



CONNECT

**PATIENTS AND THE POWER
OF DATA**

Sylvia Wyatt and John Loder

About the Young Foundation

The Young Foundation brings together insight, innovation and entrepreneurship to meet social needs. We have a 55 year track record of success with ventures such as the Open University, Which?, the School for Social Entrepreneurs and Healthline (the precursor of NHS Direct).

We work across the UK and internationally – carrying out research, influencing policy, creating new organisations and supporting others to do the same, often with imaginative uses of new technology. We now have over 60 staff, working on over 40 ventures at any one time, with staff in New York and Paris as well as London and Birmingham in the UK.

The Young Foundation
18 Victoria Park Square
Bethnal Green
London E2 9PF
United Kingdom

Tel: +44 (0) 20 8980 6263
www.youngfoundation.org

Acknowledgements

The authors would like to thank many people for their help in developing the ideas in this discussion paper including:

Bob Gann
Head of Strategy & Engagement
NHS Choices

Lauren Kahn &
Candice Motran
Young Foundation

Jeremy Wyatt
Professor of eHealth Innovation & Director,
University of Warwick

Dr Mohammad Al-Ubaydli
CEO Patients Know Best

Contents

Introduction	4
Background	5
Linking patients and data	7
Seven actions for empowering patients with data	
1 Integrate record systems around people not organisations	10
2 Give people control over their own identifiable data	12
3 Elicit, record and act on patient preferences	14
4 Patients as partners in research	16
5 Transparent data on professional performance	18
6 Help patients help each other	20
7 Move data not people	22
What next?	24

Introduction

“Information is a health and care service in its own right: it must be freely available to all who need it.”

*Andrew Lansley – Liberating the NHS:
The Information Revolution*

The information revolution of the last few decades has the potential to transform the way healthcare functions. Its greatest potential lies in its capacity to change the way that patients interact with the health service, giving them more control over their own health and care. Patients have too often been left in the dark about what is happening to them, and denied the information that they need to fully participate in the decisions about their own health. This participation is not only a patient's right, but is vital in improving the quality of care.

This discussion paper explores how the tools of the information revolution give patients more control over their own health and care, thereby enabling clinicians and health professionals to enter a more balanced health contract. It shows how organising information around the patients can lead to better care, how patient control of data can give a fuller, more accurate picture of their health, how patients can make an active contribution to research, drive-up professional standards, draw on their own experiences to help one another, and how proper use of information can deliver more care to the best setting for the patient.

This paper is designed to prompt comment, feedback and debate from patients, health professionals and policy makers. By exploring seven actions it shows how information might help transform the experience, and benefits, of care. It also includes examples of innovative projects that are already beginning to unlock this potential.

Seven ways the power of information can serve patients:

- 1 Integrate record systems around people not organisations
- 2 Give people control over their own identifiable data
- 3 Elicit, record and act on patient preferences
- 4 Patients as partners in research
- 5 Transparent data on professional performance
- 6 Help patients help each other
- 7 Move data not people

Background

A great deal has changed concerning the nature of disease, our understanding of healthcare delivery and technological capability in healthcare in the last ten years, and the engagement of patients and the public. For example:

- There are many more people with long-term conditions
- The balance between patient and clinician is swinging towards patients with an increase in consumerist attitudes
- There is increasing technical ability to analyse complex streams of data in real time
- Hurdles of communication and collaboration have been hugely reduced by the internet
- The regulations around research consent have become ever more complex, even as the quantity of available data grows
- The size and cost of technology has decreased enormously and is often affordable by individuals
- There is an increasing emphasis on more proactive management of care replacing crisis management

In parallel, successive governments have recognised the importance of patient information, as shown in the timeline below:

1980s Small-scale patient information services introduced

1994 Major Government: The Patient's Charter and Health Information Service

1997 Blair Government: The New NHS and NHS Plan

1998 NHS Direct telephone services: Three initial pilot schemes

1999 – 2007 NHS Direct Online, NHSD digital TV, Expert Patients Programme, information prescriptions, Patient Prospectus for Long Term Conditions

2007 NHS Choices

2008 NHS Direct online integrated with NHS Choices

2010 Equity and Excellence, Consultation on Information Revolution

In July 2010, the white paper 'Equity and Excellence: Liberating the NHS' set out the Government's strategy for the NHS in England. Its stated intention is to 'create an NHS which is much more responsive to patients, and achieves better outcomes, with increased autonomy and clear accountability at every level'. The overall direction of government can be summarised as follows:

