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# DOCTOR KNOW

## A KNOWLEDGE COMMONS IN HEALTH

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## INTRODUCTION

**The way we create, access and share information is changing rapidly. Every time we look something up on Wikipedia, rate an experience on Tripadvisor or enter search terms in Google, we are taking advantage of the increasingly sophisticated way in which technology and digital tools are allowing us to capture, refine, synthesise and structure our collective intelligence. With the ongoing advances of the semantic web, new sources of and different applications for data and cultural shifts towards greater openness and transparency, our capacity for creating and navigating complex knowledge grows.**

These trends in the creation and application of knowledge have huge implications for how we access, create and apply information in health, a field where knowledge held by patients, doctors, medical researchers, nurses, carers, community providers, families and others is all critical in improving our individual health and well-being. Where information is vast and complex – and the need for accuracy and reliability can be a matter of life and death – our ability to orchestrate knowledge in a useful way is a central concern for any health system.

In this paper, we argue that society's growing ability to mobilise knowledge from different fields and sources is beginning to show the potential of a 'knowledge commons' in healthcare: an open system of knowledge with researchers, practicing clinicians, patients, their families and communities all involved in capturing, refining and utilising a common body of knowledge in real time. Over the next few decades, this has the potential to reframe our understanding of healthcare as a highly knowledge-centred system, with informed patients able to take more responsibility and agency over their own health, supported by an integrated network of healthcare providers and practitioners drawing on the most up-to-date and relevant knowledge to best care for our needs.

This raises questions: How does the health system tap into the collective intelligence of the different actors involved in creating knowledge about health, and leverage different types of knowledge? What are the opportunities presented by new technologies and digital tools to orchestrate health knowledge in a coherent and useful way? And, how can we ensure that health knowledge remains reliable and accessible to the right people at the right time?

Some components of this system are already in place, or will soon be. The UK Government has committed to making all patient records accessible and available as anonymised data for research by 2015. Cheap biometric sensors, smart phones, telehealth equipment and

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increasingly well-structured patient records will all contribute to a considerably larger data set. This includes not only biomedical data, but data that is broader, more granular and which takes account of patients' whole lives. Advances in digital technology allows us to gather and analyse much larger quantities of data, collaboratively structure and refine knowledge in a more systematic way, and access relevant, useful knowledge in real time.

Cultural and political movement towards greater openness and transparency, campaigns to encourage greater citizen participation in research and ownership of information and the rise of commons-based licensing agreements, consumption models and communities, also have important application in health. Of course, the commons principle of openness presents substantial issues around privacy, and there are legitimate questions about the reliability of knowledge derived from outside a research context. There is also the important aspect of accessibility. Digital inclusion and literacy cannot be a determinant of whether someone can access information about their health. Finding ways to address these issues is fundamental to realising the potential for a knowledge commons approach.

A health knowledge commons has the potential to allow us to better understand and react to our own or another's health in real time. It also has the potential to stimulate innovation in open science and academia, as access to different sources and new combinations of data generate new knowledge about the causes of disease. A knowledge commons will have particular relevance for the kinds of knowledge which the system presently struggles to create: applied knowledge, such as knowledge from ordinary practice, and knowledge about how people respond to conditions in their daily lives. As long-term conditions are the main challenge facing healthcare in the developed world, reliable information that helps people pursue autonomous lives is critical.

This paper contains four sections: firstly, we set out a brief architecture of a knowledge system and the different types of knowledge involved; secondly, we consider the issues with the creation and application of knowledge in the current system, involving healthcare providers, medical academia, patient-held and applied knowledge and considering how this interacts; thirdly, we look in more detail at some key trends mediated by technology, design, data management and presentation that have the potential to change how we orchestrate knowledge in health, with some examples; finally, we consider what this means for the development of a knowledge commons and the steps to get there.

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# 1 A BRIEF ARCHITECTURE OF A HEALTH KNOWLEDGE SYSTEM

One of the challenges in considering a knowledge commons in health is the complexity of the many different types of knowledge involved, their relative utility and reliability. Any attempt at structuring this kind of system would need to respect how different types of knowledge were presented, and be explicit about different degrees of certainty – what knowledge is proven, what is only relevant in a particular context, what is a grey area etc. This section considers what we mean by knowledge in this context, the different uses and users of a knowledge commons in health, and how a knowledge system should work.

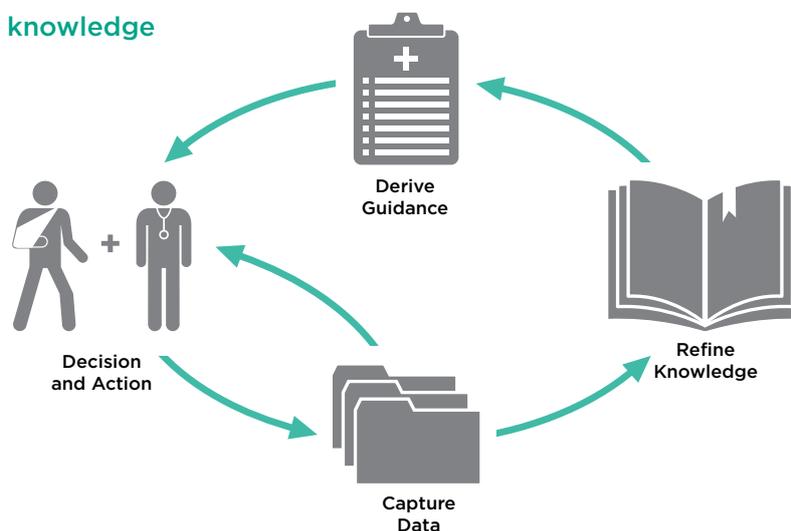
## What do we mean by knowledge?

There are at least two complementary uses of the word knowledge. One is ‘how’ knowledge – the understanding of how to do something, for example tie a shoe lace, speak French, or stitch a wound. This is often referred to as procedural knowledge. The other is ‘what’ knowledge, which is our understanding of what is the case: that Paris is the capital of France, or that a bacterium is the main cause of ulcers. This is propositional knowledge. We hold propositional knowledge for a variety of purposes, but a chief purpose is to help us make decisions about the world.

Here we are primarily concerned with **propositional knowledge that informs decision making about health, by anyone making a choice about their or another’s health** (such as patients, clinicians and managers). These decisions are about more than deciding on the right course of treatment, and include diagnosis, testing, prognosis, referral, screening, self-care, resource allocation and strategic policy.

We also make a distinction between data and knowledge. The former describes a particular state (e.g. a patient’s haemoglobin level or end-of-life preference) while knowledge is widely applicable (e.g. that transfusion will raise haemoglobin levels, but is not usually indicated in someone who is at the end of their life). As well as being a necessary part of an individual treatment decision, data are the raw material for the creation of knowledge, and the job of a knowledge production system is transforming data into knowledge – in the form of theories or models drawn from research which guide our decisions and behaviour and which can be applied in practice. This is described in functional terms in Figure 1.

Figure 1:  
From data into knowledge



For example, how do we learn that diabetes is controlled by insulin, and how do we use that knowledge to improve health outcomes in diabetics? As visualised in Figure 1, data gathered from patient interactions and research is both used to help guide the care of that patient and refined into knowledge, through analysis and distillation into evidence, which is in turn translated into steps to guide treatment or action. This decision and action may be carried out by a clinician, a patient or carer, or an alliance of all three.

### What sort of knowledge system do we want

**We want knowledge that guides us to the right decision as often as possible. That is to say we want knowledge that is precise, applicable, accessible and relevant.**

Firstly we want knowledge that is **relevant** to our concerns. There is more value to knowledge about common conditions than rare ones, all other things being equal. Similarly we would wish our knowledge to cover the range of possible influences on health. We therefore need a variety of different kinds of knowledge, including:

- **Clinical knowledge** tells us about how to make a diagnosis and what treatments cure or ameliorate diseases. It is the body of knowledge that guides clinicians and patients in predicting and altering the course of disease: which drugs, surgical techniques or therapies are effective in improving outcomes. While this body of knowledge is informed by biomedical knowledge, it is quite common to know how to treat a condition without knowing exactly how the treatment works. Similarly, medical understanding of a disease might not necessarily mean having a clear idea of how to do anything about it.
- **Experiential knowledge** is knowledge about how a condition manifests itself, such as knowledge of pain or of particular symptoms, and the impact of disease on quality of life.
- **Contextual knowledge** is knowledge about how healthcare best happens in practice, under uncertain conditions, with constrained resources, and against the backdrop of people's real and complex lives, geographies and social interactions. Contextual knowledge requires a degree of judgement, interpretation and intuition.

Secondly a great deal of our health knowledge occupies a middle ground between certainty and ignorance. Conditions and treatment are often understood in general terms, but knowledge might be limited in relation to specific cases. A good knowledge system gradually improves the **reliability and precision** of our knowledge, from knowing what factors are relevant, to be able to predictably improve outcomes on average, to finally being able to tailor a treatment to individual patients. A good knowledge system would slowly increase the range, reliability, and precision of our knowledge, reasonably quickly and cheaply.

Thirdly we want knowledge to be applicable in practical circumstances. This means that our knowledge must contain not only general theories, but also knowledge of how to apply these theories in practice – the appropriate diagnostic tests, and management plans to make treatment successful, and understanding of how treatment is affected by and works in context.

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There are many different individuals involved in creating and applying different types of knowledge, including:

- **Highly engaged patients** – people living with a particular disease who are actively involved in learning about their health, either as a consequence of the severity of a particular condition and its degenerative factors, such as motor neurone disease, or with a view to preventing a disease's development, such as cancer.<sup>1</sup>
- **Engaged patients** – people living with a long-term condition that requires on-going monitoring and treatment, such as diabetes, asthma, depression or heart conditions.
- **Families and carers** – people involved in supporting another's condition who want to find out more information about suggested tests or treatment.
- **Clinical practitioners** – specialist and general clinical practitioners working within a hospital or general practice setting who need access to up-to-date knowledge.
- **Community health practitioners** – community nurses, carers, specialist health workers, health visitors, pharmacists, opticians and other service providers.
- **Researchers** – academics and researchers within academic institutions and universities, medical colleges and teaching hospitals, and within R&D functions of pharmaceutical companies, medical device developers and other businesses.
- **Businesses** – including clinical service providers, medical technology producers.
- **Commissioners** – clinical commissioners concerned with the efficient and effective purchasing of drugs, treatments, services and so on to achieve health outcomes for a specific population.
- **Citizens** – people not formally engaged with the health system but wanting to access information about public health, lifestyle and preventative care, such as diet, exercise, social and demographic factors, directory services and so on.

