



Patient Empowerment

THE BAZALGETTE SERIES

Investigating the use of data in health care
for research, prevention and better care



PREVIEW

The Bazalgette Series is a group of seminars hosted by OptumLabs® that investigate the use of data in health care for prevention, better care and research. The series is named after Sir Joseph Bazalgette, an engineer who redesigned the systems to bring clean water to Londoners by separating sewerage and drinking water in the 19th Century; thereby reducing the burden of communicable disease.

This seminar, Patient Empowerment, and the subsequent seminars, provide ongoing discussion and debate around the system redesign required to transition the health system from one of cure to one of prevention.

Each seminar re-imagines different aspects of the health system and proposes alternative methods to support data driven health care delivery and system transformation that is more suited to the epidemiological change in disease that has occurred in the 21st Century.

We believe that re-thinking these separate elements of the health system will generate topics of discussion that provide comprehensive proposals for delivering improved health to the population.

THE TOPICS TO BE ADDRESSED BY THE SERIES INCLUDE:

- Data Infrastructure
- Data Governance
- Research and Innovation
- ◀ Patient Empowerment
 - Enabling Clinicians
 - New Analytical Methods
 - Learning Health Systems

The series aims to re-imagine the use of health data as the new engineering to tackle the burden of non-communicable disease.

KEY TAKEAWAYS



- Patient empowerment is about providing personalisation and giving control
- Patients need to be involved at all levels of the decision making processes
- A new dynamic is emerging in the relationship between doctor and patient and this will require further engagement with both groups
- Digital delivery solutions need to involve the patient at the centre of the discussion
- Some considerable ethical challenges will emerge around empowering individuals with information
- Using data to disseminate information to patients should be a priority for health systems

Introduction

Many experts believe that empowering patients with more information and decision making authority as regards their own health and care is a way to break down the traditional barriers between the health system, doctors and patients that limit a patient's involvement in the decisions about their health care. Recent survey results have shown that patients want to make more decisions about their health care, and efforts to empower patients with information and options are a way of achieving this.¹

Further, empowering patients through the aggregation and dissemination of data is seen as a vital component to many of the pressing challenges facing health care. The rise of chronic diseases and patients with complex, multimorbid conditions has increased the difficulty of coordinating care and therefore engaging patients in the management of their conditions will be key to addressing this new reality. Data and digital solutions hold great promise in furthering patient empowerment initiatives.

According to various studies conducted by a number of health care stakeholders and organisations, system leaders looking to encourage patient empowerment should ensure that policies and decisions enhance a patient's:

- understanding of their condition
- participation in making decisions about their care
- self-management of their health and care
- ability to express views and preferences in a way that makes a meaningful impact on their health
- confidence to ask questions and challenge professionals and organisations
- ability to join networks or groups of other patients in similar circumstances.²

Patient Empowerment is likely to be a defining issue over the next decade. Successfully addressing the need for patients to access the right information at the right time will require health system leaders to challenge existing thinking and processes and ensure patients are at the centre of the decision making process.

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◀ Patient Empowerment is likely to be a **defining issue** over the next decade

1. Cordina J, Jones E, Kumar R et al. Healthcare consumerism 2018: An update on the journey. <https://www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/healthcare-consumerism-2018?cid=other-eml-alt-mip-mck-oth-1808&hkid=ea967970a2ee4007b84aa85b319f48ab&hctky=10442193&hdpid=b3f0804e-fa23-4bb3-b2c0-135c6fe21c66>. Published July 2018. Accessed Aug. 20, 2018.

2. All Party Parliamentary Groups on Global Health; HIV/AIDS; Population, Development and Reproductive Health; Global Tuberculosis; and Patient and Public Involvement in Health and Social Care. Patient empowerment: for better quality, more sustainable health services globally. http://www.appg-globalhealth.org.uk/download/i/mark_dl/u/4009611296/4609762637/APPG%20Patient%20Empowerment%20Report.pdf. Published May 2014. Accessed Sep. 22, 2017.

NATIONAL VOICES



National Voices is a coalition of 160 health and social care charities in England. They advocate for people having as much control as possible over decisions that affect their own health and care – as patients, carers and members of communities. They advocate for people to be partners in the design of services and partners in research, innovation and improvement.

Their three priorities are:

- Supporting national policy and system design
- Supporting the vital role that the Voluntary, Community and Social Enterprise sector plays in health and care
- Supporting the adoption and spread of person-centred approaches

National Voices developed the “I Statements” that ensured care plans are person-centred through the appropriate narrative.³

Key principles for empowering patients

Empowering patients requires an understanding of the needs of the patient and actively configuring services around those needs. It means enabling patients to make decisions in conjunction with their care team, and ensuring that the patient’s decisions are respected and supported.

