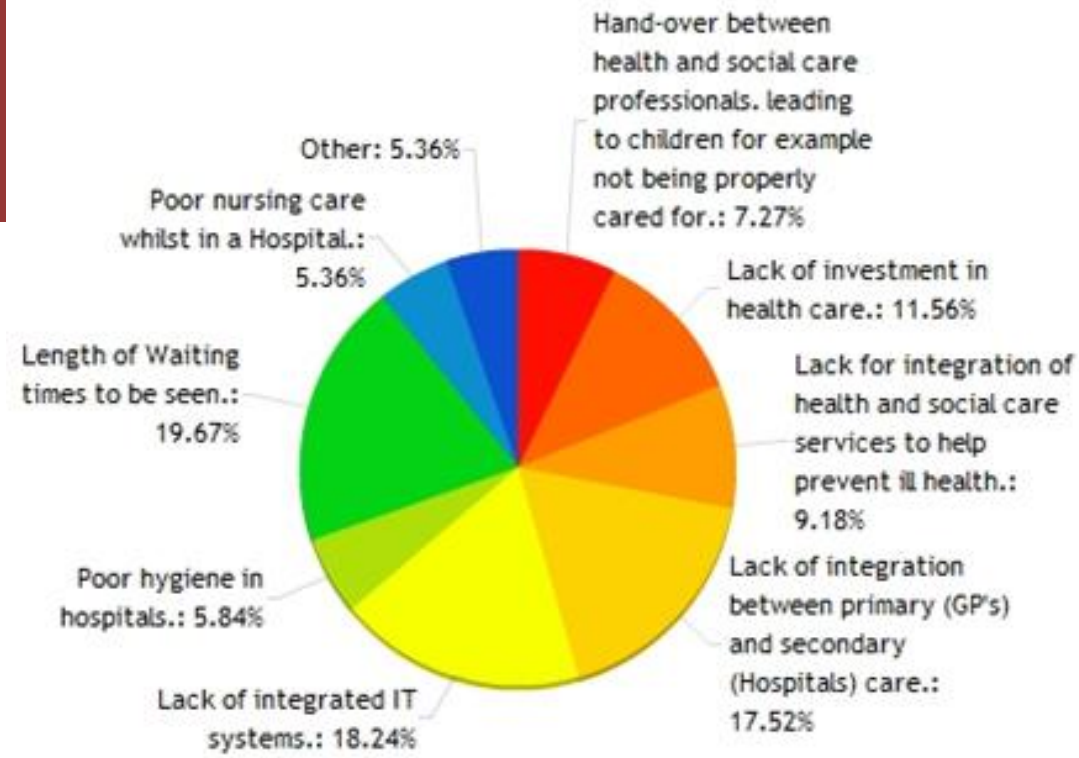
Greatest failing in the delivery of Health Services?

"Privatisation & Bad management"

"Lack of empathy from HP's"

"Poor access to out of hours primary care"

"Poor use of GP resources."



"Lack of patient involvement"

"Budget constraints and pressure to meet targets"

"Mixed quality care with a cost-cutting focus"

"NHS seems blind to investing in prevention and will only spend on cure when emergencies arrive."

"Not listening to the patient is the greatest failing of the NHS's! Thinking that they know best when you are the one suffering but once it is proven that there is a problem things get much better"

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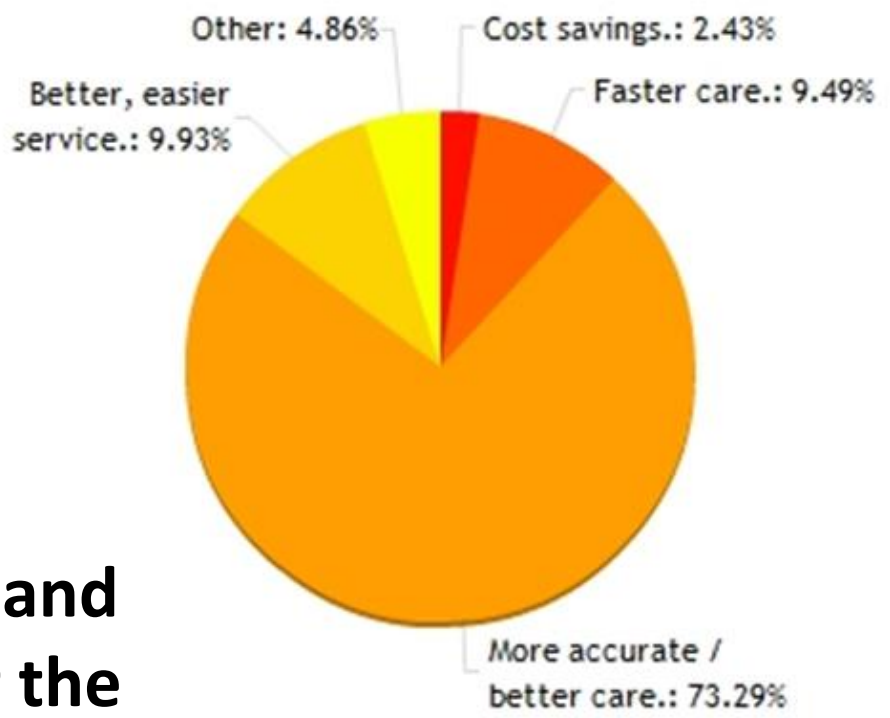
Greatest Benefit of Sharing EHR being sensitively shared amongst the NHS?



