The Chartered Institute for IT

Enabling the information society

Liberating the NHS: An Information Revolution

Patient requirements of IT to engage in health

13 December 2010

Speakers

Marlene Winfield

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National Voices

Open debate

- What information requirements, communication and technology tools will patients want to help them manage their health and engagement with the NHS?
- What concerns do you have and what are the tolerances?
- What is the role of Government, NHS, Clinician, Patient and IT?
- What do patient organisations need in the way of technical support to be partners to patients and clinicians?



Marlene Winfield

NHS
Connecting for Health

An Information Revolution: The Vision

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2010

NHS
Connecting for Health

Patients and information are the two most under-used resources in the NHS Dr. Richard Fitton



Cartoon with thanks to the British Medical Journal

Eldorna Smith: Not yet, but soon?????

NHS Connecting for Health

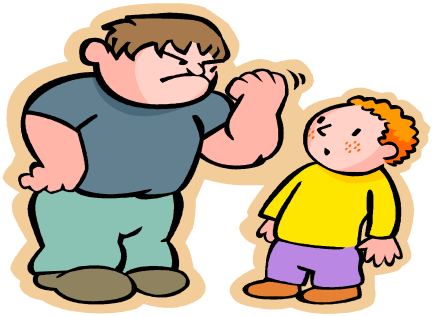


Eldorna (50) has diabetes. Her grandmother had diabetes and lost a leg. Her mother had diabetes and, determined not to lose a leg, spent her whole time with doctors.

Wanting a different life, Eldorna has joined the Information Revolution.

Eldorna has always wanted to know the best ways of looking after herself but her doctors and nurses seemed reluctant to act on what she learned outside the NHS.

Although she was willing, she did not always feel supported to take more control. And sometimes she felt actually discouraged.



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Then along came the Information Revolution and things changed. Eldorna is an enthusiatic warrior!



Encouraged now by her diabetes service, she has taken an online diabetes management course. An online personal health organiser brings information and tools to her.

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Eldorna has access to her Summary Care Record for urgent and emergency care. She and her GP have agreed to add a health summary and her care plan to it. That way she always knows where she is and where she's headed next.

They have also agreed to add plans for what to do in a crisis (such as a diabetic coma). Knowing the NHS can be clear about these things makes her feel more in control.

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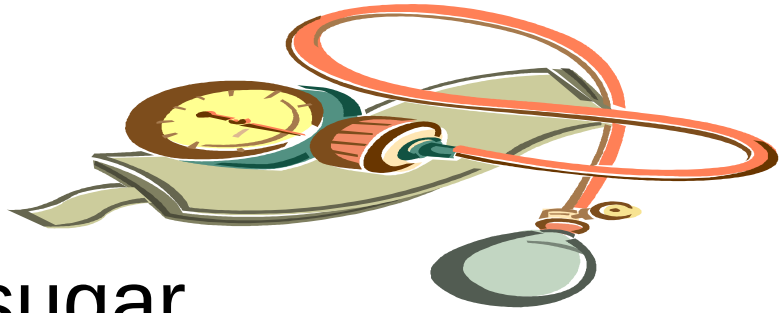
There are times when Eldorna needs to see her full GP record. Using security procedures, she accesses it from home. Though she knows that nothing on computers is risk free, she calculates accessing her records and using online health tools are risks worth taking.

When Eldorna needs to make decisions about medicines, she prepares for the consultation with information sent to her from NHS Choices, Diabetes UK and elsewhere. The medicines in her records have links to information about them.



Eldorna keeps a check on her blood pressure, blood- sugar, and weight. She compares them with past results.

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To cut out unnecessary visits, Eldorna's diabetes nurse offers a secure way to contact her online. Eldorna sends her self-monitoring results and gets advice about changes to her medicines or diet. If she is concerned about bruising from injections, she can attach a digital photo.



She is alerted if she needs to make an appointment. She also gets copies of letters and, if needed, an Information Prescription.



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When Eldorna needs services like foot care, she uses the *Good Diabetes Guide* to the best people and places. It is based on NHS outcome data plus ratings by service users. When she has care, she adds her own ratings.

confusedabout diabetes.com helps her keep up with new developments and has aids to making treatment choices that prepare her for consultations. She knows both sites meet the Department of Health Information Standard.