- Engage more patients in understanding how they can improve their own health
- Ensure that there are 'no decisions about me without me'. This would include decisions about research also
- Ensure that patient preferences and experiences are used in clinical decision making
- Empower patients, carers and families to do more for themselves and their loved ones
- Get more patient experience into the knowledge base by enabling patient-led and published research
- Empower communities to organise care locally

The greater emphasis on patient, carer and family involvement and responsibility, together with huge opportunities enabled by existing technology, means that we have the political support and the technical ability to change the way in which health and social care is delivered. This direction of travel has been reinforced in the consultation on Liberating the NHS: Information Revolution, which has just been completed. A new information strategy is due in 2011.

Connecting patients and data

It is clear that patients want more choice and control regarding their own health. They are demanding control over where, how and by whom they are treated. We are entering an age of "no decision about me without me".

Information plays a primary role in empowering the patient. Denied proper knowledge about their condition, both general and specific to them, patients are unable to participate in decisions about their treatment as equals. Properly informed patients can play a full role in the decisions that effect them. Furthermore, this paper argues that building a healthcare system around the patient is a force for increasing quality. It is about seeing patients as a positive resource for healthcare, rather than simply as a cost.

This can happen in a number of ways. Firstly, patients deliver much of their care themselves. Even if the patient sees a healthcare professional on a weekly basis for one hour, they will still look after themselves 167/168 hours a week or 99% of the time. The extent to which patients understand their own condition, have the right information on their own particular situation, and understand the effect of their wider lifestyle upon their condition, can make a significant difference to their own outcomes. The nature of the task that faces the NHS at present makes this task all the more pressing. The NHS was conceived at a time when infectious disease was the main burden. Now, long-term conditions such as COPD (Chronic Obstructive Pulmonary Disease) and Diabetes, form the bulk of the NHS's

work. Patients are inevitably far more involved in the delivery of care for these conditions than they would have been for Tuberculosis.

The information revolution means that we can do much more than provide patients with generic text about their disease. It is possible to provide personalised information built on their own medical history, and even on their genetic profile. This can be a powerful tool to allow patients to manage their own affairs (Sections 01 and 02).

Secondly, quality care takes proper account of patient wishes. Medical decisions are not always, or even often, a simple deduction from symptoms to treatment. They are judgements where the outcomes are often uncertain. A decision to pursue a particular path of treatment will often carry significant risks with it. The best decision must be made together with a patient who is in full possession of the relevant facts. Best care must also take full account of their particular circumstances and wishes, especially when it may be difficult for patients to express those wishes, such as at the end of life (Section 03).

Thirdly we should acknowledge that patients already control the data which drives medical progress forward. Research is based on the outcomes for real patients, and the speed at which medical science progresses depends on the participation and agreement of patients. The information revolution is a significant change of scale in our ability to connect data, and taking advantage of it depends on reforming the way patient consent works (Sections 04 and 05).

TABLE 1 - WHAT PATIENT-CENTRED CARE MIGHT MEAN FOR THE USE OF DATA		
Existing system	Changes in how care is delivered	Data implications
Paternalistic – clinically led	Democratically led	Include patient insights and wishes in record
'Do to'	'Do with' Co – production	Patients understand and control their data
Patients find it hard to assert themselves	Informed confident patients	Timely and comprehensible information
Fragmented information	Integrated information around patients	Use of single identifier, personal data stores
Patient feedback to professional difficult	Rating individual providers and organisations	Feedback mechanisms much more commonly used
Small role for non NHS organisations in service provision	Social enterprises and third sector being asked to provide more local support	Open standard record format to all better communication for all providers
All care face to face, mediated by professionals	Remote support for self care mediated by technology where appropriate	Tele-healthcare information included in the record
Complexity of system and GP as guide	Patients empowered to navigate system to manage own condition	User-friendly web services
Academically driven research	Patients partners in research	Patients involvement in research methods and protocols

Fourthly, patients have a voice that can be a powerful force for improvement, but only if they have the relevant information. Informed patients can put upward pressure on clinical performance both through choice and through advocacy (Section 05).