"Transparent"

"Better communication between doctors"

"Cost savings/More accurate"

"Self management of my medical care"

"Patient safety and cost savings for the whole country"

"Less repeating of history taking, as often have to answer same with each health professional you are seeing"

"Reduction in Human error"

"Benefit to patient is whatever helps staff to work efficiently"

"More efficient and faster, no duplication"

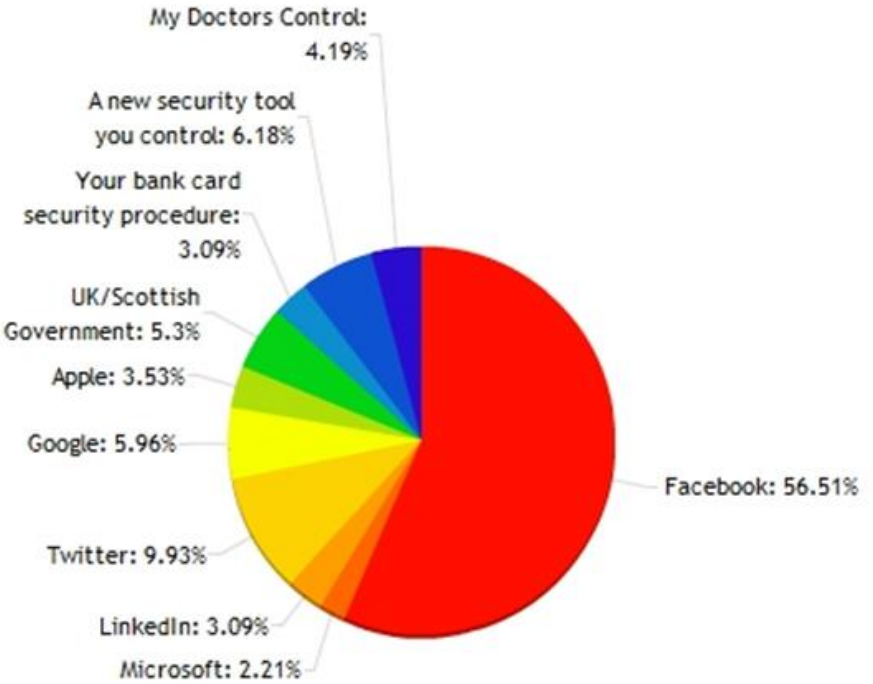
To access your health record, which of the following would you most trust to provide your identity?

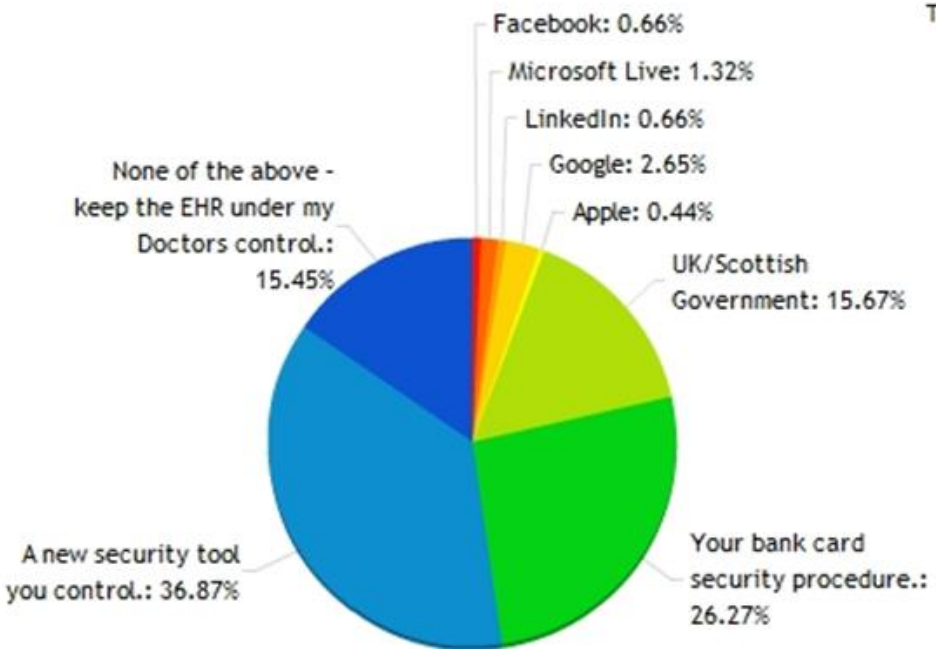
1. Facebook
2. Microsoft Live
3. LinkedIn
4. Twitter
5. Google
6. Apple
7. UK/Scottish Government
8. Your bank card security procedure.
9. A new security tool you control.

To access your health record, which of the following would you least trust to provide your identity?

1. Apple
2. Facebook
3. Google
4. LinkedIn
5. Microsoft
6. Twitter
7. UK/Scottish Government

To access your health record, which of the following would you most trust to provide your identity?





To access your health record, which of the following would you least trust to provide your identity?

Conclusions

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Conclusions

“There seems to be a demand for the access to electronic health records”

“Cost savings may be possible with the sharing of health records”

“Two-thirds of people have not electronic communications with the health sector”

“Majority think that citizens should own data with a partnership with NHS”

“Citizens are becoming more understanding with how they present their identity. High levels of assurance required … bank level security”

“Booking appointments on-line, accessing records online and repeat prescriptions seems to be the services most wanted”

“Trust is becoming key, and a company such as Facebook is not trusted for health record access”

“Benefit to patient is whatever helps staff to work efficiently”

“IT Changes and security seems to be major barriers”

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