These various groups access and apply the types of health knowledge differently. For example, a patient wanting to learn more about their particular condition would benefit from access to experiential knowledge of others living with the same disease. This knowledge, although not formalised within the medical arena, may be extremely beneficial to a patient making a choice about a course of treatment, if only as a comparison. However, a clinician might draw on experiential knowledge in prescribing treatment, but would not want to rely on this for diagnosis. Any knowledge system must therefore make the relative reliability of sources' knowledge clear so as to guide decision making in a legitimate and safe way.

In addition, we must be clear about the uses of knowledge. Health knowledge exists to guide a whole range of clinical actions: diagnosis, testing, treatment, prognosis, referral, screening, and so on. A knowledge system must also be structured so as to reflect who needs what knowledge, at what points in time and in the most relevant format. What is the right architecture for a system to ensure that the right people access the most relevant, reliable and useful knowledge? How to account for different levels of confidence in application and interpretation of knowledge? What are viable options for structuring knowledge, acknowledging bias, and taking account for a variety of applications?

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## 2 WHY A HEALTH KNOWLEDGE COMMONS?

**The success of modern medicine is one of the crowning human achievements of the 21<sup>st</sup> century. Infectious diseases such as tuberculosis, diphtheria, cholera, measles, polio, yellow fever and smallpox – once common killers – are now virtually eradicated in developed countries. More recently, huge strides have been made against cancer, HIV/Aids and forms of chronic disease such as stroke, diabetes, dyslipidaemia and ischaemic heart disease.**

The UK in particular benefits from an extremely sophisticated institutional system supporting the health knowledge cycle, including research councils, universities, evidence centres, centralised intermediaries such as the National Institute for Clinical Excellence (NICE), clearing houses such as the Cochrane Collaboration and NHS Evidence, strong professional development and teaching bodies, medical networks and a plethora of established medical journals such as the British Medical Journal (BMJ), and distribution channels such as the Medical and Nursing Royal Colleges and teaching hospitals. The NHS as the national public health service brings huge advantage in co-ordinating this system at a national scale.

However, all healthcare systems today face a new set of challenges and opportunities, which offer the potential to address some of the limitations of the current ways in which knowledge is generated and applied in health and respond to the way in which the health system as whole needs to change in the future. Firstly, the changing scope of data and health knowledge given the changing nature of disease; secondly, the process of refining data into knowledge; and finally, applying this knowledge in practice.

### The changing scope of data and health knowledge

Many have observed that there is a substantial need for innovation in the models of healthcare delivery, given the changing nature of disease and the pressure on health systems from the costs of managing long-term health conditions and providing more complex treatments.<sup>2</sup> In part as a result of such advances in curing disease and improved longevity, the dominant demands on the system come from treating chronic diseases such as chronic obstructive pulmonary disease (COPD), diabetes, asthma and heart failure. Supporting patients living with these conditions to live autonomous lives requires a different sort of healthcare supported by different sorts of engagement, as is summarised in Table 1.

**Table 1: The changing model of healthcare (based on a table in the Kerr report into the future of the NHS in Scotland, 2005)<sup>3</sup>**

Old model of care	New model of care
Focus on acute conditions	Focus on long-term conditions
Reactive management	Prevention and continuing care
Hospital centred	Embedded in homes and communities
Disjointed episodes	Integrated with people's lives
Doctor dependent	Team based, shared record
Patient as passive recipient	Patient as partner
Self-care infrequent	Self-care encouraged and supported
Use of information and communication technology (ICT) rare	Dependent on ICT and devices

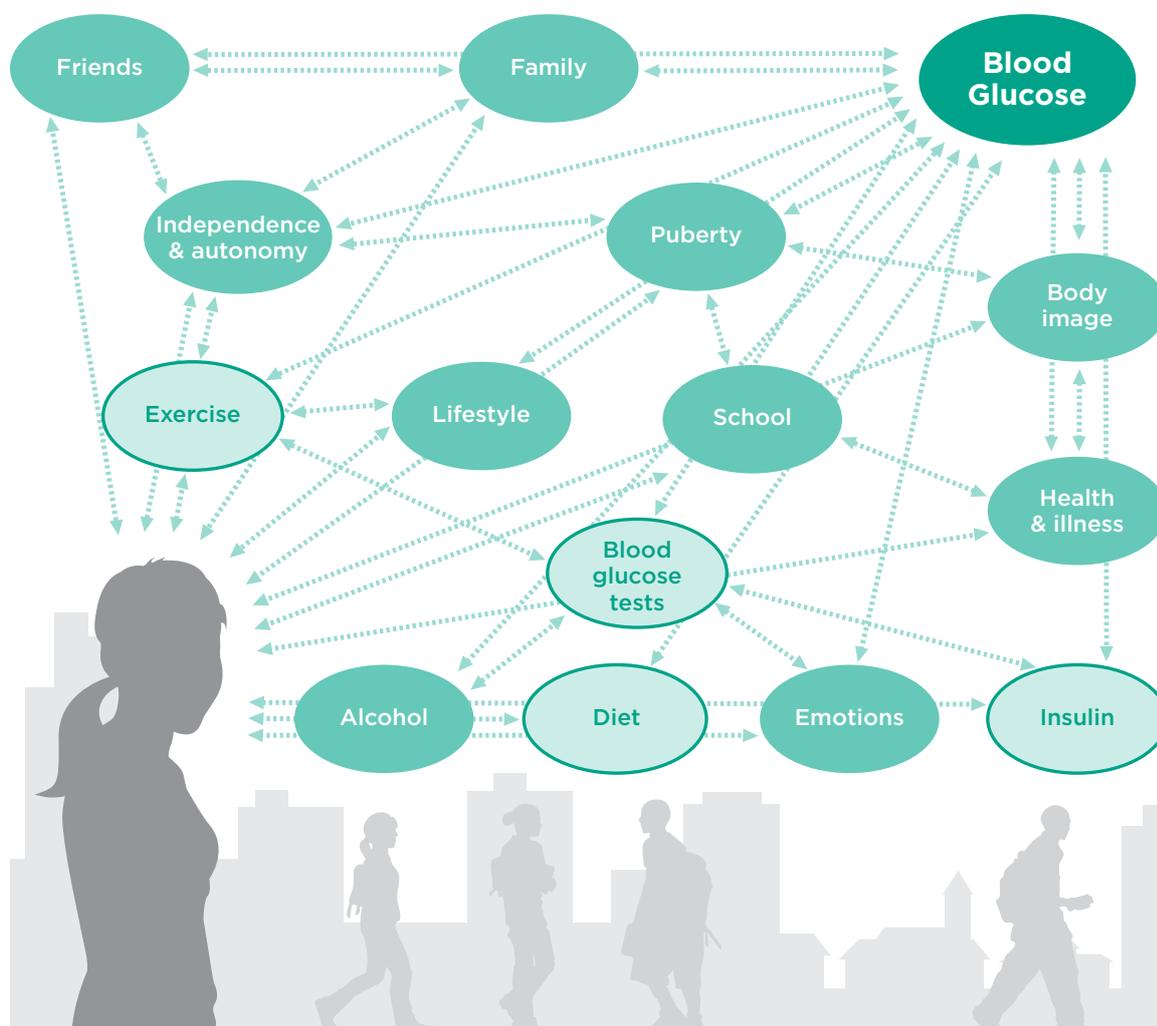
Table 1 contrasts the reactive, doctor-centred model of old with the emerging model in which the doctor is supported by a wide range of other professionals – and increasingly, by the informed, autonomous patient. Information and communication technology play an important part in this new model, but need to be accompanied by a shift in attitude and professional culture towards what we could call *clinical subsidiarity* – devolving clinical decisions to the person closest to the patient, which may often be the patient. This has been enshrined in recent health policy in the phrase “*no decision about me without me*”, which should perhaps evolve to “*decisions about me made by me*”.<sup>4</sup> This has significant implications for the way in which knowledge is orchestrated in health.

Firstly, the move to promoting wellness and the long-term management of chronic conditions changes the objective of medical knowledge, exposing the fact that **health can in many cases be defined by the ability to live an autonomous life rather than by physiology alone**. When an absolute cure is possible, this distinction is not particularly important – restoring physical condition maximises autonomy as far as the clinician can affect it. However, when this is not possible (such as with chronic disease), maximising autonomy becomes central. Clinicians and patients need to work together to help elicit the patient's preferences, set appropriate goals and responsibilities in the management and treatment plan, co-design health services and software applications that respond dynamically to changing circumstances and unforeseen events, and equip patients to make informed and effective decisions in their day-to-day lives.

For example, an accurate prognosis that allows a patient to know if they will be in good or poor shape tomorrow would be invaluable, even if it made no actual difference to health outcomes, as it would allow people to plan their lives, rather than be prisoners of their condition. In making decisions such as these, it is important to note that the experts on coping with the complexity of life with a long-term condition are not doctors but patients; so gathering, validating and sharing their knowledge becomes critical.

Secondly, **more account needs to be taken of complex non-physiological factors** that have a significant effect on health outcomes. Social, emotional, behavioural and practical factors all combine in a complex web in the management of long-term conditions. Consider a diagnosis of childhood diabetes; for both the child and their whole family, this can require complex and profound adjustments. Figure 2 shows some of these.

Figure 2: The complex interacting system of adolescent diabetes management



Thirdly, medicine currently fails to **learn from routine management**. For many diseases, development of the best management approach is an iterative process. Patients are individuals, who often have multiple co-morbidities. Further, standard medical knowledge is far from a complete recipe, and doctors often go beyond established protocols. Treatment effects are somewhat uncertain, and there is a considerable need for adjustment and iteration before the correct course is found. Indeed the negotiation of this process is one of the key skills of the physician. What this means is that there are thousands of small-scale undocumented experiments taking place in surgeries and hospitals across the country every day. However, we currently do not extract any learning from these for the system, which stays with the individual physician, if they are able to make use of it.<sup>5</sup>

### Reliability

As is often acknowledged, the process of refining data into knowledge – even when it concerns the formal research process – is **somewhat unreliable**. In a now famous paper in *JAMA*, John Ioannidis examined the most cited papers (1,000 plus citations) in the best regarded journals in the world – largely drawn from *The Lancet*, the *New England Journal of Medicine* and the *Journal of the American Medical Association*. Of those with claims

of efficacy whose results had been tested, 41 per cent were either found to be wrong, or the impact was much smaller than the original study suggested.<sup>6</sup> Sponsorship of trials by the pharmaceutical industry may be part of the explanation, but given that randomised controlled trials with hundreds or thousands of participants represent the gold standard in research, the reliability of smaller studies published elsewhere is likely to be lower.