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The lab sends routine test results to her mobile phone, with links to how to interpret them.



To help prevent future problems, her personal health organiser automatically reminds her to make and attend eye and foot appointments, to reorder medicines, and to enter her self-monitoring results.

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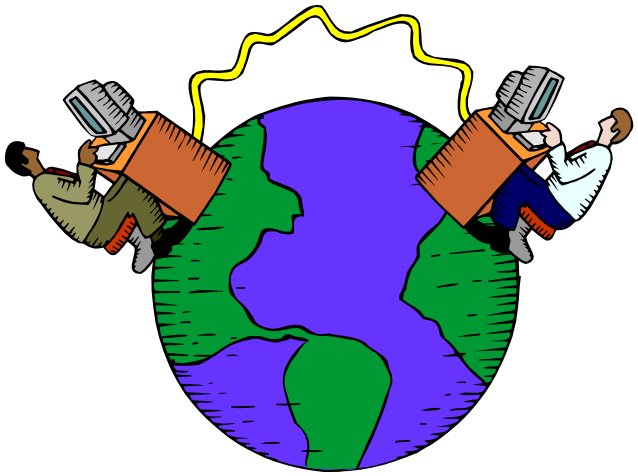
Eldorna has the peace of mind of knowing that if she needs advice at home or abroad, she can make her health information available to anyone she chooses. She can also decide how the NHS and others share her information.



Her son Nate lives in Australia and Eldorna has given him access to her records, just in case. This too gives her peace of mind and a feeling of being in control.

In a yearly meeting, Eldorna and her diabetes nurse review her care plan. She rarely visits her nurse more often as they can both follow her progress online.

She has joined a diabetes community on Facebook and visits diabetes blogs on NHS Choices or Diabetes UK to share experiences with other people living with diabetes. They often have useful tips.



With the Information Revolution, Eldorna has chosen to make her diabetes fit into her life, not the other way round.

No longer the ‘silent partner’, she has the information she needs - and the support from her clinicians - to be a full partner in decisions about her health and care. Her diabetes is well-controlled.



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What is good about the vision?

What concerns you about it?

Does it go too far or not far enough?

What will make change happen safely and effectively?

What could prevent change?



Dr Justin Whatling

Policy driven patient engagement topics

- Access and control over care records
- Share in decisions about their care
- Choice*
- Information to find out more easily about available services
- Increased use of technology for patients with long term conditions
- Rate providers on quality of care

* provider, consultant led team, GP Practice, treatment, diagnostic testing, care for long term conditions, end of life care

Access and control over care records

- What can we learn from patient-held paper records?
- Does health trust patients to hold, own and record data about their health?
- Do we understand who best to capture what kinds of data?
- How will people want to access their care records?
- What about families and third parties?

- What do we mean by ‘control’?
- What do we mean by ‘ownership’?
- Will people want to hold their own care records?

- What are the information governance, privacy and security concerns?
- Will people donate their data?
- What is the universally understandable consent model?

Co-production

“doctors need patients as much as patients need doctors and that, when that relationship is forgotten, both sides fail”

Anna Coote, King’s Fund

- **Co-production of public services by service users and communities** is the production of public services through the contribution of service users and communities, making use of their resources, expertise and willingness to give legitimacy, together with professional service providers.

But…. range of utility services

- Community and social networks
- Communication tools
- Wellness aids
- Self-diagnosis tools
- Decision-aids
- Digital therapies
- Behaviour change programmes
- Search tools
- Record management tools

- Transaction tools
  - Booking
  - Medicines management
  - Test ordering and interpretation
  - Interactive care planning
  - Self-monitoring and auto-feedback

European citizens' use of E-health services: A study of seven countries

Table 3: E-health activities and consequences in the total sample and among Internet users[3].