Fifthly, patients are in a position to catalyse resources from their communities that the state cannot access. Friends, neighbours and family are vital sources of care for patients. We all depend on our nearest and dearest in times of ill-health, as much as we do on professionals. Providing these people with the relevant information and knowledge can make their contribution more timely and effective, and decrease their anxiety and stress. Patients can also be a resource for one another. The practical business of living with a long-term condition can be made significantly easier by connection with those who have already faced, and overcome, the same problems. The information revolution allows us to build networks of individuals around a common interest or concern far more easily and effectively than ever before. (Section 06).

Finally, if patient wishes are to be properly expressed, and the financial integrity of the NHS is to be preserved, ways have to be found to change the setting of care from hospital to home. The information revolution can play a crucial role here also. It is possible for staff to closely monitor a patient in their own home, and to target care in a far more accurate manner, based on superior data analysis (Section 07).

How is The Young Foundation involved?

The Young Foundation's ambition is to encourage government to ensure that Britain leads the way in building a new patient-centred healthcare service using the power of data. Building on NHS Choices, the NHS could lead the way in developing transparent, patient-centred information, policy and practice. The UK's leadership would encourage other countries to adopt this approach. The potential health benefits of this approach, to people in the UK and others that joined, could far outweigh the financial benefits to individual organisations of owning and selling information.

Investment is needed to support these changes in the way in which data, information and evidence are generated and used, so that the system revolves around patients rather than organisations. This paper sets out an agenda for how this might be achieved.

01/

Integrate record systems around people not organisations

Currently many different personal records exist, at least one for each ‘organisation’ or sector – hospital, GP, community, etc. Each of these records are incomplete and often inaccurate. Patients often have to give the same information repeatedly, and often find that the proper information has not been passed from one part of the system to another. Clinicians can find themselves unsure of exactly what the previous course of treatment has been, what tests have been done, what has, and has not, been explained to the patient, and so on. Indeed, patients who are interacting with multiple professionals at once often find that clinicians are having to rely on the patient to be their own medical record, as no complete picture of that patient’s treatment is accessible. This fractured data causes waste through repeated tests, inconvenience due to patients reiterating their history over and over, and error as clinicians make decisions without the best information possible.

Ensuring that all data relevant to the patient is collected together and seen from a single perspective can help ensure accurate, complete and convenient information, as well as the best quality care. For this to be possible, it will be necessary to have a single number that allows records to be related to one another, such as the NHS number in England or the CHI number in Scotland. While less

than glamorous, an identifier of this kind is vital for much of the potential of the information revolution to be realised.

This does not mean we should have a single patient record for everything. Privacy concerns need to be taken into account. For example, people often want to keep their genitourinary medicine and psychiatric records separate from other records. It will be essential instead to have open standards for data transfer, so that systems can talk to one another. This allows variable levels of access to records, but the possibility of the patient seeing all the data that is relevant to them.

Properly designed and linked, this data can have tremendous value for patients (see Boxes 1-1), and improve the quality of care. While implementation in the UK has so far been difficult, examples from elsewhere show how popular systems of this kind can be. In the US ‘Kaiser Permanente’ members used their online record system to access 25.8m test results in 2010. Patients can understand their care more clearly by accessing their notes, and receive test results and information in a timely and secure manner.

Finally, patients can be sources of data, as well as consumers of it. While the information contained in the standard medical record is vital, it is only a tiny fraction of the possible information about an individual’s health. Patients can give a far more detailed picture over time using new technology than in a ten minute consultation. For example, ‘Patients Know Best’ (See Box 2-1) allows patients to send their daily blood sugar information to specialist nurses who can advise them on how to adjust their insulin dosage. Tele-healthcare systems can provide monitoring of respiratory rate and oxygen

saturation as well as weight gain, insulin levels and many other physiological changes. A record built around the patient can incorporate these new and growing

sources of information, and allow clinicians to take full advantage of them.

BOX 1-1

THE SCOTTISH CARE INFORMATION - DIABETES COLLABORATION

The SCI- DC is a national program that aims to provide a combined patient record for all individuals with diabetes and a region-wide register of all people with diabetes.

The system combines information from a number of different people who support patients with diabetes, (including your GP practice, hospital diabetes clinic, podiatrist and dietician) and combines all the information into a single record. This gives all authorised professionals access to the most up-to-date information about a person’s diabetes.

This helps to reduce duplication and allows decisions about diabetic care to be made on the best information available.