Whether Ioannidis' results are explained by the nature of science or bias, there does seem considerable opportunity to improve. And indeed there is considerable effort to improve the quality of research results, by the use of higher evidentiary standards, reporting guidelines and more emphasis on meta-analyses (for example the Equator network).<sup>7</sup> However, this more careful approach seems likely to exacerbate a second problem. The progress of an idea from inception to the publication of an influential article that demonstrates clinical efficacy is slow – a median 24 years.<sup>8</sup> While larger trials with more careful follow-up may improve the reliability of results, they might also slow down the already **glacial pace of generating research results**.

Further to this, the creation of applied knowledge has been comparatively neglected.<sup>9</sup> As mentioned above, applied knowledge is knowledge about how treatment is implemented in practice, under uncertainty, constrained resources, and against the backdrop of real and complex lives. It includes knowledge about how to diagnose a condition, how to balance risks in deciding on a course of treatment, and how patient and clinician can work together to deliver that treatment in an effective chronic disease management programme. This encompasses understanding of organisational processes. Healthcare is not a craft practiced by individuals, but a service delivered by a complex system involving many individuals and institutions. The way this system is arranged has profound consequences for health outcomes.

However, while this area is vitally important to health systems worldwide – probably more so than uncovering the molecular mechanisms of disease – it is challenging to fundamental research, and consequently has only received a fraction of the investment of biomedical science. Improving how a condition is managed often requires a complex service redesign, composed of many individuals and interventions whose effect together creates the impact. This can make a full RCT challenging,<sup>10</sup> though the Medical Research Council (MRC) has led work on understanding this challenge.<sup>11</sup>

## Applicability

A pragmatist would argue that clinical knowledge is only useful when it guides patient or professional decision making, and thus improves health.<sup>12</sup> For professional knowledge to be applied successfully to an individual patient, four things have to be in place:

- A clear description of the current status of the patient, their problem, their capabilities and preferences for diagnostic and treatment options – usually held as data in the medical record;
  - Access to the relevant medical knowledge;
  - Application of that knowledge to the specific patient to create a management plan, including where appropriate a course of treatment;
  - Successful execution of the management plan over time.
-

All of these stages can be problematic. First, clinicians still often do not have access to all the relevant patient data when they need to make a decision. Second, the body of medical knowledge is now so vast and growing so quickly, that it is becoming humanly impossible for unaided healthcare professionals to deliver patient care with the efficacy, consistency and safety that the full range of current knowledge could support. PubMed, the online database of medical research, has 21 million articles, with 500,000 being added every year – and a doubling time of 19 years.<sup>13</sup> The capacity of individuals to access the most current, high-quality knowledge pertaining to their practice or specific cases remains a challenge (if not an insurmountable one).<sup>14</sup> Third, application to the individual patient sometimes requires complex logic to be followed (e.g. which combination of chemotherapy drugs is most likely to be effective and minimise side effects) or calculations (e.g. of drug dose) to be carried out, and often remains a challenging expert judgement. Further, even when the knowledge exists and is well synthesised and understood, it is extremely easy in the course of a complex activity for mistakes to be made – for the knowledge to be applied incorrectly.

As **effective self-care becomes increasingly important**, knowledge needs to be made useful to support patients to care for themselves. Patients with chronic conditions typically spend the vast majority of their time away from a clinician, so their health outcomes will be critically affected by lifestyle and behaviour. Anything that highlights early warning signs, allowing patients to take action to avoid a deterioration or crisis in their condition, would be very significant. Motivational help e.g. to support medication adherence is also important in this context; a long-term condition can test one's emotional capability and resilience, and active and determined self-care of a serious health condition is a challenge for anyone.<sup>15</sup>

Of course medical knowledge is complex, and patients will continue to rely on clinical interaction to manage their treatment to a certain extent. However, it would be complacent to assume that people are as informed and as active in their own self-care as they could be. When long-term conditions are the main medical issue for around 17 million people in the UK, a passive patient population and over-reliance on a medicalised model of knowledge cannot be the answer.

### The paradox of health knowledge

This list of issues, while perhaps not wholly consensual, is not particularly controversial. Our more substantial point is that, despite the sophistication of the UK's current health knowledge system, we are not drawing on this knowledge as best we might to improve our health. It is perhaps a paradox that as our knowledge base has grown, it has become increasingly difficult to navigate and make use of in order to improve care and outcomes.

How could a commons approach address these issues? How in the future can the health system draw on new sources of data, new modes of distillation of data into knowledge, and new ways of applying that knowledge in practice? What sort of system could make different kinds of knowledge available for different applications?

### 3 THE POTENTIAL FOR A HEALTH KNOWLEDGE COMMONS

In essence, a knowledge commons is defined by the principle that knowledge is a shared resource made accessible and intentionally open – rather than subject to ever greater restrictions through intellectual property legislation, patenting and licensing. The concept of a knowledge commons has developed in line with the expansion of digital information, as digital platforms offer unprecedented access to information through the Internet and the tools to create and share knowledge openly online. Pioneers of the knowledge commons movement include Wikipedia as an online, collaboratively-built encyclopaedia, Linux and the open source software movement, Creative Commons licensed art and open scientific collections such as the Public Library of Science or the Science Commons.<sup>16</sup>

The notion of a knowledge commons in health implies a system where participants share data and knowledge openly with a view to accelerating improvements in health outcomes, through discovery of new drugs or pathways of self-care and clinical research, better application of knowledge and more self-care and prevention through more informed citizens taking more responsibility for their own health. The components of a commons might include databases on the results of clinical trials, libraries of drug and chemical compounds, computational models predicting drug efficacy or side effects, shared tools or methods for research, practice and innovations in service design, personalised data analysis based on demographic, behavioural or health data and comparisons with others, with a personalised interface and interactive system.<sup>17</sup>

Given the highly sensitive and complex nature of health, a health knowledge commons would need to have the right regulatory and governance system, and the means of sanctioning and highlighting the varying reliability of knowledge and degrees of uncertainty. The quantity of medical information that is produced is huge, and beyond the practical ability of most clinicians to keep abreast. Some degree of aggregating and filtering is therefore necessary to ensure the most relevant information is available to the person who needs it and the means of illustrating varying interpretations of data according to perspective.<sup>18</sup>

Though perhaps still difficult to realise as a whole, there are a number of key current trends that begin to illustrate what a knowledge commons in health might achieve. Firstly, our increasing ability to capture and process ‘big data’ that can illuminate different perspectives on what affects health and well-being; secondly, collaborative analysis tools that facilitate distributed problem solving and the generation of new knowledge through combination; finally, a commitment to openness and transparency.

#### Capturing and assembling big data

According to Moore’s Law, the number of transistors in integrated circuits has doubled every two years over the history of computing hardware. That’s to say, the ability of our computer systems to process and hold information is growing exponentially, and is continuing to do so. As memory and processing speed gets faster, so the amount of data we can interpret gets bigger, leading to new advances in areas such as genomics, nuclear physics and biomedical research. The data science historian George Dyson describes the big data phenomenon as “*when the human cost of throwing away data became higher than the machine cost of storing it*”.<sup>19</sup>

Presently most formal knowledge in healthcare is based on data gathered in the research setting. However, while more data does not necessarily equate to more knowledge, there is a clear opportunity to learn from the routine practice of medicine, and more broadly from

patient's whole lives. Progress in understanding has often grown alongside changes in our ability to gather and analyse data. This is perhaps best seen as an increase in resolution; we are looking at the same phenomena, but seeing in more detail.

With advances in mobile phones and home-based sensing devices, we also have access to much richer sources of longitudinal data, allowing us to capture more granular data in real time relating to people's lived experience of disease, behaviours, physiology, social networks or health outcomes.<sup>20</sup> As a result, much of the opportunity in future will be to extract knowledge from information gathered outside the research context, in a practical setting. This data will come from a variety of sources:

Firstly, from existing data that is made more accessible. In the course of their ordinary clinical interactions, patients and doctors already generate large amounts of data. Historically much of this has been inaccessible, either held on paper or in databases that cannot effectively share the information. However this is rapidly changing, with existing data being able to move around the health system in a much more effective way via open patient records (anonymised where appropriate). The direction of NHS policy is to open up far more data and information. The NHS Information Centre has already published data including presenting and prescription data from all GP practices in England – data that was previously proprietary – with the purpose of making this data more widely available for improvement and innovation.<sup>21</sup>

Secondly, from rich data recorded as part of ordinary clinical practice. Following promising results from large-scale telehealth trials we know that health outcomes for some people can be improved through real time monitoring.<sup>22</sup> At the moment this is a fairly expensive exercise, due to the cost of the equipment and support. However if this cost can be reduced, then real time monitoring of some patients with chronic conditions could become part of normal practice. For patients at risk of stroke or heart attack, it seems plausible that real time data could provide crucial early warning signs, as we develop more sophisticated ways to analyse the data.

Thirdly, patients will record data for their own reasons. **PatientsLikeMe** is a well-rehearsed example of this, but it deserves revisiting.

## PatientsLikeMe

PatientsLikeMe (PLM) is an online platform where patients with life-altering conditions share structured information about their symptoms, treatments and outcomes. Members can view this data as individual-level graphical health profiles and aggregated reports, discuss health and offer and receive support on forums and through private messages. As of August 2012, PatientsLikeMe has 160,000 users with over 1,000 conditions being recorded. Similar to other online communities, members of PatientsLikeMe 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 each other by referring to concrete data displayed for each member. The members of PatientsLikeMe 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.

PatientsLikeMe also publish this data in peer-reviewed journals, such as in a study published in *Nature Biotechnology* to explore the impact of the drug lithium on ALS patients using data collected from the open platform and a patient-matching algorithm.

