

THE YOUNG FOUNDATION AND HEALTH

Data and the patient

March 2013

About The Young Foundation

We are The Young Foundation and we are determined to make positive social change happen. We pioneered the field of social innovation with The Open University, Language Line and Care4Care. We work closely with individuals, communities and partners building relationships to ensure that our thinking does something, our actions matter and the changes we make together will continue to grow.

youngfoundation.org

Health at The Young Foundation

We believe the challenges facing the health and care systems require imaginative and radical action.

At the Young Foundation we work with and across the NHS and social care to help create, promote and implement new ideas. We have worked with hundreds of innovation projects and enterprises within and around the NHS. We support them not only to succeed in their immediate goals, but to spread and diffuse their insights widely through the system, supporting the spread of innovation at pace and scale.

We broker new partnerships and relationships, believing the power of communities and broader civil society has huge potential to improve outcomes. Innovators are an undervalued resource within the NHS but, with proper support, we know they can make real change happen.

With a long history of supporting successful and pioneering innovation, the Young Foundation also shapes the future through publishing research and policy papers that prompt new thinking and action on issues such as loneliness, resilience, patient empowerment and the role of communities.

With a network of expert staff and associates across the UK, we can help you with any aspect of innovation in health and social care – from developing a particular idea, to building an innovation culture with your own organisation, to connecting you with people, expertise and innovations that can transform the way you work.



Introduction

We believe the major issues facing the NHS cannot be solved without changing the way the NHS uses information. The NHS need to be more proactive, integrated, and patient centred, or it will crumble under the twin pressures of an ageing population and austerity. The technical solutions exist, the policy pressure is in place, and we believe that real and exciting progress will be made over the next few years.

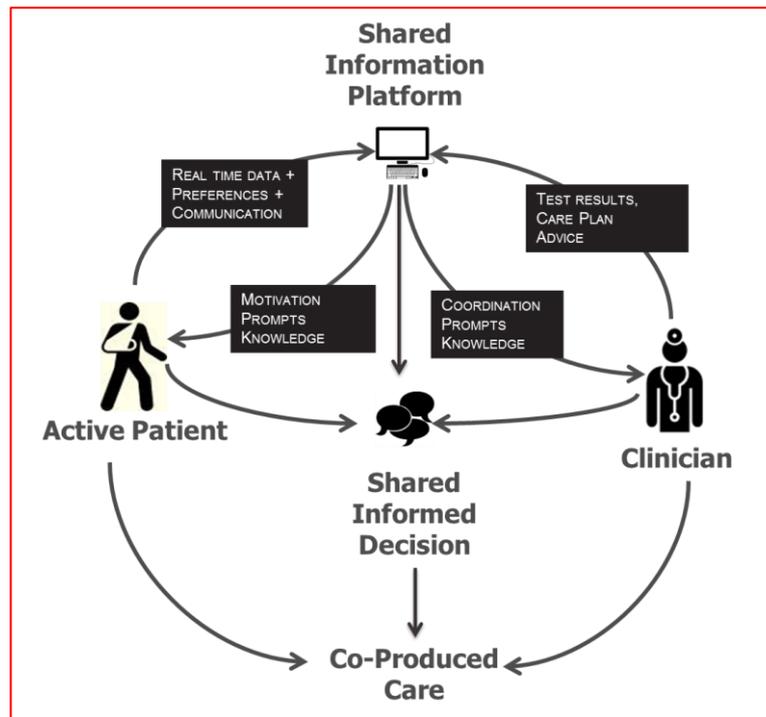
| Where we are | Where we need to be | Role of Information |
|---------------------|--------------------------------|---|
| Reactive | Proactive/ Preventative | Requires predictive information |
| In Silos | Integrated | Unified view of the patient |
| Done to | Done with | Patient access to the right information Individual goal tracking Personalised advice |

The new world

Imagine a world where your smart phone, iPad or computer really helped you manage your health, and any health or social care services that you receive, in one interface.

The typical patient with a long-term condition primarily wants to live their life as fully as they are able, yet they are likely to also need to monitor and record their symptoms, test results, and medication. They will have to book appointments and may want to seek advice from someone in the team of clinicians that support them.