Health systems developing policies to enable patient-centred support should focus on two key themes: personalisation and control, in which patients are actively involved in the discussions around their own health and well-being. To address these themes, NHS England set up the personalised health and care framework, and the NHS England personalisation work group to ensure personalisation and control are incorporated into patient representative activity.

The themes of personalisation and control are credited with encouraging positive changes in behaviour that lead to healthier lifestyle choices. They also contribute to a more coherent and coordinated approach to an individual’s care plan. As an example of putting these themes into action, implementation of Personal Health Budgets in England represented a major step towards patient empowerment. Evidence suggests that personal budgets provided an early success of incorporating personalisation and control into health care finance and delivery.⁴

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Challenges in delivering patient centred support

It is important to recognise the barriers faced by patients who seek to be active participants in their care. More attention should be given to incorporating patients into policy development and decision making at Board level in health care organisations such as hospitals, GP practices and Clinical Commissioning Groups (CCGs) to ensure that policies deliver on specific patient interests and needs. Training is also required for both health care professionals and patients to adapt to this new dynamic that puts patients in greater control of their care.

There are also challenges in communication between professionals and patients. In September 2018 the Academy of Medical Royal Colleges launched an initiative to guide specialists to communicate with patients using clearer language when discussing medical conditions and treatment.⁵ Developing a relationship in which patients and the health care system are more equal partners in the decisions around an individual’s health care will be hard to achieve if communication is confusing to the patient.

3. National Voices. A narrative for person-centred coordinated care. <https://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf>. Published May 2013. Accessed Oct. 22, 2018.

4. House of Commons Committee of Public Accounts. Personal budgets in social care. <https://publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/74/74.pdf>. Published June 8 2016. Accessed Feb. 3, 2019.

5. Campbell D. New drive to encourage doctors to write to patients in plain English. <https://www.theguardian.com/society/2018/sep/04/new-drive-doctors-urged-write-patients-plain-english>. Published Sep. 3, 2018. Accessed Sep. 12, 2018.

Digital delivery in patient empowerment

Digital transformation can enhance the relationship between doctors, patients and citizens. It can enable patients to understand more about their health and be more actively involved in decisions that affect it. Further, digital solutions and campaigns can also encourage and enforce behaviour change; for example, Public Health England's Stoptober campaign that encourages people to quit smoking for 28 days or devices like Fitbits that are designed to increase and maintain an individual's physical activity.

Recognising digital transformation's potential, in 2018 NHS England laid out its '*Empower the person: roadmap for digital health and care services*'. The roadmap presents a series of digital measures that will provide more information to patients and encourage more interaction between individuals and the health system. The goal of the roadmap is for the patient experience to become more personalised with advice, support and care tailored to each individual.⁶ As the health system embraces patient empowerment, its basic guiding principle should be to place patients at the centre of the discussion.

The health system needs to continue developing a mature data ecosystem so that information can be provided to people that supports them to be more active participants in their own health.

University Hospital Birmingham

University Hospital Birmingham (UHB) has developed and delivered digital solutions that directly support patients to be more involved in their care. UHB has developed an online patient portal, called *myhealth*, which allows patients in long-term care to remotely access elements of their healthcare record and upload information including letters from their doctors, prescribed medicines and laboratory results.

Support from the Board of UHB as well as involving patients extensively in the development of UHB's digital road map have been credited as factors for the successful implementation and uptake of the portal. For example, *myhealth* was piloted with 10 patients in what served as a proof of concept to build Board support, and further development occurred only after this support was received. Importantly, UHB's organisational structure treats informatics as a health function that acts as a quality indicator, rather than under the authority of the finance department – an important distinction from the way that other trusts and organisations are structured.

As a result, UHB has measured return on investment through the level of empowerment attained rather than short-term quantitative returns. This allows UHB to develop digital solutions over a longer term, which is essential to developing tools with a deep understanding of patient needs and preferences.

Initial results from an evaluation of the experiences of a selected cohort of *myhealth* users from UHB are promising, showing that:

- 92 % of patients stated they think *myhealth* has been beneficial in improving their involvement in the healthcare they receive
- 24 % of respondents have displayed or reviewed their *myhealth* record during an appointment
- 56 % of respondents reported that *myhealth* has saved them from telephoning the hospital and 12 % that it had saved them from making an appointment
- 24 % of patients stated that using *myhealth* had prompted them to make a call to the hospital

In addition, patients have appreciated accessing health services remotely as it provides greater flexibility — which has led to increased levels of patient engagement. Patients are also able to prepare for consultations by submitting some queries before their appointment to ensure time spent with their consultant is productive and useful. Some patients have set up support networks by connecting with other patients through the portal so as to feel part of a community.