PatientsLikeMe allows patients to record the progression of their condition, and compare that to a projected prognosis. This puts them in the position of being able to judge whether changes in their treatment, diet or lifestyle or other factors are likely to be making any difference to the progression of their condition. While the validity of these judgements does depend crucially on the quality of the prognostic model, and the good sense of patients, PatientsLikeMe does clearly demonstrate the enthusiasm of patients for recording quite detailed data about their treatments, lives, and progress, where that data can be put to use by them. In the areas where PatientsLikeMe is strongest (for example amyotrophic lateral sclerosis (ALS)) it now has more data on patient progression than any clinical trial that has ever been conducted, though with the caveat that there may be an element of bias with a subset of patients who enjoy recording their data.

Similar sites allow individuals to record their mood (e.g. Moodscope), mobility (e.g. MyClinical Outcomes), and a host of other details. And indeed for some individuals there seems almost no limit to what they are prepared to record.

## Quantified Self

The Quantified Self or movement refers to a growing grassroots network of individuals who monitor, track and quantify their health and well-being using a variety of metrics and conducted through monitoring devices. Adherents utilise embedded devices, such as the FitBit activity monitor, to collect detailed data on their health and mood with the goal of optimising their well-being. This information is then uploaded to online platforms which contextualise the data and provide advice based on it. These emerging technologies are prototypical models of how individuals can accumulate and share information on their health independent of formal institutions, and demonstrate the democratising impact of personalised health technologies on individual health and well-being.

As an example of a Quantified Self technology, Jawbone UP is a wristband which interacts with an iPhone app to record information on an individual’s activity, sleep quality and eating habits. In utilising the online platform, users can communicate with each other and share their quantifying experiences. Jawbone UP – and other devices of this sort – in combination with smart phones, represent a newly affordable purchase for those interested in monitoring their health. They also represent the advent of widespread data-sharing which could be hugely significant for healthcare.

Patients will also gather data that is not directly related to a health condition, but concerns their health or well-being in a general sense. An interesting example of this is Myfitnesspal.<sup>23</sup> This app allows the user to search for the calorie content of everything they eat, and to record their exercise regime, giving a net calorie intake or deficit for the day. This can be compared with their weight loss goals to help them reach a target weight. This application is backed up by a large database of food products (more than 1.9 million). The app can be combined with a wearable sensor (FitBit) which tracks how many steps you take per day, altitude climbed, and sleep cycles. This site is therefore gathering a rich dataset about people's diet and exercise. Correctly analysed, for example using Mendelian randomisation methods, this database has the potential to get closer to an answer about what works with respect to maintaining a healthy weight, a question that presently lacks a rigorous answer.<sup>24</sup> Imagine dietary advice based on real successes and failures, rather than the subjective, biased and unsupported advice that tends to dominate the dieting industry at the moment.

Another interesting dimension to big data in healthcare will be the social connections of patients. We now know that certain health risks are affected by the social networks in which individuals are embedded, for example obesity.<sup>25</sup> Facebook and other social networking sites can give us a clear picture of the social connectedness of individuals. Geotagging and apps such as foursquare can tell us how people are interacting geographically.<sup>26</sup> Personal finance apps such as Mint can let us know how people spend their money.<sup>27</sup> Presently the data to draw these sorts of conclusions about social influences comes from a small number of very detailed cohort studies, such as the Marmot study on the impact of stress at work on health. Big data could produce information of even greater richness, on a far larger scale that could inform new methods for analysing cause and effect, such as Mendelian randomisation or well-calibrated prediction rules (albeit with challenging applications in practice).

Overall, then, we are now building datasets that are extremely large and contain granular data about real patients, including a much fuller picture of their lives, including diet, exercise, and other lifestyle factors, and showing both the treatment they received and the outcomes they achieved. Of course it must be noted that these data relate to treatments that are not randomly allocated, which present considerable issues to which we return below.

### Collaborative structuring and analysis to refine data into knowledge

People have always collaborated as a means to solve problems and create new knowledge. Yet today's digital tools and processes make it possible to collaborate faster and at a much greater scale than ever before. Online platforms allow people from all over the world to come together and solve problems or contribute to a growing knowledge base in a more distributed way, allowing us to work together to refine, interpret and make use of complex information.<sup>28</sup>

Though there are still relatively few examples, collaborative platforms that allow individuals within or beyond the health system to input structured information relating to health outcomes and that facilitate problem solving in relation to health research challenges, demonstrate the opportunity for a commons approach to health knowledge.

An example of Internet-based professional collaborative rating in healthcare is MORE, the McMaster Online Rating of Evidence tool used to select the most appropriate content for the Evidence-Based series of journals and the McMaster PLUS evidence service.<sup>29</sup>

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## McMaster Online Rating

The McMaster Online Rating system is an online information management system that assesses the quality of evidence resulting from medical research, and tailors its alerts to newly published evidence sent to clinicians according to their clinical disciplines. The system hierarchically organises medical information using a qualitative metric, and alerts physicians to the latest and most relevant developments in their field. Within the context of the health commons and the future of healthcare more broadly, its significance lies in the fact that it represents a means of applying precision medicine. By utilising the specified evidence provided by the system, physicians can personalise their treatments and apply more specialised research results to treat individual patients – a step away from population-based medicine and towards personalised healthcare.

In MORE, the central office pre-filters the huge number of new publications in the 110 highest yielding journals potentially relevant to informing clinical decisions, using relevance and methodology criteria. The results of this stage – usually about 6 per cent of each month's publications – are then divided up by clinical specialty and extracts sent to selected individuals drawn from a global network of over 8,000 practitioners for final rating (including 4,000 physicians across 61 disciplines, 3,000 nurses across 36 care specialties, and 1,000 rehabilitation professionals in 21 areas of practice).

The rating criteria are novelty and relevance to practice, and each article is judged independently by between three and 20 clinicians (i.e. three to four per relevant discipline). The central office only writes its carefully worded, structured abstract summarising the key study methods and findings if there is close agreement of all raters on both of these criteria. Articles that score less highly but retain clinical relevance and interest are disseminated e.g. through Evidence Updates. Those using MORE to rate articles describing primary research rate them high for novelty but lower for relevance to practice; for systematic reviews the reverse is true.

To be successful, other collaborative models will need to build on infrastructure already in the public domain, complementing and supporting existing efforts at sharing information whilst drawing relevant data from them. One fundamental characteristic to create an open and collaborative model is a clear code of rules for accessing and sharing data; a founding commons consensus, set out in a constitution (such as through 'social chartering').<sup>30</sup> Pre-negotiation of the terms and conditions of access to data, but with enough flexibility to permit the adaptation of prices and conditions of access to changes in circumstance and demand, is a critical part of this process. Clarity in this area would provide a major public and private benefit of the commons model: liberating patients, researchers and health care practitioners from the legal blocks which hinder progress in traditional collaborative medicine.<sup>31</sup>

## Fold-It

Fold-It is an online computer game that engages its players in a collaborative research project about the dynamics of protein folding prediction and the degree to which human protein folders are more effective than computers at protein structure prediction. Puzzles on Fold-It ask players to predict the structure of a protein based on its amino acid structure, with a goal of eventually having human folders working on unknown protein structures and automating the strategies humans come up with to improve software. Data from the game is captured and used to drive research into processes for analysing protein structure, in essence becoming an effective collaborative research platform.

Effective collaboration is made easier by knowledge being structured, with clear and unambiguous statements of what the relevant data is, and exactly how to draw conclusions from that data. Algorithms which underlie risk stratification tools are a form of structured knowledge. Patient histories are fed into it, and a risk rating comes out which helps make decisions with respect to that patient or group of patients. As long as the prediction made is accurate (both discriminating and well calibrated) this prognosis might help them make judgements about whether any changes in their lifestyle or treatment are genuinely helping.

Another example of structured knowledge is clinical decision support. This has been an active area of research and innovation for many years, with well-developed ways of translating clinical guidelines into systems which automatically read off patient data and apply relevant guidelines to produce contextual and helpful advice for the clinician in deciding on treatment. Through sophisticated languages such as 'PROFORMA' we are already able to represent clinical guidelines in this way, but usage is still not mainstream.<sup>32</sup>

Effective collaboration depends on knowledge being structured in a way that means the most relevant data is inputted and produced. Structured knowledge is analogous to structured data. For example, the algorithms which underlie risk stratification tools are a form of structured knowledge. Patient histories are fed into the algorithm, and a risk rating comes out which helps make decisions with respect to that patient or group of patients. As long as the prediction is accurate (both discriminating and well calibrated) this prognosis might help them make judgements about whether any changes in their lifestyle or treatment are genuinely helping.

As this knowledge takes the form of explicit links between input and output, the logic and probabilities involved can be exposed for anyone to see, and more importantly, to adapt. Structuring knowledge in this way makes large-scale collaboration possible, opening out the process of encoding clinical knowledge into treatment to a wider range of participants to propose improvements to the model, or adapt it to a slightly different patient group. There are already examples of this in practice; PatientsLikeMe has published over 27 research studies based on data collected by patients.<sup>33</sup>

## Openness and transparency

We are experiencing a substantial cultural and technological shift towards much greater openness and transparency in what data we share and expect to be shared. Ubiquitous social networks and social media platforms make more information more openly available. Governments, businesses, research institutions and public services are all increasingly making commitments to transparency and opening up their data for others to use.<sup>34</sup>

Confidentiality of medical data and privacy concerns about identifiable data are an important consideration in health, concerns which are at odds with the concept of a knowledge commons that is defined by openness. By law in the UK all medical information that can be linked with a specific individual is treated as highly confidential, and cannot be processed (held or used) without the explicit and informed consent of the individual.<sup>35</sup> Less confidential but still identifiable data cannot be used or shared outside of its limited original purpose. Where the data cannot be linked to a specific individual, typically because it has been anonymised in some way, the rules on the research use of this data are becoming more relaxed.