In the new world the patient owns a confidential health record accessed online; this contains a plan of care, records of treatment and medication, test results, links to useful information sites and copies of all their communication via email with the different people they see. It tells them when their next appointments are, sends them reminders and can be accessed from anywhere in the world. It allows them to book appointments with their GPs and others online. It allows them to request repeat prescriptions which are automatically dispensed by their chosen pharmacy. It allows for apps to be used to monitor daily symptoms and treatments when out and about and for these to be automatically downloaded into the system. Additional standalone systems that are relevant for each person, like end of life systems, can be added on, as can useful tools and information that is available on the web.



Because the technology is patient owned, it is far more likely that data will be recorded in real time. In addition technology is now being developed to use smart phones and scales to monitor vital signs, oxygen saturation levels, and take spirometry readings. If it is easy to record data, a true quantitative answer can be given to the question ‘How have you /your symptoms been?’. This allows for a much more targeted and specific consultation, as well as allowing patients the important ability to track their health and progress over time.

All these elements exist within systems which are currently being implemented in the UK, one example of which is Patients Know Bestⁱ. The real paradigm shift occurs when the access to this information allows the patient to interact with the system in a different way, so changing the culture of decisions being made for the patient, to genuine partnership decisions being the norm.

Al Mulley writing in a recent Kings Fund publication and in the BMJⁱⁱ speaks of the ‘Silent Misdiagnosis’ where, whilst the clinician accurately diagnoses the clinical condition, they do not explore what the patient would prefer of the different treatment options available. His report calls for decision making tools to be developed for patients to use in conjunction with clinical staff, to enable the patient to be supported to choose the right treatment for them as an individual. Our model adds two further elements to this work and suggests using a system like Patients Know Best as a ‘hub’ through which all the other information systems flow. The two additional elements are:

- Patients inputting specific information about themselves into the system / decision making tool; so as to create an individual profile relating to their beliefs about illness and treatments prior to their consultation, thus enabling clinicians to address specific barriers to self-management and support treatment preferences more effectively and efficiently. Concordⁱⁱⁱ is a web-based software platform developed at UCL that incorporates much of this functionality.
- Patients using a personalised decision making tool to choose their care delivery model; whom advises them / provides care and in what setting. The MAGIC

shared decision making project supported by the Heath Foundation is using these processes in practice.

Having chosen what drug or other treatment input to manage their condition, the patient could then choose from a range of options offered on the basis of their severity of symptoms and degree of complexity, as to whether they receive most advice by email, phone, in primary or secondary care, by nurse or by doctor or another member of the team. This has the potential of changing clinical time and skill mix to where it most adds value and the patient choosing from an appropriate list of choices, a care delivery method that most works for them.

The policy push

The Health Secretary's announcement of a 'Paperless NHS' and the NHS Mandate objective for us all to have access to our GP records online by 2015 gives the political impetus for what we believe could be a quantum shift towards making this aspiration a reality. Through these initiatives technology should allow the patient to become an asset in their own healthcare, the conduit through which all parts of the system interact; truly ensuring the system acts in a way that is 'Nothing about me without me'

The technology enablers

Little that has been mentioned in this paper requires technology that is not already in widespread use. The world of smart phones and internet access via TVs means that there has now been a shift in who can access information about health and disease. 76% of adults had access to broadband in the UK in 2012. Not only does this mean we are far more likely to be informed consumers but also the way we live has changed; we bank online, grocery shop, and research any kind of information need at the touch of a button. Yet the NHS has as yet not taken full advantage of the kind of solutions that are available in every other area of life. In this new world consumers expect information and services to be delivered via technology and the momentum is now so advanced that the NHS has no choice but to catch up.

Further information:

- Visit our website and read the 'Connect: Patients and the Power of Data'^{iv}.
- Follow @the_young_fdn or @YF_Health on twitter
- Contact John Loder – john.loder@youngfoundation.org

ⁱ <http://www.patientsknowbest.com>

ⁱⁱ <http://www.kingsfund.org.uk/publications/patients%E2%80%99-preferences-matter>

ⁱⁱⁱ Concord is a trademark of Spoonful of Sugar © 2013' www.sos-adherence.com

^{iv} <http://youngfoundation.org/publications/connect-patients-and-the-power-of-data>