The single record will allow all the health professionals who help to look after people with diabetes to have access to the most up-to-date information about your condition. We have set up a security protocol to ensure that only people who need access to your information will be able to access it.

The system also allows practices to audit the care they provide and to identify people who need to be reviewed. The register is used to call people for eye-screening on a regular basis. Data that has all patient-identifying information removed is also used for the annual Scottish Diabetes Survey undertaken by the Scottish Government and for research into diabetes.

02/

Give people control over their own identifiable data

Once we have created a view of the patient that includes all their relevant data, there is the issue of who controls this data, and who can have access to which elements of it, and when. We argue that the patient is the best person to control access to their own data.

Firstly, giving people control over their identifiable information would overcome many of the issues surrounding access and the sharing of records between organisations. Since the patient herself is in control, she can give permission to view as much of her records as is necessary. Rather than the complex, stifling and ineffective regulations that currently govern access and sharing of records, we could leave the decision up to the patient. The data silos of primary, secondary and community care would disappear. The patient can also share parts of their data with their family and informal carers, if they choose. They can also specify which parts they would like shared.

Secondly, patients take good care of their records if they are allowed to access and control them. A 2004 study shows 70% of patients found an error or omission in their medical records, and 23% found an error or omission that could be described as

important.* Patient control of records could be considered the equivalent of letting council house tenants buy their houses – not only did it give them assets that they could benefit from the assets benefited from the care of the owners.

Thirdly, the value of data rises as it can be combined with other data. Patients will wish to combine their data with other data sets in a way that gives them increased understanding. For example, 'Patients Like Me' allows patients with Motor Neurone Disease to pool their (self-entered) data, and thus to compare their own progress with that of the average progress of similar patients, and can see if any changes in their lifestyle or treatment could improve their relative performance. For a progressive illness such as MND, this has previously been very difficult, but can now be done simply. For more detail see Box (4-1).

The software necessary to allow patient control, with proper authentication and variable accessibility already exists in initiatives such as 'Patients Know Best' (see Box 2-1) Microsoft HealthVault and we would expect to see it become more prominent in coming years.

* Pyper, C, Amery J, Watson M & Crook C (2004). Patient's experiences when accessing their on-line electronic patient records in primary care. British Journal of General Practice, 54, 38-43.

BOX 2-1

PATIENTS KNOW BEST

Founded by Dr Mohammad Al-Ubaydli, who is unusually a practicing doctor, a trained programmer, and a patient with a long term condition, 'Patients Know Best' is a patient-controlled medical records system. As a patient Dr Al-Ubaydli often found himself being the only person with all the information relevant to his treatment, simply because he was the only person who had been to all the appointments. If he did not ensure that the right information was with the right people, no one would. He wanted to play this more engaged role in his treatment, and for other patients to be able to do the same; and so PKB was born.

The philosophy behind PKB is to think of the patient, and their family and carers, as members of the clinical team. This is not driven by the rhetoric of patient-centred care, but by an attempt to find a way of dealing with the increasing pressures on medical staff, as well as the need to increase quality. Patients can access their own medical notes, monitor their health, and exchange health information securely with doctors in real time. Especially for patients with long-term conditions, who are often the only people in full possession of all the details of their treatment and history, this can be an invaluable aid in controlling the interactions of all involved, for the best results. Patients can help, and their help is needed.

The site is free to NHS patients, and organisations such as Bupa and the Thalidomide Trust are also starting to offer access. It is integrated into the NHS secure network and the system is available for use by any patient, with any clinician, anywhere in the world.

www.patientsknowbest.com

03/

Elicit, record and act on patient preferences

'No decision about me without me'.

I am the person most interested in my own health and I am not alone; most people want to know how to look after themselves better. But people are at their most vulnerable when they are ill, so their preferences about treatment options and preferred places of care need to be established routinely and updated regularly. The person's preferences need to be accessible and understood by everyone concerned – carers, family, emergency services and clinicians.

Patients' views, experiences and insights are a valuable part of their records. Clinicians are increasingly recognising the value of the patient's experience, alongside their own clinical knowledge, and deciding treatment 'with' patients and not 'for' them, involving close family members wherever possible. However, much more needs to be done to ensure that care is co-produced with the person and their carers.

