

executive briefing



Opening up healthcare innovation

Innovation solutions for a 21st century healthcare system



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The Advanced Institute of Management Research (AIM) develops UK-based world-class management research. AIM seeks to identify ways to enhance the competitiveness of the UK economy and its infrastructure through research into management and organisational performance in both the private and public sectors.



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- Working in cooperation with leading international academics and specialists as well as UK policymakers and business leaders...
- Undertaking a wide range of collaborative research projects on management...
- Disseminating ideas and shared learning through publications, reports, workshops and events...
- Fostering new ways of working more effectively with managers and policymakers...
- To enhance UK competitiveness and productivity.

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Our more specific objectives are to:

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- Raise the quality and international standing of UK research on management
- Expand the size and capacity of the active UK research base on management
- Engage with practitioners and other users of research within and beyond the UK as co-producers of knowledge about management

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Current AIM research projects focus on:

UK productivity and performance for the 21st century.


How can UK policymakers evaluate and address concerns surrounding the UK's performance in relation to other countries?

National productivity has been the concern of economists, government policymakers, and corporate decision-makers for some time. Further research by scholars from a range of disciplines is bringing new voices to the debates about how the productivity gap can be measured, and what the UK can do to improve the effectiveness of UK industry and its supporting public services.

Sustaining innovation to achieve competitive advantage and high quality public services.

How can UK managers capture the benefits of innovation while meeting other demands of a competitive and social environment?

Innovation is a key source of competitive advantage and public value through new strategies, products, services and organisational processes. The UK has outstanding exemplars of innovative private and public sector organisations and is investing significantly in its science and skills base to underpin future innovative capacity.



Adapting promising practices to enhance performance across varied organisational contexts.

How can UK managers disseminate their experience whilst learning from others?

Improved management practices are identified as important for enhancing productivity and performance. The main focus is on how evidence behind good or promising practices can be systematically assessed, creatively adapted, successfully implemented and knowledge diffused to other organisations that will benefit.

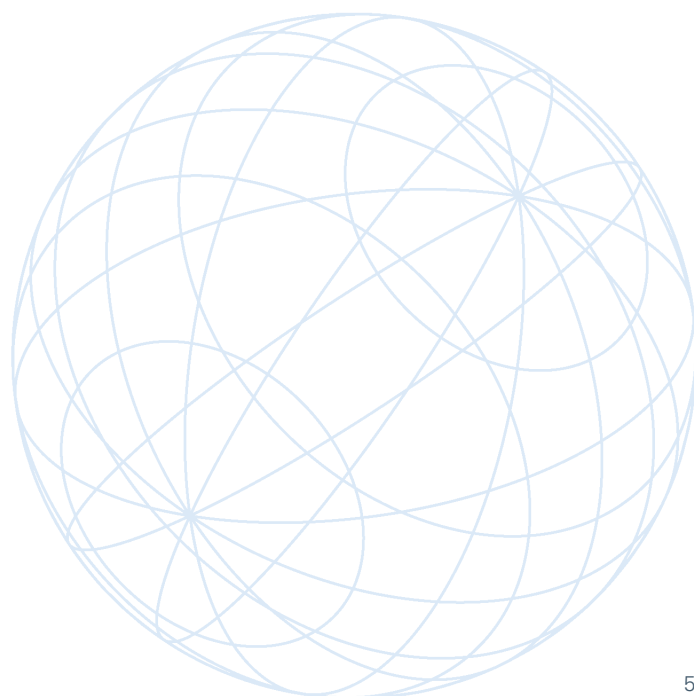
executive summary

Healthcare systems in the early 21st century face a crisis. Rising demand and expectations are increasingly out of step with the funding models available. Without radical innovation it seems unlikely that we can sustain the kind of healthcare which we associate with highly developed societies.