UHB, working with the local Sustainability and Transformation Partnership, plans to extend access to *myhealth* to include information from the wider health and care community and ensure the tool offers a comprehensive holistic wide view of an individual's health status. This extension could lead to broader changes in patient behaviour due to engagement with and control of more aspects of their care.

◀ Information can be provided to people that supports them to be more active participants in their own health

◀ Support from the Board of UHB as well as involving patients extensively in the development of UHB's digital road map have been credited as factors for the successful implementation

◀ UHB has measured return on investment through the level of empowerment attained rather than short-term quantitative returns

6. NHS England. Transforming Digital Health. <https://www.nhs.uk/transformation/>. Published 2018. Accessed Aug. 2, 2018.

PATIENTS KNOW BEST



Patients Know Best (PKB) is an online patient portal that allows patients to access their medical record and empowers patients to manage their health. Uniquely positioned, PKB is able to store information behind the NHS N3 network but also provide access via any web-enabled device.

This platform enables patients to track their symptoms, communicate with their health network, connect different devices and access all their medical information from one avenue. This helps patients to coordinate their care with their care teams and be more informed about the decisions that they take about their health.

In addition to trusts delivering patient empowering tools, patients themselves are developing digital innovations based on personal experiences of uncoordinated care and its effects on patient experience and control. PKB, developed by a patient with a long-term condition, has been rolled out across Surrey and Sussex Healthcare NHS trust for patients of Inflammatory Bowel Disease (IBD).

The tool allows patients to remotely monitor their condition and pre-warn their clinical teams as to flare ups which can be treated before patients require a hospital visit. PKB also allows the clinical team to monitor treatments at scale and ensure patients are administered more appropriate and less invasive treatments.

Patients receiving treatment for IBD across Surrey and Sussex were able to use the information provided in the tool to avoid higher dose treatments that led to negative side effects. Some of the specific benefits attributed to PKB included:

- Reduced side effect rates by up to 30 %
- Increased positive response rates to treatments
- A reduction in hospital visits by up to 40 %
- A reduction in days taken off work by up to six days a year.⁷

Further considerations for system leaders

One of the key challenges encountered by organisations in delivering digital tools for patients involves ethics. It can be difficult for organisations and leaders to determine the appropriate level of information to distribute through a digital portal, and what information an organisation should provide to a patient through other forms of communication.

While it may be desirable for a patient to access information remotely from the comfort of their home, organisation leaders need to contemplate the significance of information being made available. For example, is it appropriate for an individual to receive a diagnosis for a severe life changing disease, such as HIV or cancer outside of a consultation, without a clinician to explain an immediate course of action? Should medical notes that contain terminology that could potentially be misinterpreted be viewed by patients that could cause unnecessary distress? Is there sufficient digital literacy among patients to interact with clinicians in this way or could an initiative that is driven to increase inclusion have the reverse effect and exacerbate health inequalities?

Another area of consideration is how empowerment applies to carers, those who look after others and, particularly, for parents and relatives of young patients. How should patient empowerment be considered in the context of vulnerable individuals unable to make decisions themselves so that they are protected and not exploited? These key ethical questions will need to be explored extensively as more patient information is digitised and the demand by patients to access this information increases.

7. KSSAHSN. Taking the lead on AI Artificial Intelligence in healthcare. <https://www.kssahsn.net/what-we-do/publications-and-resources/innovate/Documents/Innovate%20issue%2012%20WEB%20FINAL.pdf>. Published April 20, 2018. Accessed Nov. 20, 2018.

Further, greater empowerment has led to an increase in medical record access which brings with it more patient scrutiny of their own information. Experience has shown this increased patient scrutiny can take up clinicians' time in the form of patient queries. The system will need to ensure that the information that is available to patients is understandable less likely to require excessive clinician clarification.

Conclusion

As society has become more digitised and people are increasingly empowered across different industries, expectations are changing within the health and care sector. System leaders and organisations should embrace this change and recognise the potential benefits of placing patients at the centre of health and care service delivery.

The expansion of digital technologies in health will lead to difficult conversations around the release of power from within the medical community, a challenge to the existing doctor/patient relationship and the emergence of difficult ethical dilemmas. However with the epidemiological landscape changing significantly, the increasing complexity of disease and the prevalence of long-term conditions on the rise, the health system must enable patients to take a more active role in managing their health – challenging the historic asymmetric clinician vs patient dynamic in health systems.

The digital progress being made across the health and care community will significantly enhance the system's ability to enable patients to be active participants in their health and care needs, and support the system and clinicians to provide high quality health and care services. Available and effective data is instrumental to this aim.

Over the coming decade, the doctor patient dynamic will fundamentally change requiring a more connected more agile more fluid health system tailored to patient needs.



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