A person's preferences for the last 12 months of their life are often missing from their records. What treatments do they want or not want? Who do they want to look after them? Where do they want to be cared for? Few people presently write 'living wills' but it would be relatively easy for these to be drawn up routinely alongside financial wills, guided and witnessed by solicitors, and lodged with

families, GPs and solicitors (see Box 3-1). This would help families come to terms with end-of-life issues before a crisis intervenes and removes choice. It would also help avoid last-minute admissions to hospital or care homes when the patient had been clear in their wish to die at home.

One useful step along the way to co-producing such End of Life care has been taken by the Scottish Emergency Care Summary (ECS), which now also includes an 'Advanced Care Plan' which aims to detail an individual's end-of-life preferences. There are also examples of co-production of services with people possessing mental health issues and/ or learning disabilities, who have advocates that act on their behalf and in their best interests when their competence is impaired. Sadly, this is rarely the case for people with dementia.

BOX 3-1

LIVING WILLS

This declaration is made by me _____
of _____
at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions about my own future, then let this declaration stand as the testament to my wishes.

If it is the opinion of two independent doctors that there is no reasonable prospect of my recovery from physical illness or impairment which is expected to cause me severe distress or to render me incapable of rational existence, then I request that I be allowed to die and not to be kept alive by artificial means. Any treatment which merely prolongs my dying should be withheld or withdrawn. I also request that I be treated with whatever quantity of drugs or medicines required to keep me free from pain or distress, regardless of the effect on my physical health and survival.

Witness _____

04/

Patients as partners in research

However research is carried out, it requires informed patient consent. Issues around consent have mushroomed into a complex maze, fraught with vested interests, conflicting view points and legal ambiguity; where too much weight is given to a few who voice the need to protect patients' privacy in all circumstances and at all costs. Clinical research on what works and what does not, is being strangled by the red tape of data protection which requires informed consent at all stages. As a result, research is becoming more expensive and slower, even though the analysis of data is cheaper and faster than ever. This problem has been recognised and the EU Data Protection Directive is being reviewed across Europe.

These issues urgently require an open debate and resolution. However there is an alternative opportunity, opened up by the information revolution, to take advantage of the variety of views that exist on privacy and anonymity, together with personal control of records. Internet users display a massive range of attitudes to privacy, from those who are happy to advertise the intimate details of their life to millions, to privacy obsessives who encrypt their shopping lists. Previously we have had to take a one size fits all approach to medical privacy, and consequently had to set the bar high. However, as we give patients more control over their data, it becomes much easier for them to volunteer their data, or parts of it, for research use. We can take advantage of this variation in the appetite for privacy, to

encourage the voluntary provision of data. Initiatives such as UK BioBank showcase this approach, showing how the health of 500,000 people aged 40-69, from all around the UK, is affected by their lifestyle, environment and genes.

Research will also begin to take advantage of new data sources which will increasingly be driven by patients. Patients are motivated and capable of recording a great deal of detail about themselves and the progress of their conditions. As outlined below (Box 4-1), 'Patients Like Me' (PLM) is a disease-based medical community where patients enter a great deal of information about themselves. The value of this information lies in the ability of patients to compare their treatment and progress to large numbers of other similar patients. PLM now has detailed information on almost 100,000 patients across 18 disease categories. In those areas where it has been operating the longest, such as Motor Neurone Disease, PLM has more data on more patients than the largest clinical trial ever conducted.

This community is pursuing its own research agenda. As a community it decided to investigate the effect of Lithium on patients with Motor Neurone Disease, following an intriguing but small-scale study. While not a clinical trial, given PLM's large and detailed database, statistically interesting results can be extracted rapidly and cheaply. Lithium looks likely to be ineffective, but this is a trend that is gathering momentum. Patient groups in the US have already established tissue and specimen banks, created new cell lines for testing lead compounds, established patient registries, formed clinical trial networks, and raised significant money for high-risk research that often cannot secure public funding.*

* Frydman GJ. Patient-Driven Research: Rich Opportunities and Real Risks. *J Participat Med*. 2009(Oct);1(1):e12.

BOX 4-1

PATIENTS LIKE ME

PatientsLikeMe (PLM) is an online platform where patients with life-altering conditions share structured information about symptoms, treatments and outcomes. Members can view these data as individual-level graphical health profiles and aggregated reports, discuss health and offer and receive support on forums and through private messages. PLM currently has communities for amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson's disease, Fibromyalgia, HIV, Chronic Fatigue Syndrome, mood disorders, Epilepsy, and a number of rare conditions. PatientsLikeMe currently has 97,000 members.