The healthcare sector has always been characterised by innovation – in treatments and drugs, in hospital and care systems, in primary and acute care pathways and in chronic disease management. But arguably the system suffers from the problem facing all kinds of organisations – a recognition that, despite huge commitment and investment in generating innovation, ‘not all the smart guys work for us’. The ideas behind ‘open collective innovation’ essentially involve finding ways to spread the knowledge net much more widely, bringing into the innovation process a wider range of players and mobilising their experience and creativity in the search for novel and sustainable solutions.

One key direction in which healthcare innovation can open up lies in harnessing the innovation potential of patients and their carers. We already know of many examples where patients have been a key source of innovation; in today’s environment the challenge is to find ways of scaling this to help deal with the innovation crisis. One powerful route is opened up via interactive web-based platforms which build and mobilise communities with common interests. This report discusses the potential of Web 2.0 interactive platforms and provides examples of several which appear to offer considerable additional traction in developing innovative solutions to the healthcare issues faced by such patients.

Without radical innovation it seems unlikely that we can sustain the kind of healthcare which we associate with highly developed societies.



introduction: challenges in healthcare

In many countries around the world, healthcare costs are soaring at an unsustainable rate which considerably exceeds GDP growth. For several major countries, such as the UK, France, and Germany, healthcare costs consume around 10% of GDP and are increasing at roughly twice the rate of economic growth (see figure 1). This is partially due to a demographic change where populations of developed economies are ageing and those of developing economies are growing. Western countries, in particular, are witnessing diminishing birth rates and increasing life expectancy.

Rapidly rising costs might be acceptable if they were accompanied by gains in efficiency or quality of care. However, some countries spend less on healthcare than others while at the same time their people live longer. In the UK, for example, healthcare expenditure per capita is significantly less than that in Denmark, yet people are expected, on average, to live 1.5 year longer (see figure 2). Other figures from a US publication estimate that \$700 billion out of a total \$2.5 trillion US healthcare budget is considered wasted due to inefficiencies, overtreatment, and error. In other words, higher spending does not inevitably lead to better outcomes for patients.

In many countries around the world, healthcare costs are soaring at an unsustainable rate which considerably exceeds GDP growth.