The NHS Information Strategy revealed this Government's intention to work towards greater transparency with health data, and the NHS Information Centre is obliged to publish increasing amounts of data on performance, clinical outcomes, prescriptions and complaints. This agenda is tightly bound to the intention to make each patient records information available to that patient by the end of this parliamentary term, and to make anonymised patient data open to researchers. However, openness is more than just the release of data. This needs to be matched with a cultural shift in the way in which healthcare professionals and patients can access information, with the right incentives to record relevant data at the point of care and the right skills to interpret data correctly.<sup>36</sup>

Such a culture of openness has significant implications for research. As suggested above, one of the issues in assuring the reliability of medical knowledge is publication bias, and the commercial and academic tendency to promote positive rather than negative results. This lack of openness limits our ability to collectively learn from both positive and negative findings, and the currency of publication and citation creates the incentive for researchers to withhold rather than share data and discovery. Open Clinical is an example of a research project based on more of a commons approach, where knowledge bases for protocol-based decision support systems is shared and learning is collaborative, with a goal of optimising knowledge management in medical practice.<sup>37</sup>

## Open Clinical

Open Clinical is an online collaborative effort involving organisations, companies and individuals operating through open access websites with the goal of optimising knowledge management through decision support in medical practice. It operates primarily through a portal providing access to developments in medical decision making, journals, directories of protocol representation languages and relevant products, and encourages discussion and contribution from all members. Open Clinical is an excellent example of a collaborative effort involving researchers, industry and healthcare professionals, and provides a model for future efforts in this area. Important characteristics include simplicity and ease-of-access, encouraging contribution and perpetual refinement of its information, and its niche of delivering specialised information to a diverse audience of both patients and professionals.

## What might a health knowledge commons mean in practice?

If more and better data, collaboration tools and a principle of openness are the components of a knowledge commons in health, what are the outcomes? Where might a commons approach hold particular value and what innovation would it lead to? We think there are four important areas where this approach to orchestrating knowledge in health will create value:

- **Research and discovery** – both in evaluation of the significance of clinical findings for diagnosis, prognosis and the efficacy of treatment and in generating hypotheses and prompts for new discoveries.
- **Diagnosis and prognosis** – to more accurately predict the progression of disease, and diagnosis and treatment based on real time, dynamic information.
- **Changing relationships** – when people feel better informed, they are able to take more control. The ability to not only access but also generate useful knowledge about health is an important prerequisite for a more balanced and equal relationship between patients and clinicians, and the spread of decision support tools.
- **Prevention and wellness** – more accurate knowledge about which habits and risk factors affect our health should encourage more self-care and personal responsibility, shifting the focus of health from illness and treatment to wellness and prevention.

### Research and discovery

The simplest way to use data to improve our knowledge is to confirm that new treatments are fulfilling the potential they showed in clinical trials. The generalisability of the results of even well-regarded clinical trials is far from perfect. While this is to be expected, it does mean that drugs and treatments can be adopted incorrectly. Take the example of SSRIs such as Prozac. The most authoritative meta-analysis suggests that these have no clinically significant effect on any but the most depressed patients.<sup>38</sup> If this is true, many billions of pounds have been wasted globally over the last few decades. In a knowledge commons, it would be possible to know much sooner what was happening to patients prescribed SSRIs, and to spot early on that trial results were not being replicated in practice.

More and better data as generated through a knowledge commons could also generate new hypotheses or provide prompts for new discoveries. The history of medicine is replete with examples of clinical discoveries which result from a correlation being spotted somewhat serendipitously. For example, the initial insight that led to the discovery of steroids happened when Philip Hench of the Mayo Clinic noticed the remission of rheumatoid arthritis in those who were suffering from jaundice.<sup>39</sup> This led to a hunt over many decades for the agent that caused this remission, and eventually to the discovery of steroids. Medical treatments have often emerged from examining a correlation that seems surprising and potentially beneficial, and isolating the drug that causes it; with the treatment coming in advance of any understanding of the underlying mechanism. In fact examples of new treatments being designed, based on a fundamental understanding of disease processes are relatively few and far between. The promise of genomics was to facilitate exactly this process, but progress has not lived up to expectations.<sup>40</sup>

With the increasing specialisation of medicine and research, there are a declining number of clinicians who both carry out research and treat patients.<sup>41</sup> People who are both in a position to spot an interesting correlation, and are primed to recognise its significance are relatively low in number. The medical profession is increasingly split between researchers

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and practitioners, and research into basic medical science is incentivised by the publication of articles, not the creation of new treatments.

Open and linked data could help the research community – and patients – to identify any number of surprising correlations which are presently hidden from them, and will probably do so more effectively than the previous serendipitous system. It could also include data on a broader range of factors, including social connection, diet, exercise and stress, which are hard to include in a trial setting. These correlations will then need to be confirmed in more controlled settings, but even if only a fraction prove to be robust, this will be useful.

The points made hitherto are about prompts for further research, rather than anything that can provide evidence of a causal link. A more ambitious possibility is to add to learning about the causes of disease from routine data. As has been mentioned, treatment is often a trial and error process. Patients are individuals, who often have multiple comorbidities. Further, standard medical knowledge is far from a complete recipe, and in some conditions doctors often go beyond established protocols. Treatment effects are somewhat uncertain, and there is a considerable need for adjustment and iteration before the correct course is found. Indeed the negotiation of this process is one of the key skills of the physician. What this means is that there are thousands of informal, undocumented micro-experiments going on in surgeries and hospitals across the country every day. However, we do not extract any learning from these for society, so any learning stays with the individual physician. As this routine information is more frequently recorded in a digital format that can be shared and interrogated, potentially this learning can be released. However, routine data means that treatment allocation is of course not randomised, leading to biases, including placebo effects, confounding by indication, Simpson's paradox, and other problems.<sup>42</sup>

There are two approaches that could be adopted to draw more robust conclusions from routine practice. The first is to use alternative methods which do not require randomisation, such as instrumental variable methods (i.e. finding a variable which affects the availability of the intervention of interest, but cannot affect the dependent variable in any other way – also called Mendelian randomisation) or using well-developed predictive models to compare against the actual outcome in a particular condition.

An example of instrumental variable method is a study of the effect of bone marrow transplant on the survival of children with AML (leukaemia). This was tested by examining the correlation between having a live related sibling and the child's survival. This is because having a live related sibling affects the availability of a bone marrow transplant, but cannot effect a child's survival in any other way. It is therefore legitimate to conclude that any correlation between having a live related sibling and a child's survival is due to the efficacy of bone marrow transplants.

The alternative approach involves integrating a research approach with routine practice. One way of doing this is N of 1 trials.<sup>43</sup> In an N of 1 trial, the clinician and a patient with a long-term condition agree on the two drugs (or drug and placebo) to compare, and on the main symptoms or other outcome measures to be used as a metric of success. The drugs are then changed in a randomised alternating pattern unknown to both patient and doctor over a period of between five and ten weeks, while the patient records their symptoms as often as needed. The trial is then un-blinded and the drug which results in the best outcome for that patient is identified. An app has been developed to support this process, and there is work on synthesising the results of many N of 1 trials to create new insights about the probability that a drug will help an individual patient reach their goals. If many more clinicians collectively promoted and participated in N of 1 trials, thus earning them membership of the knowledge commons, the results could be aggregated into a statistically respectable and significant whole. This much more disciplined approach to 'off-label' treatment could result in significantly faster progress in addressing clinical research questions.

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One advantage of this approach is that it would cope much more efficiently with diseases that are much more variable between patients in their responses to treatment (or are really a bundle of diseases, disguised under a single name). Consider the following quote from Cancer Commons, a knowledge commons for cancer.

*“Modern molecular biology supports the hypothesis that cancer is actually hundreds or thousands of rare diseases, and that every patient’s tumour is, to some extent, unique. Although there is a rapidly growing arsenal of targeted cancer therapies that can be highly effective in specific subpopulations, especially when used in rational combinations to block complementary pathways, the pharmaceutical industry continues to rely on large-scale randomised clinical trials that test drugs individually in heterogeneous populations. Such trials are an extremely inefficient strategy for searching the combinational treatment space, and capture only a small portion of the data needed to predict individual treatment responses. On the other hand, an estimated 70 per cent of all cancer drugs are used off-label in cocktails based on each individual physician’s experience, as if the nation’s 30,000 oncologists are engaged in a gigantic uncontrolled and unobserved experiment, involving hundreds of thousands of patients suffering from an undetermined number of diseases. These informal experiments could provide the basis for what amounts to a giant adaptive search for better treatments, if only the genomic and outcomes data could be captured and analysed, and the findings integrated and disseminated.”<sup>44</sup>*

While the extent to which this description of cancer is accurate is certainly debatable, it perfectly plausible that some cancers and other conditions are of this type. If this is the case, we need to learn from routine treatment if medical progress is to be sustained.

## Cancer Commons

Cancer Commons is an online service designed to provide a more specialised approach to the treatment of cancer. The goals of the programme are to provide a personalised approach to cancer treatment, to accumulate knowledge on individual cancers, and to disseminate the knowledge through an open source collaborative framework. It is structured so as to connect ‘advisory boards’ of specialists – drawing on collaboratively obtained knowledge – with patients through Web-based applications. It demonstrates that specialist advice can be accessed by patients without direct institutional access, effectively; by utilising the Internet, Cancer Commons provides an additional medium of support and expertise to patients through bypassing the traditional patient–doctor relationship. This is a model which could be emulated for other medical problems.

## Prognostic models and citizen clinical science

In certain fields of applied knowledge there is the opportunity to use a knowledge commons approach to establish useful understanding without the need for randomisation. One example is prognostic models that accurately predict the progression of disease or response to therapy.

Prognostic models are essentially equations or algorithms that link relevant facts about the patient to an outcome, such as the trajectory of their conditions. They can thus be encoded as small pieces of software. A genuine commons would mean that the logic and code behind these models was shared, allowing the models to be continually updated and iterated as new data and insights come in, analogous to the open source software movement. In a big data era we are in possession of a large amount of granular data about patients’ recovery/progression, as well as relevant background data such as age, time

since diagnosis etc. We can mine this data to build a model of disease progression, and to predict individualised results. As can be seen from the PatientsLikeMe example, there is a clear appetite for this among certain patient groups for their own use.

Accurate, well-calibrated prognostic models would be useful to help patients to plan their lives, and also to check if they are responding to treatment as expected. As these models evolve, they could begin to offer predictions about response to treatment for individual patients. Health systems and patients would find it very useful to be able to identify who will respond to standard treatment, who will need a more customised approach, and who needs to understand that little can be done for them. This would effectively be a much more sophisticated development of present predictive risk models such as PARR (which only predicts risk of hospital admission), but with the addition identifying those most likely to be helped, and how. Clearly this could enable and impact the targeting and rationing of services, and is thus politically sensitive. However, given real and growing financial constraints, health systems must put their resources where they do the most good.