Similar to other online communities, members of PLM offer one another support based on their own personal experience, and advise each other on how to improve daily life and long term health outcomes. What distinguishes this patient platform from others is that members tailor questions and consult by referring to concrete data displayed for each member. Online communities are notoriously abundant in sympathy and stories but thin on practical information. The members of PLM don't simply share their experiences anecdotally; they quantify them, breaking down their symptoms into hard data, inputting their condition and treatment details including dosage, efficacy and side effects, along with information on symptom history, tracking and a variety of biological information. All this data is entered onto simple data-entry forms and turned into graphs and charts via the site's software. Patients are able to share their experience using patient-reported outcomes, find other patients like them matched to demographic and clinical characteristics, and learn from the aggregated data reports of others to improve their outcomes.

The site offers two types of data – both individual and aggregated – thus giving patients insight into both the specificities and full variety of experiences associated with interventions, and not only what happens 'on average', as is often the case.

The site gathers patient information on two levels. Firstly, there's a quantitative breakdown of symptoms and dosages, and secondly there are forums, where members share advice, and provide more nuanced feedback on a particular treatment issue or drug. The site is designed so that relevant 'hard' data informs conversations in the forum and vice versa.

As mentioned above, the 'Patients Like Me' community has set research goals based on this dataset, and has published several pieces of research, including a collaboration with the Department of Clinical Neurology at Oxford University.

www.patientslikeme.com

05/

Transparent data on professional performance

Transparent feedback mechanisms are largely missing from healthcare; particularly feedback about care outside hospitals. Despite explicit complaint mechanisms, many errors and inconsistencies in clinical practice which can lead to poor care, never surface. A more complete picture of how patients perceive their experience, and the progress they make ‘out of the sight’ of clinicians, is necessary to accelerate improvement in the NHS. The information revolution can play an important role in facilitating this.

Feedback loops help ensure that systems are responsive to local needs and changes. The Department of Health has been encouraging feedback mechanisms to develop at individual, practice and organisational levels through NHS Choices and Care Quality Commission (for example, the star rating of NHS Trusts, practice based feedback about clinical treatment). More recently Patient Opinion is enabling people to find out what other people think of local hospitals, hospices and mental health services (see Box 5-1).

Patients are the ones who receive care, and they are thus the only ones who

know how they were treated. How can an institution understand how well it is operating without seeing itself from its users point of view. Companies that treat customers poorly lose business and politicians who treat voters badly lose elections, but clinicians or organisations who provide poor care often carry on regardless. Indeed, they may not even know they are doing it.

Despite the importance of feedback, it does need to be appropriately moderated. Some clinicians care for riskier patients than others so there is more risk of a poor outcome. Also there is a need to avoid the ‘flaming’ that can occur where people with vested interests feedback inappropriately.

Combined with detail on clinical outcomes, carefully managed feedback mechanisms which take casemix into account, can be a powerful spur to innovation and improvement. ‘Moderated’ feedback from patients can allow people to make choices and avoid poorly performing institutions and individuals, and the health service gains the information that it needs to improve itself.

BOX 5-1

PATIENT OPINION

Patient Opinion is a website dedicated to sharing experiences and opinions of health services, and to making the insights of patients available to the NHS. On the site, patients can see what other patients are saying about their health care, share stories so others can learn from their experiences and see how health services have responded to comments. Stories are anonymised, reviewed and published on the site for all users to browse. Subscribers can then respond to postings, generate reports to compare their own patient feedback with that of other hospitals, set up data feeds that direct comments to the manager responsible for that service and ask ‘Patient Opinion’ to run surveys on their behalf.

Patient Opinion is a social enterprise - a business created to make a difference to the NHS. Any surplus profit made is invested to improve the business and to invest in helping the voice of patients have more effect. Most importantly, patients and carers can ‘tell it like it is’ as they know what the service was like and generate lots of great ideas about how it could better.

Hospitals and Primary Care Trusts (PCTs) use the data from ‘Patient Opinion’ in three main ways:

- To plan how to develop and improve services
- To give doctors, nurses and managers a feel for what patients are saying about the service they manage
- The Care Quality Commission receives all published stories and uses them to improve services

06/

Help patients help each other

Patients can become masters of their conditions. After living with conditions for many years, they often acquire an in-depth knowledge that comes from practical experience of living with a long term condition on a day-to-day basis; knowledge that few clinicians can lay claim to.