Activities (Have you used the internet to...)	Count	% in total sample (N = 7903)	% among Internet users (N = 4906)
Interact with web doctor/health professional you have not met	1485	19	30
Approach family doctor or other known health professionals	325	4	7
Self-help activities	1325	17	27
Order medicines/health products	1016	13	21
Read about health or illness	2567	33	52
Decide whether to see a doctor	2254	29	46
Prepare for an appointment	1830	23	37
Look up information after an appointment	2139	27	44
Consequences (Has information you obtained from the Internet led to any of the following)			
Feelings of anxiety	754	10	15
Feelings of reassurance or relief	1464	19	30
Willingness to change diet/lifestyle habits	1611	20	33
Suggestions/queries about diagnoses	1612	20	33
Change of medicine without consulting a health professional	192	2	4
Making, cancelling or changing a doctor's appointment	445	6	9

[1]Sample weighted for population size.

BMC Public Health 2007, 7:53

European citizens' use of E-health services: A study of seven countries

Table 5: Importance of different e-health services in the choice of a doctor in the total population and among Internet users.

Doctors' facilities	Total sample (N = 7903)		Internet users (N = 4906)	
	count	%	count	%
E-mail communication	2738	35	2228	45
E-mail prescriptions	1774	22	1380	28
Order/change appointments online	2658	34	2099	43
Doctor's office has website	3107	39	2343	48
Reminders via SMS	2744	35	1914	39
Access to own electronic patient record	2873	36	2175	44
Cost of services	4305	55	2654	54
Information on the doctors' practice	4424	56	2902	59
Recommendation by others	4852	61	3232	66
General accessibility	5867	74	3826	78

[1] Sample weighted for population size. Included in the table are those who answered 4 or 5 on a 5-point scale where 5 was very important

BMC Public Health 2007, 7:53

Challenges

- How do people want to engage in their health and wellbeing?
- How can ICT assist this?
- Where are the quick wins for engagement and taking workload off of the NHS?
- How do we deal with inclusivity, culture and language?
- How do we help people weigh up the risks versus the benefits of engaging?



Adrian Sieff

National Voices

People shaping health and social care

Information ≠ power

- Down the well
  - activation
  - health literacy
- Pot of gold
  - tools and resources

Changing relationships

what say king Solomon and the Beckhams?





National Voices

People shaping health and social care

Priorities

What role information?

- Increasing participation in treatment decisions
- Rolling out real participative care planning for long-term conditions
- Integrating information, education and support

- Choice of provider; data sets and infomatics to support this are of second order importance

National Voices
People shaping health and social care

Changing roles

what are the information needs?