Disagreements about what outcomes to predict and which modelling methods to use might result in several competing versions, until data decided on the best. A similar process could be used for diagnostic models, and for treatment and self-management protocols.

An important potential research contribution of prognostic models is to reduce our reliance on clinical trials in some situations. If we can develop a well-calibrated model that accurately predicts outcomes in a defined patient group, we can then potentially use its predictions to substitute for controls in a randomised trial. The reasoning is that in a trial, we compare outcomes in patients exposed to the drug against those not exposed but otherwise identical. Randomisation is the best way to achieve this, though Mendelian randomisation (instrumental variable analysis) is an emerging alternative. If, however, we can accurately predict what would have happened to each patient had they not been treated with the new drug, we have a kind of ‘evaluation machine’ which eliminates the need for a controlled experiment. This kind of approach has rarely been used in the past due to the lack of well-calibrated prediction rules, but could become more common in future with the increasing availability of comprehensive high quality longitudinal datasets on people living with long-term conditions.<sup>45</sup>

Large collaborative platforms could also allow patients themselves to systematically research ways of coping with their own health in the real world. Patients would experiment with explicit protocols for managing their condition, and in groups create results that were at least suggestive of a causal relationship. The relationship between research and self-care here would be very close, and would amount to an iterative ‘citizen science’ of long-term conditions, embedded in and directly benefitting the global patient community. Clinicians and central organisations might have quite a small part to play, with most decisions devolved to local patient groups, who then propose apparently successful new models to the wider patient community for further randomised testing.

Given the numbers of people with the top five long-term conditions, it might take only days to recruit the thousands of patients needed to conduct a confirmatory randomised trial in such a network, though follow-up of each patient might take several months or a year. However, since the data will be collected electronically and quality assured by instant querying of missing values, analysis could start immediately after the trial ends and the extended cycle time for conventional trials would be shortened to just a few weeks longer than the follow-up period. This kind of model already underlies existing platforms such as PatientsLikeMe, and has clear traction with patients. As they become more exact, they would be very useful in allocating resources. If they reached a sufficiently high level of exactitude, they could be compared with outcome data in an ‘evaluation machine’ approach, and used to make causal claims about the efficacy of novel forms of treatment compared to a ‘normal’ outcome.

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Another area of interest would be short-term predictive models for use by patients. A good example of information that is not valued clinically but which could be immensely useful to patients is “*Will I be ill or well tomorrow?*” Even if there is little that can be done about the answer, the autonomy and control of one’s day-to-day life that comes from knowing if tomorrow is going to be a ‘bad day’ is hugely valuable. Reducing the anxiety and uncertainty of ill health, and planning a life around their illness are of enormous value to the patient, perhaps more so than many of the outcomes on which the healthcare system is incentivised.

## Diagnostic models

Diagnosis has usually been based on a thorough history and examination of the patient. It is an underrated triumph of the medical profession that diagnosis can be done so well, given the relatively thin information on which it is based: we do not have conscious awareness of much of what is going on in our bodies; we often cannot recall that which we are aware of when the time comes to speak to a doctor; it is hard to communicate this sort of information with any precision; and finally our recollection is inaccurate. Diagnosis is therefore a highly expert skill.

Richer data could provide a productive basis for building diagnostic models, based on a host of up-to-date information about the patient (building on Sackett’s Rational Clinical Exam model).<sup>46</sup> Initially these models might be an opportunity for a clinician to clarify a difficult diagnosis – “*wear this sensor for a week and the data will help me decide what the problem is*”. As these models reached a higher level of sophistication and precision they could become a new form of screening, run over large datasets to spot health problems early.

Taking this processing of real time information a step forward would involve moving from real time prognosis to dynamic treatment selection. Real time information about the patient would inform which treatment is selected and when. This is essentially what home telemonitoring or telehealth should enable, however we are still at the early stages of understanding who will use telehealth, what kinds of data to gather, and how to process and respond to it. Again, the protocols here could be evolved communally, with their efficacy compared. Richer data can enhance this process. A simple example is the Met Office’s Health Outlook app. This alerts COPD patients to upcoming changes in temperature, which are known to trigger exacerbations, allowing patients to take preventative actions.

As with many of the trends identified in this paper, we see this approach being as useful for the patient community as for the clinical one. Digital technology gives patients who are struggling with a long-term condition the opportunity to take a collaborative approach to understanding what steps they can take to improve their lives and to live better with their conditions. While online forums and discussion groups represent a significant improvement over what was available to patients previously, they are still long on anecdote and relatively short on fact. Patients who are recording how their diet, exercise, environment, social life, or treatment is affecting their health are in a position to move beyond exchanging anecdotes and begin to establish facts. By aggregating and analysing their data in the ways we describe they have a chance to understand what is helping them and what is not.

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Figure 3: Year of Care personalised dashboard

1

## Annual COPD review

You have read a review in the last 12 months.

You should see your doctor or nurse at **least once a year** for a COPD review. During your review, you should be asked how well your medicines are helping with your symptoms and whether you have had any side effects.

2

## Spirometry test

You have not had this test and should contact your surgery at the first opportunity.

Your diagnosis of COPD should be confirmed by a post-bronchodilator spirometry, also known as a 'blow-test'. This test checks how well your lungs work by measuring the amount of air you can blow out. This helps to decide upon the treatment your doctor should offer.

3

## Stopping smoking

Your records show you are currently a smoker and are trying to quit.

Giving up smoking and sticking to it is **extremely important** if you have COPD. Your doctor should encourage and help you to do this.

4

## Inhaler technique

Your records show you are currently a smoker and are trying to quit.

The medicines you use depend on how severe your COPD is, how it is effecting your everyday life, and what side effects you may experience. You should only be given an inhaler once you've been shown how to use it and you are confident that you can use it properly. Your technique should be checked annually. If you need a refresher, please contact your surgery.

5

## Pulmonary rehabilitation

You haven't been referred to a course in your local area.

Certain patients could benefit from a pulmonary rehabilitation course. It is a programme of care designed for your individual needs. During the **twice weekly session, for 6-8 weeks**, you work with a healthcare professional in your local area to help you to make the most of your physical abilities and to become as independent as possible.

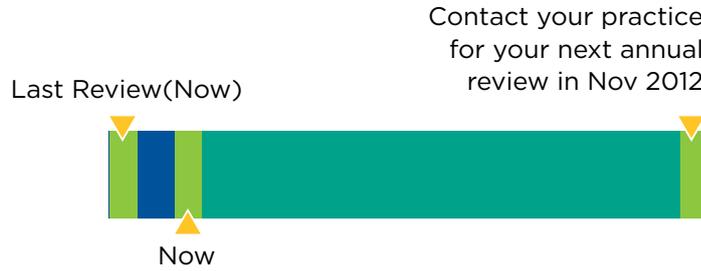
6

## Support with self-management

Contact your GP to talk about getting a self-management plan with a rescue pack.

Sometimes your symptoms may become particularly severe. These are called 'exacerbations' or 'flare-ups'. You should **be given advice about how to spot these** early and prevent them from getting worse. You may be given a **rescue pack** to keep at home to help prevent exacerbations.

This chart shows the date you should book your next annual review for



1. Annual COPD review
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

**What is a spirometry test?**

It is when you take an inhaler to open up your airways, before taking a deep breath and blowing as hard as you can into a sensor.



1. Take an inhaler



2. Blow into sensor



3. Measures lung capacity

2. Spirometry test
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

If you are a smoker and you tried stopping but couldn't, your surgery should be the first point of contact for deciding which method of quitting would most help you. They can direct you to the appropriate service.

Talk to your surgery to find out what help you can receive

Phone your Local NHS RED quit on: 0208 926 5275

Ask your chemist about a nicotine alternative

NHS Smoking helpline 0800 022 4332

3. Stopping smoking
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

There are different types of inhalers. Please make sure your doctor/nurse has shown you the right way of using it.

**You may consider:**



Should you breath out before use?



How hard should you be breathing in?



How long should you hold your breath?

4. Inhaler technique
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

**What is a pulmonary rehabilitation programme?**

It helps to support you to live better with COPD. It includes breathing techniques, exercise, useful information and advice on your diet.

Ask your GP if you are suitable for a pulmonary rehabilitation programme

If you are suitable your GP will refer you

5. Pulmonary rehabilitation
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

**What's a rescue pack?**

It contains antibodies and steroid tablets so that you can start these as soon as possible when your COPD starts getting worse.



Bad breathing



Rescue pack



Talk with your GP

6. Self-management
- \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_

## Changing relationships with patients

When people feel better informed, they are able to take more control. The ability to not only access but also generate useful knowledge about health is an important prerequisite to a more balanced and equal relationship between patients and clinicians, and the spread of decision support tools.

Pilot projects focusing on co-production in health, such as Nesta's People Powered Health programme, have shown how creating an equal relationship between patient and professional in the design and delivery of care for long-term conditions brings with it a number of challenges to the system. In particular, challenges around sharing information and responsibility for care with patients, changing professional culture and helping clinicians to see the value of working in partnership with patients, and capturing data relevant both to the person as well as to the health system.

For example, the Year of Care (YOC) diabetes programme introduced a personal care plan and the sharing of results and other information with the patient prior to consultation. This has demonstrated the value in engaging patients actively in the decision making process around their conditions, and providing the relevant information. This value comes from the perspective of both patients and the professionals in both primary and specialist care settings.

The dashboard illustrated in Figure 3 – which was co-designed with COPD patients to enable them to better manage their condition and prepare for consultations – builds on the same premise as the Year of Care care plan, but takes this one step further by providing patients with personalised information about their condition, for example how to work an inhaler, what services are available or how to make the most of a GP consultation. To encourage patients to engage with preventative services, the guide goes as far as breaking down the cost of these and emergency services – by for example outlining the cost between an inhaler (£38) and GP emergency call-out (£128). However, whilst this points to the potential value in sharing data and engaging patients more in the management of their own care, it also demonstrates the limits of current approaches to engaging patients actively in managing their own condition. Firstly, the Year of Care dashboard is paper based, making it hard to capture, track and share usage data between people and organisations over time. This also still requires a consultation to take effect, rather than a digitalised version facilitating new kinds of interaction between patient and professional. Secondly, this does not capture the whole variety of information relevant to a patient's life. Patients engage with multiple services and relationships that directly or indirectly affect their condition and care. This might include primary and secondary care, community-based options such as time banks, walking groups or peer networks, as well as non-health related services such as social care, housing or debt advice. Health data is rarely captured in all of these settings and is rarely shared and integrated between agencies.