This hard won practical wisdom includes both general principles and specific facts. By 'general principles' we mean the rules of thumb that will be useful for those who have to live with a condition. Despite the importance of these, it is information about the quite specific circumstances that the information revolution makes much more available.

General principles have always been available. But no patient is truly typical, and thus there are situations where the general principles are not relevant. Instead, very specific questions need answering, and online communities of patients are capable of answering them. A brief look at a diabetes forum picked up the following issues, and responses.

- The best brand of insulin pump holder for an active 5-year-old.
- How to deal with the DVLA after having had a hypoglycemic attack while driving.
- How to persuade a two-year-old to best handle finger prick tests.

Initiatives such as Heath Talk Online showcase this approach. www.healthtalkonline.org

While an expert clinician may have an answer to some of these, they are unlikely to have the answers to all of them. Furthermore, it may be months before the patient can secure an appointment, whereas other patients can answer the question now. There is a mass of information that is relevant to the lives of patients, but is presently dispersed and inaccessible; held in the heads of thousands of patients across the country.

Although this paper is mainly focused on information, this is not the only thing that communities of users can exchange. They can provide important emotional support. For those with rare conditions or in unusual circumstances, there is great value in knowing that one is not alone and in belonging to a like-minded group when it comes to behavioural change. From WeightWatchers to AA, social dynamics can be a powerful source of resolve for those working to overcome their appetites.

Patients can also catalyse support from their community in a way that the state cannot. We all freely help our friends, family, and community by doing tasks that would be prohibitively expensive to buy - and often do them in distinct ways that benefit the recipient much more than if this service was paid-for service. The social networking function of the information revolution can amplify and support this process. See Box 6-1.

There will be concerns that the information that patients give one another may be inaccurate. While this is clearly a legitimate concern, online communities have evolved effective filtering mechanisms. Most

internet users access Wikipedia every week, and find it an invaluable source of information. However it is an information source entirely built by amateurs correcting one another's mistakes, and building a source of gradually increasing accuracy. This is far superior to watercooler rumours based on misunderstood newspaper

stories, themselves distortions of underlying research. In addition, people generally use common sense when assessing 'evidence'. We might use Wikipedia to learn about our favourite comedian, but if it came to filling in our tax return or diagnosing a medical condition we might choose a more authoritative source.

BOX 6-1

TYZE: NETWORKS WITH A PURPOSE

Tyze is a social media platform that enables friends, family members and medical professionals to set up private, secure, online networks to organise support and communications for vulnerable individuals.

Tyze has pilot sites in the UK in Merton and Croydon, as well as in New Jersey, California and across Canada. In their first year of operation, Tyze delivered hundreds of networks in the US and Canada, as well as their first networks in the UK. Each network benefits between 6 and 20 carers, friends and family members as well the people at the centres of the networks, who are people with disabilities, the elderly and individuals experiencing physical, mental or emotional limitations. On a wider level, this also serves to deliver significant benefits to agencies and organisations who provide care services as well as help reduce isolation, increase community engagement and improve health outcomes. Like other social networking sites (eg Facebook), users are able to post messages and use the platform to keep in touch with friends, family and paid supporters. But Tyze is not like other social networks- a number of innovative features distinguish the Tyze approach.

Tyze networks:

- have a purpose as they are created around a specific person and situation, and no two networks are alike
- fulfil both practical and emotional needs such as sharing important information, scheduling events, organising tasks and coordinating and keeping track of appointments, as well as strengthening relationships, reducing isolation and celebrating and empowering the person at the centre
- reinforce real-world connections, contributions, outcomes and relationships
- provide a new, distributed model of care-giving which build connections between formal and informal systems of care, making it easier for formal care providers to work collaboratively with friends and families of the people in their care, and reducing communities' reliance on professionals.
- facilitate connections, benefitting from the skills of a trained network connector who takes the lead in organising the network

www.tyze.com

07/

Move data not people

For patients with long-term conditions, a spell in hospital is much more likely to stabilise the patient than to approach a cure. Often these admissions represent a failure to provide the best care for the patient at the right moment. Furthermore, moving care out of hospital is the only way the NHS can meet the financial challenges of the present environment while maintaining quality.