CLINICAL EXPERT

Believes **knowledge** creates behaviour change

Gives expert advice and prescription

Scientific focus on **condition**

PATIENT: EXPECTANT

Believes **clinicians role** is to improve health

Passive recipient of care

ENABLING CLINICIAN

Believes **supported self-efficacy** plus **knowledge** create behaviour change

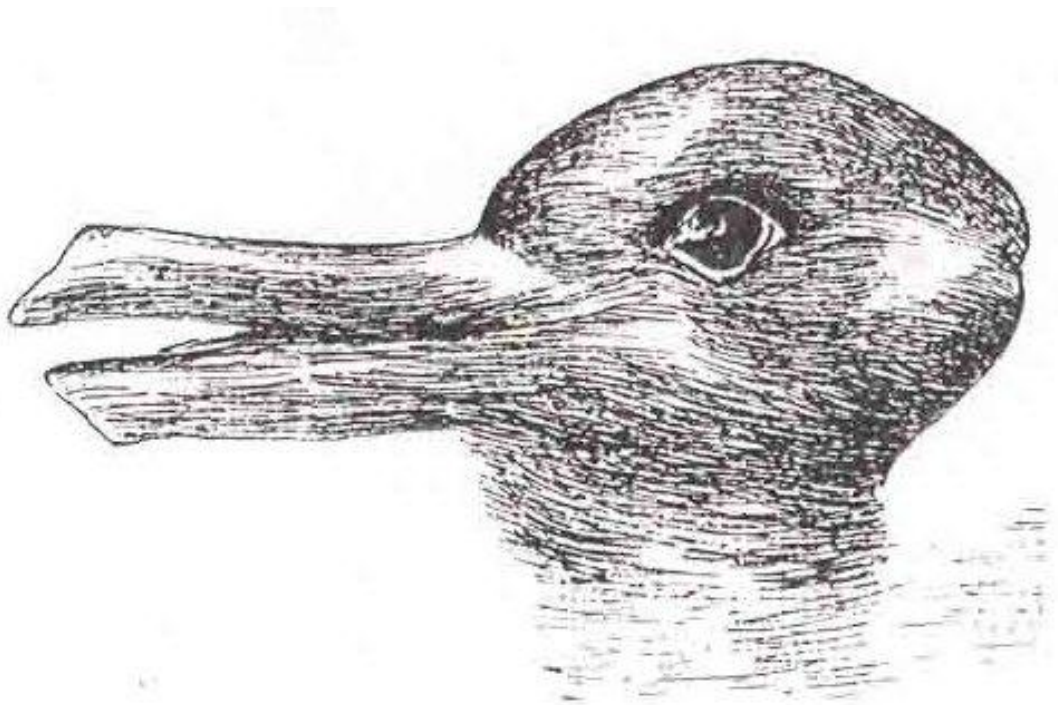
Provides enabling **support**

Empathetic focus on **person**

PERSON: EMPOWERED

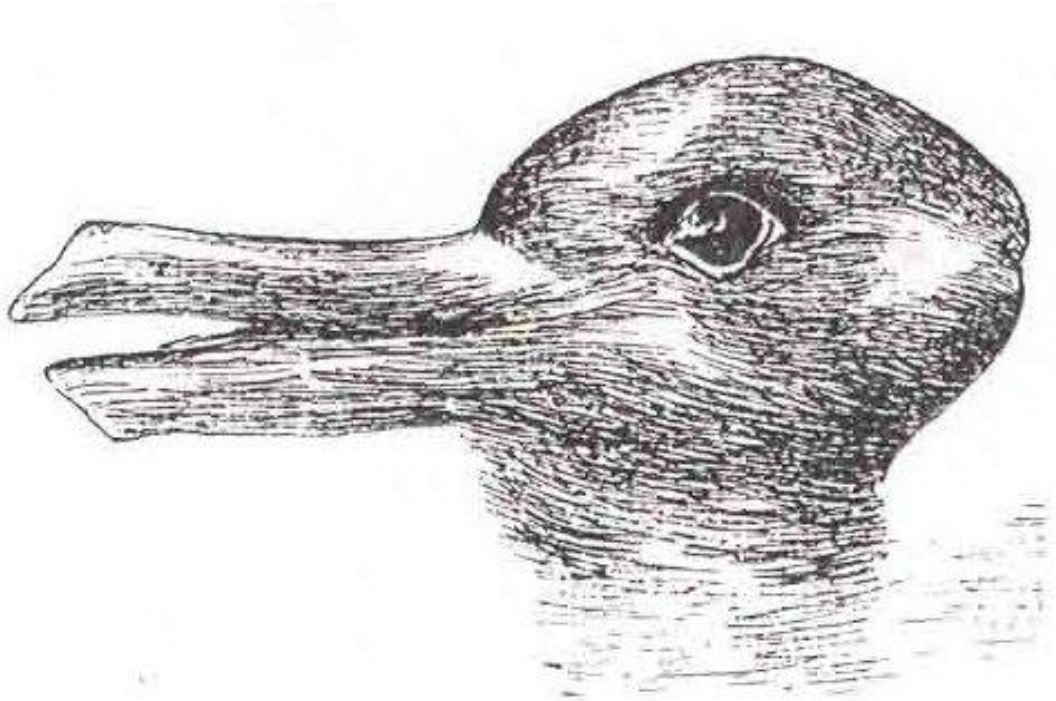
Believes **supported self-efficacy** plus **knowledge** create behaviour change

Determines and **enacts** goals



Receiving information

to see differently is to do differently



National Voices

People shaping health and social care

Information priorities

Who does what

- **NICE** (standards) and **DH/NHS Commissioning Board** (commissioning guidance): integration of information with patient decision making at all relevant points in care pathways
- **Commissioning consortia** improve information provision across the pathway (eg discharge from hospital); use patient experience data to track this.
- **Professionals and patients** need training and support to make use of integrated information in this way – voluntary organisations and 'experts by experience' are a workforce waiting to be employed for this.

National Voices

People shaping health and social care

Changing relationships

king Solomon and the Beckhams



Song of Songs

I am my beloved's and
my beloved is mine



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