Therefore, an ambitious but important area for development on the basis of a health knowledge commons is decision aids, to facilitate more informed and equal interaction between patients and clinicians. Clinical decision support systems analyse the patient record, help elicit patient preferences and suggest treatment options to the clinician and patient, based on encoded guideline recommendations. Decision support tools can use software to allow access to the most up-to-date research about a particular issue, guide treatment decisions based on specific data relevant to the patient and can facilitate shared decision making by surfacing and translating different interpretations and knowledge.

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The lack of relevant digital infrastructure – including a lack of electronic patient records, tools for electronic ordering of tests or drugs and encoded guideline knowledge – mean that decision support systems remain difficult to achieve. Trials show that we do not yet know how to design decision support systems for patient benefits to accrue consistently, not to mention the changes in clinical practice that would need to sit alongside. However, larger quantities of real time information and growing demand from increasingly articulate patients to have an opportunity to analyse and make choices based on their own data, demonstrate the potential for innovation in this area.

### Prevention and wellness

Access to more reliable, specific and actionable health knowledge could also have significant potential for encouraging prevention of disease, both in preventing the development of an existing condition or in encouraging positive choices to maintain wellness. As prevention is necessary before an illness is fully manifested, relevant knowledge in this instance relates to potential precursors of dysfunction of health or risk and protective factors, respectively.<sup>47</sup>

A health knowledge commons should therefore be relevant and accessible to people not currently within the health system, whether in informing diet or exercise, tracking health improvements or personal health risks, or in simply encouraging a mindset of taking care of one's wellness and mental and physical health. Taltioni is one example of a knowledge platform that allows citizens to monitor their health in this way.

#### Taltioni

Taltioni is a citizen-led system for holding health information developed by the Finnish Innovation Fund Sitra, to provide a new health knowledge system for the population of Finland. Information is owned entirely by citizens, who have the choice to upload their own data in a structured way and the choice to share this information with relevant health providers or researchers as they please. The infrastructure is being developed as a co-operative by Sitra, a Finnish telecommunications agency and health service providers, and the ambition is to have over 300,000 citizens contributing to the platform in the next two years.

Taltioni is intentionally for citizens, not patients. In that sense, it is a platform that encourages wellness rather than manages health. In encouraging people to record and review their demographic, health and lifestyle data, the aim is to support people to take better care of their own health and fitness. Yet even if only a minority of Taltioni's users choose to share their information for research and with health service providers, this nonetheless provides considerable resource for furthering research and innovation in the market of health services in Finland.

## 4 WHAT NEXT? MAKING A KNOWLEDGE COMMONS HAPPEN

Knowledge and knowledge systems are not easy concepts to grasp. The issues involved in developing a ‘commons’ approach to health knowledge also mean contending with difficult issues around patient confidentiality and the sensitivity of health data; the question of who has access to data and for what intent. The nature of a commons is that it is open to everyone to generate value from shared resources, prompting questions about the ethics of using patient data or health knowledge for private profit or controversial trials. Public concerns regarding the use of health data and the deep-set culture of clinical practice are not trivial challenges to overcome either.

However, the reality is that much of this is already happening. Some patients are already actively participating in systems like PatientsLikeMe and MyFitnessPal which are capturing and using data for clinical research and development. There is a burgeoning market in lifestyle technologies that monitor and feedback our behaviour, such as the FitBit or Smartphone apps that record our diet, exercise routine and sleep cycle. As our experiences and expectations of accessing and sharing knowledge in other fields grow more personalised and synchronous, so our expectations around interaction with the health system will continue to rise.

Though still far from universal implementation, the premise of open patient records and of routinely using patient data for research is becoming more widely accepted. In the context of the NHS, clinical research and disease management systems are already at a considerable advantage in that research practice is already relatively collaborative and there exists a sophisticated infrastructure of intermediaries active in disseminating structured information, such as MyDex.

### MyDex

MyDex establishes a personalised system of data ownership and sharing, allowing individuals to gain control of their own data. It creates a central ‘hub’ of personal data for an individual, and has an extensive system of privacy and sharing controls that facilitate selective direct sharing of information with organisations or other individuals. This allows the user to maintain more efficient ownership of data, and also to more comprehensively manage their interactions – in terms of information sharing – with external agents and organisations. It is significant in that it provides an excellent model of the personal ownership of data – although it is focused around confidential personal information, such as passwords, it is not difficult to foresee its application to medicine and patient records.

The prospect of a health knowledge commons builds on all of this work, and brings it together into a vision for the health system that is centred on knowledge, and that draws on the collective intelligence of us all to improve health, well-being and productivity. Developing a health knowledge commons is therefore a systemic innovation, and requires iterative action in a range of different domains and contexts rather than a centralised strategy to implement a static approach. Such a systemic innovation requires:

- **New technologies, products and services** – e.g. apps, sensors, quantified self technologies, shared decision making and decision support tools, better automation;
- **New policies and regulations** – such as for better structuring of data and clinical guidelines, open patient records, using anonymised patient data for research, and new governance frameworks around data access;
- **New business models, and forms of organisation** – e.g. collaborative research platforms such as PatientsLikeMe, open research networks and citizen-led models like Taltioni;
- **Behaviour and culture change** – e.g. greater openness and transparency, a shift in relationship between patients and professionals, new skills such as translation and interpretation of knowledge and aligning of incentives.

The health knowledge commons is not a short-term objective, but an ambition for how health will look in 20 or 30 years' time. However, there are a number of current initiatives and actions that relate to this long-term vision that should be supported. This section will consider what needs to be in place to make a knowledge commons happen, both in relation to action in the short term and more speculative recommendations for future innovation.

### New technologies, products and services

There has been a flourishing of new healthcare technologies and products that allow for more widespread creation and application of health knowledge, many of which are detailed throughout this paper. Technologies such as sensors capable of recording rich data accurately and effortlessly greatly enhance the opportunity for automated data capture, overcoming the challenge of incentivising regular check-ins. Consumer devices such as smart phones and games consoles contain sensitive devices which are already being adapted for health purposes, and health-specific sensors are also being designed.

However, this remains a new field, and many questions still exist such as when and how patients are happy to record their own data and to participate in self-monitoring activity. Key to the knowledge commons is understanding the personal drive of individuals in entering their data.

One purpose may be **motivational**: setting goals, tracking them, and sharing your success, is an effective motivational tool. A second opportunity would be knowledge about how to carry out a **complex task**. For example, motion-sensitive games consoles such as the Wii and Microsoft Kinect can detect if a series of rehabilitation exercises are being carried out correctly, and track improvement in range of motion. Patients whose condition imposes complex requirements on their lifestyle, such as those with cystic fibrosis, may find a combination of these two useful. Tracking of diet and physiotherapy may help a patient stick to a demanding regimen, and advice on how to carry out complex exercises could be very useful. **An important area for research and development is to experiment with developing communities that successfully collect large amounts of data.**

Advances in digital technology combined with minor changes in routine data collection also offer the opportunity for generating more robust data. N of 1 trials have the potential to both generate valuable research, and improve day-to-day patient experience. They might even help both patients and primary care clinicians better understand the value of randomisation and increase recruitment to clinical trials. **We would like to see active support for demonstration projects around N of 1 trials.**

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Another important area for development is in decision support tools, for both clinicians and patients. Active user communities such as PatientsLikeMe and MyFitnessPal translate up-to-date individual data into guidance that patients believe is useful in their day-to-day lives. This guidance can be prognostic, or it can suggest dynamic self-care options. The data can be used to iteratively improve the prognostic or treatment options. Similarly, clinicians and managers willingly enter data when that data gives them something useful in return. Finding out what kinds of information are useful to them, when and how to generate it, should be an active area of research and innovation. Simple prognostic models, of which several are available (for example in stroke), could motivate patients to share their own data, and allow for iterative improvement of the prognostic model.

As an area for future enquiry, we should explore how these prognostic models could become more reliable, to the extent that they might be useable to judge the efficacy of new treatments. This would open up a very different and much more rapid treatment discovery process. **We would like to see more research funding for prognosis, both for the development of specific prognostic models and to develop better understanding of the psychology of prognosis and the methodology of developing reliable, useful prognostic models/clinical prediction rules.**

### New policies and regulations

Realising the potential of data from more dispersed sources means developing common standards and formats to allow data to be combined, shared and analysed effectively (almost as a pre-condition). If the data recorded on different GP systems, pieces of telehealth equipment or on websites is incompatible in format or structure then the potential for integration is lost. The NHS is currently promoting common standards through the interoperability toolkit; however there is still much ground to cover here, with huge amounts of legacy data held in systems which are not compliant.

Data and knowledge from research can also be structured in a much more helpful way. In many areas of science (e.g. genetics), it is standard practice for researchers to deposit their data into repositories that other researchers can access. However, this is rarely the case with clinical research and should become part of standard practice. This should include data from trials that were unsuccessful and were not published, helping to counteract publication bias. Trial results could also benefit from structuring. It should be easy and quick to call up the conclusion of a range of different trials on a given drug or treatment, rather than comb through large sets of individual papers to compare results. The ESRC already insists on data archiving as a condition of funding. **Medical research funders such as the Wellcome Trust and the Medical Research Council should insist on data archiving as a condition of funding.**

There is also an opportunity to structure knowledge, which is presently not well recorded. For example, case studies of successful implementations of new techniques or technologies are not centrally collected, and are hard to find. One way to promote knowledge sharing would be for **the National Institute for Health Research (NIHR) to incentivise researchers to systematically structure and archive implementation case studies, so we can learn more about how innovations are applied in practice.**

Clinical guidelines would also benefit from common standards for structuring their recommendations. This would allow integration into decision support systems, and potentially allow patients to understand when their care had departed from best practice. **We recommend that all publically funded clinical guideline producers such as NICE and SIGN move towards capturing their recommendation in a standard structured, coded knowledge base form, rather than as text.**

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A knowledge commons also requires that people have the right to access their own data in a standardised format, and to share it as they chose. Where data belongs to the individual, this is about ensuring that they have the right to use it as they wish, bar exceptional circumstances. This right is only meaningful if the data can be accessed in a way that is useable by individuals, and in the digital age this means structured, machine-readable data. This creates room for innovation by allowing those with a new way of making data useful to gather the data, independently of existing structures. There should be a policy incentive to promote patient data being structured in a way that allows it to be shared and analysed. **We suggest this right be enshrined in the NHS constitution, with a target that all patients should have access to their data in a standard electronic format by 2018.**