This has led to an intense focus on changing the setting of care across the system, such as through virtual wards, in which information can play a vital role (Box 7-1). By remote consultations, richer data coming through telehealth equipment, more detailed and accurate patient records, and patient-recorded data, professionals can get a far clearer view of the condition and prognosis of the patient, and can react more swiftly and appropriately to any change in condition.

This leads to a number of quality and productivity gains including:

- more choice about where people can be cared for
- proactive, preventative care
- clinical decisions based on daily data not monthly/annual disease activity
- Information from remote monitoring can be used to tailor the support the patient needs and improve patient experience

Technology is rarely enough on its own to enable people to stay at home for longer. It needs to be part of a 'bundle of care components' which will require significant advances in:

- Understanding how to analyse data to show who is at risk of deterioration
- Understanding whose prospects can be most improved by intervention
- Understanding the configuration of services that can best deliver this impact

Perhaps most importantly this will require a change in attitude and expectations. The default expectation must be that people should be cared for in their own homes; it is care in hospital that should require justification, rather than remote-care at home. This should reduce use of hospitals so it could become possible to release hospital resources.

BOX 7-1

VIRTUAL WARDS

Virtual Wards deliver proactive care at home for patients at predicted high risk of unplanned hospital admission. Rather than waiting for an unplanned hospital admission, 'Virtual Wards' take the coordination of a hospital ward to the patient in order to prevent the admission from occurring in the first place. Predictive risk-modelling is used to assess which patients are most likely to be admitted to hospital in the upcoming year (which may be a quite different group to those who were admitted most frequently in the previous year).

Patients are offered 'admission' to a virtual ward, which uses all of the systems, staffing and daily routines of a hospital ward to provide preventive care to patients in their own homes. Patients are cared for by nurses, allied health professionals, social workers and therapists working together to set out a care plan for each individual, based on a structured diagnosis of problems. These professionals also work closely with local GPs and communities, to provide a range of high-quality care supporting people in their homes and avoiding unnecessary admission to hospital.

Care plans include a monitoring program and a crisis intervention effort. The most complex cases are closely monitored at home, with continuous and serious efforts to keep ahead of potential crisis situations. Crisis interventions include 24-hour phone lines for in-bound calling, urgent care centres and rapid response home visits.

Virtual wards are now in operation across the UK in a variety of configurations.

What next?

We are just at the beginning of the revolution in the use of data in patient care. There are a number of real risks and uncertainties in the ambitions set out in this paper. The main ones include:

- Already stretched staff may resist patient control if they perceive it as adding to their workload
- Patients may perceive that more self-care and at-home care is a cut in state provision, and thus resist the changes
- Patients may open their medical data in a way they later regret, leading to a backlash

The proposals outlined in this paper will need careful and expert handling but the potential benefits for the system are too large to ignore.

We are proposing that the following will lay a strong foundation for patients to do more for themselves:

- 1 Integrate record systems around people not organisations
- 2 Give people control over their own identifiable data
- 3 Elicit, record and act on patient preferences
- 4 Patients as partners in research
- 5 Transparent data on professional performance
- 6 Help patients help each other
- 7 Move data not people

If The Young Foundation changes are put into action, we should see a rebalancing of the knowledge relationship between patient and professional leading to rapid improvements in the quality of care, safety, productivity, individual/community resilience, patient empowerment, personal/family experiences and, most importantly, from a patient's perspective, better health outcomes.

Further discussion and debate about empowering patients with data:

If you would like to participate in further debate about the action points raised in this document, provide further examples or respond in any other way, please contact Sylvia Wyatt (Sylvia.wyatt@youngfoundation.org) or John Loder (john.loder@youngfoundation.org) at the Young Foundation.

Information is the lifeblood of high quality healthcare. There have been huge technological advances about how it can be used and by whom, which have been under utilised by the NHS. It is now possible to give people control over their own data. If this were done, it would have the potential to revolutionise healthcare delivery for patients, their families and carers.

This discussion paper sets out seven practical ways and examples of each which the Young Foundation believes would transform health care delivery. These could improve patient experiences, reduced errors and omissions, improve communication and make healthcare more efficient and effective. The Young Foundation seeks to promote open dialogue and stimulate responses about how these changes could be brought about.