Some versions of the knowledge commons will involve commons members changing their disease management methodologies and observing the results. Often this could be no more dramatic than what normally happens to a clinician's practice, as they become more experienced. Or it could be a more radical change that requires careful consideration and evaluation. It is important that this distinction is observed, and that the mere fact that data is being systematically recorded should not trigger a lengthy ethics process. Part of the opportunity in this model is to iterate based on continuous feedback, which this process would make impossible. Oversight is necessary, but must be proportionate. **The National Research Ethics Service's Proportionate Review Service is an important development in this regard.**

Finally, without undermining the gold standard of an RCT in most circumstances, **the validity and applicability of alternative methods for extracting firm conclusions from routine data (e.g. the instrumental variable approach) should be examined in comparison to trials, to build their credibility in the medical community. Support for such methodology development by a credible funder such as the MRC or Wellcome Trust would greatly assist this.**

### New business models and forms of organisation

Provided the underlying data and knowledge standards and potential software applications exist, the next development is to create the right incentives and market conditions to encourage new business models and organisations to take advantage of this potential. We would suggest that there needs to be some **early-stage research funding** in the key areas outlined above:

- Creating sensors which effortlessly gather relevant information;
- Designing apps that encourage patients, clinicians and managers to enter and share data;
- Perfecting statistical techniques for extracting information from data;
- Working with clinicians and patients to gather real time data within a research methodology;
- Better understanding of how to present data to individuals to help them find it quickly and interpret it without error.

There is also a need to invest in the kind of products for patients which are not directly connected to biomedical or financial outcomes, but do result in a patient who is informed and autonomous. **There is an opportunity for NIHR working with the National Commissioning Board (NCB) and other funders such as TSB or EPSRC to commission**

**a number of knowledge commons projects which gather and process information for patients, with patient autonomy as a goal.**

A softer and cheaper form of influence would be the **NHS accrediting certain apps and communities as being interoperable and clinically sound in their advice. An NHS App Store would also promote products that support patient autonomy.**

Finally, the issue of confidentiality and consent around the use of patient data is currently under review, but suggests **the necessity of a trusted intermediary or third party who can hold individuals' data**, collected from various sources, and make that data available to authorised agents in a way that preserves privacy. Large datasets can be made available for research purposes with a fresh anonymisation each time, thereby making de-anonymisation more difficult, or they can be analysed only on a virtual workstation running on a computer with zero export facilities for the raw data, as used by the UK Social Science data archive,<sup>48</sup> Services like Microsoft Health Vault and Mydex are already capable of performing this role. **To accelerate this, standards for compatibility of data and systems with sites such as these should be enforced by the National Commissioning Board.**

### Behavioural and cultural change

For clinicians to spend time helping patients understand their condition, making choices with them, and trusting them to take more responsibility for themselves will require a shift in mindset amongst clinical professionals. It will involve giving patients more power and autonomy. While this sounds reasonable, in practice it is likely to encounter significant resistance, not least as there still remains some scepticism in this area. Clinicians may filter and edit the information they give to patients. For example, when the possibility of making a full recovery is low, a frank assessment of the situation can be demotivating for patients. With patients able, for example, to access a prognosis on their own, such filtering is no longer possible. While a knowledge commons approach does have some scope for discretion, it does involve trusting patients with more unfiltered information, and this may make many clinicians nervous. **We recommend that the GMC, Royal Colleges and other leadership organisations examine the implications for professional roles, education and training of greater patient autonomy, self-reliance and access to patient data and knowledge, and seek ways to bring about the necessary culture change.**

Similarly patients will take a more active role in determining the research direction. Online communities of patients have already decided on their own research questions and gathered data on them, and indeed had the results published in good quality journals. This has concerned many, as these may not be randomised or controlled trials, and patients may be exposing themselves to particular risks.

Showing that patients can handle more autonomy safely, and understanding what the proper limits are can be explored through demonstration projects which are carefully designed to handle these issues and sensitivities, but which start from a position of positivity about patient capabilities. Co-ordinated leadership and vision will be needed to make this a reality; changing minds and culture are as important as providing new techniques, tools and platforms. **We recommend that NIHR, other medical research funders and patient groups collaborate to investigate the benefits and limitations of patient-initiated and patient-run studies and develop funding programmes to support those models that appear more fruitful than clinician-initiated studies.**

## SUMMARY OF RECOMMENDATIONS

Recommendation	Audience	Timescale
Experiment with approaches that can develop communities that successfully collect large amounts of data.	Research funders, academic community	Short-term (0-2yrs)
Find and develop opportunities for demonstration projects around N of 1 trials.	Research funders, academic community, clinical professionals, patients	Short-term
Invest in further research and development for prognosis, both for the development of specific prognostic models and to develop better understanding of the psychology of prognosis and the methodology of developing reliable, useful prognostic models/clinical prediction rules.	Research funders, academic community	Short-term
Support the development and implementation of decision support tools for patients and clinicians.	Research funders, academic community, health providers, NHS, National Commissioning Board, local commissioners (GPs)	Short-term
Test the reliability of prognostic models through trials to explore whether they might be useable to judge the efficacy of new treatments.	Research funders, academic community, NICE	Mid-term (2-5yrs)
Research funders should insist on publishing underlying data of trials as a condition of funding, and explore other opportunities for content to be authored collaboratively in an open environment.	Research funders, academic community	Short-term
Results from a range of trials on a similar treatment should be made readily available to compare results of trials.	Research funders, academic community	Mid-term
Invest in research to better understand the translation of knowledge into practice, and how knowledge is applied, such as through implementation case studies.	Research funders, academic community, National Institute for Health Research (NIHR) research networks e.g. NHS Confederation	Short-term
Develop common standards on structuring for clinical guidelines and all publicly-funded clinical guideline producers move towards capturing their recommendation in a standard structured, coded knowledge-base form, rather than as text.	Research funders, academic community, NICE, SIGN, NHS, Department of Health	Mid-term

<b>Enshrine the right of patients to access data in the NHS constitution, with a target that all patients should have access to their data in a standard format by 2018.</b>	Department of Health, NHS, patients	Mid-term
<b>Research and experimentation to understand patient incentives for capturing data and participating in a knowledge commons approach, including characteristics of who this works for.</b>	Research funders, academic community, patients, clinical professionals, Department of Health	Short-term
<b>Trials to examine further iterations of methods for extracting firm conclusions from routine data (e.g. the instrument variable approach).</b>	Research funders, academic community, NHS	Short-term
<b>Research and development funding for new business models and product propositions for knowledge commons, including possible design and interaction.</b>	Public bodies (e.g. TSB), Department of Health, health providers, NHS, National Commissioning Board, EPSRC	Mid-term
<b>NHS accredited apps and communities as being interoperable and clinically sound in their advice.</b>	Department of Health, health providers, NHS, National Commissioning Board	Short-term
<b>Develop standards for compatibility of data and systems with external sites as gatekeepers enforced by the National Commissioning Board.</b>	Department of Health, health providers, NHS, National Commissioning Board	Short-term
<b>Leadership organisations should examine the implications for professional roles, education and training of greater patient autonomy, self-reliance and access to patient data and knowledge, and seek ways to bring about culture change.</b>	Royal Colleges, leadership and training providers, professional, patient groups and advocacy organisation	Mid-term
<b>Identify and develop demonstration projects to investigate the benefits and limitations of patient-initiated and patient-run studies and develop funding programmes to support those models that appear more fruitful than clinician-initiated studies.</b>	Research funders, NIHR, Department of Health, health providers, NHS, National Commissioning Board, local commissioners (GPs)	Short-term

## CONCLUSION AND NEXT STEPS

Greater openness and collaboration in society combined with advances in technology, in our understanding of human psychology, drug discovery and communication tools present new opportunities for research, clinical practice, self-management and interaction with the health system. Big and open data and more precise analytical tools allows us to trial and model the benefits of new models of care faster, more cheaply and on a larger scale, with more granular data than we previously had access to.

The growing supply of useful tools, methods and platforms through which we can create and apply knowledge is changing expectations of what it is possible to achieve in health, and of the balance between patient and professional inputs to health knowledge. This paper attempts to frame debate and action in moving towards a health knowledge commons, and explores the potential for a more dynamic, distributed, collective system of knowledge creation and application in health. We think this issue needs to be at the heart of health policy and the focus of research and innovation to realise the potential of a more knowledge centred system of health and care in ten to 20 years' time.

Although there is much already happening in this area, we think more rapid development is needed in a number of key areas to make a knowledge commons happen: new policies and regulations, new technologies, products and services, new business models and institutions and new behaviours and culture change. We want to play a role in this by forming and mobilising alliances for change, working with others to develop key parts of the infrastructure such as common standards and access, commons-building models and practices, and promoting and shaping further research and development to demonstrate the potential of a knowledge commons in practice.

We know that such a campaign is inevitably informed by the experience and efforts of many others and that, going forward, our work needs to build on this, and develop an alliance of support and action towards a more effective health knowledge system. If you would like to be involved, please do get in touch with us at: [healthcommons@nesta.org.uk](mailto:healthcommons@nesta.org.uk)

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## ENDNOTES

1. By 'engagement', we refer to actions individuals must take to obtain the greatest benefit from the healthcare services available to them. See Center for Advancing Health (2010) 'A New Definition of Patient Engagement: What is Engagement and Why is it Important?' Washington DC: Center for Advancing Health.
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9. See research on knowledge translation and the barriers of research into practice, for example in Lang, E. S., Wyer, P. C. and Haynes, B. R. (2007) Knowledge Translation: Closing the Evidence-to-Practice Gap. 'Annals of Emergency Medicine.' Volume 39, No.3.
10. For example, it is often not sensible to randomise patients as staff involved in delivering the new service may accidentally transfer the new practice to control patients. Whereas patients in a drug trial would continue to attend the same clinic, served by the same staff, for an RCT of a service intervention it is often necessary to randomise staff, or even hospitals (Wyatt, et al. 1998), effectively running two discrete services simultaneously. This imposes significant cost. Patients may have existing long-term clinical relationships and not wish to be allocated to a new service with unknown staff. This is not to say that RCTs of a process improvement are impossible, but that it is a complex issue that can require ingenious study designs.
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