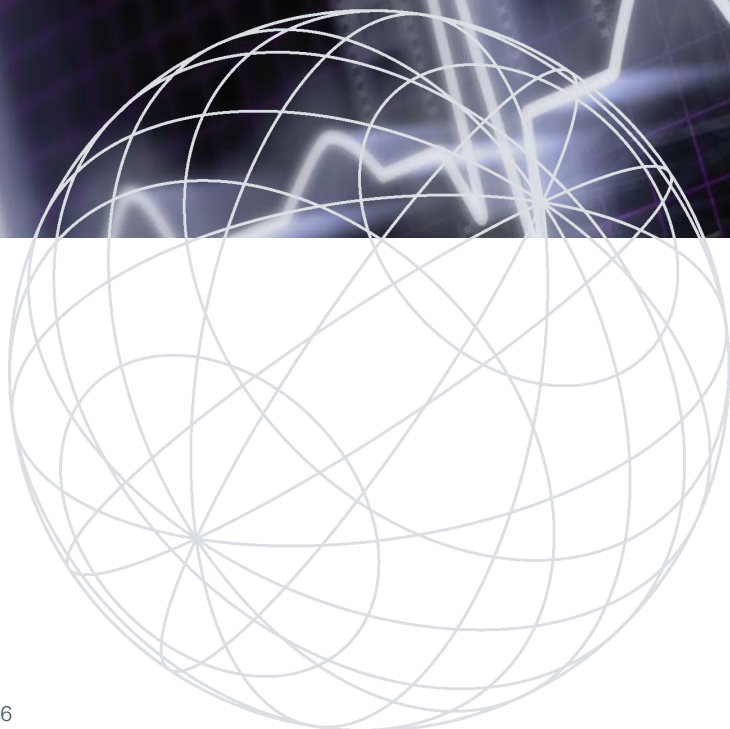


Figure 1: Healthcare costs are rising globally at unsustainable rates

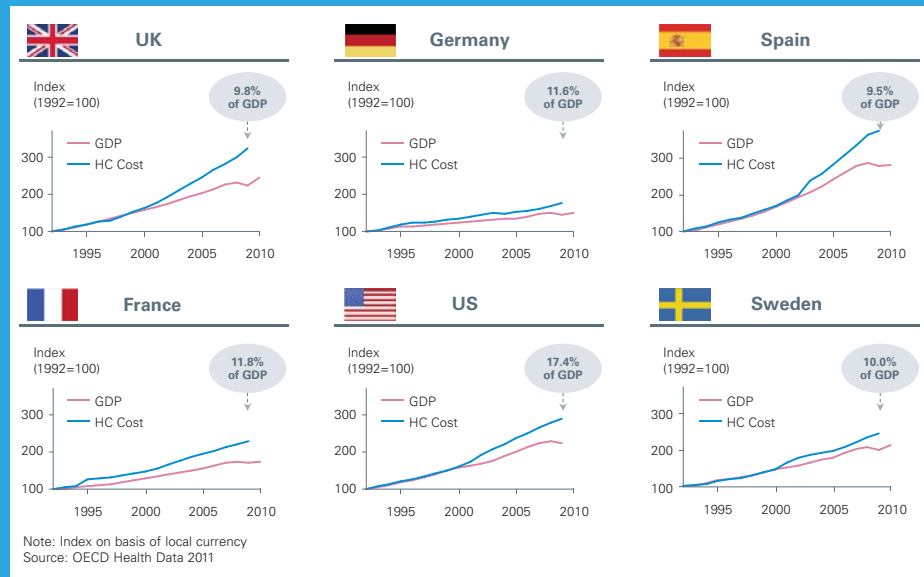
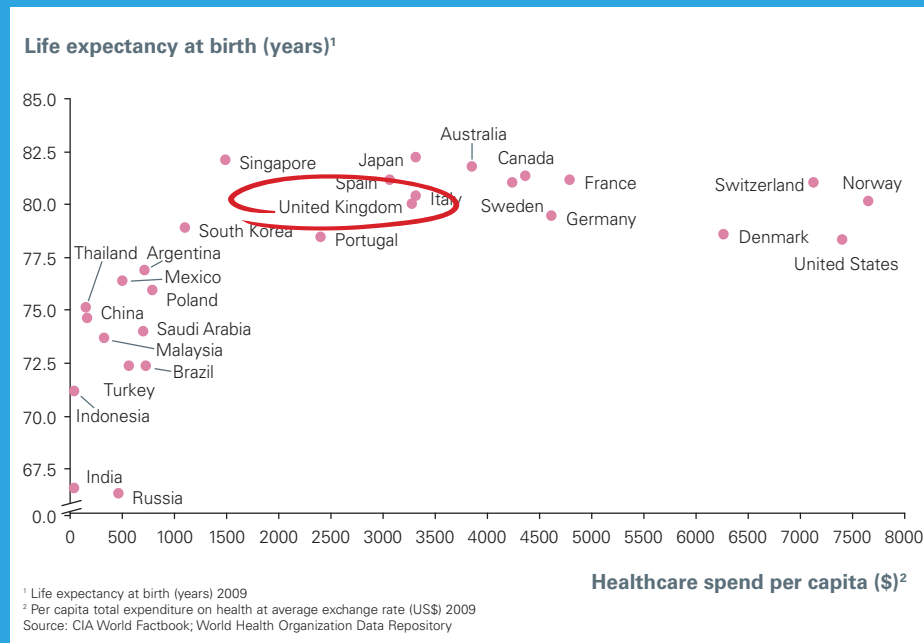


Figure 2: Higher costs are not buying better healthcare – 2009 healthcare spend per capita versus life expectancy for selected countries

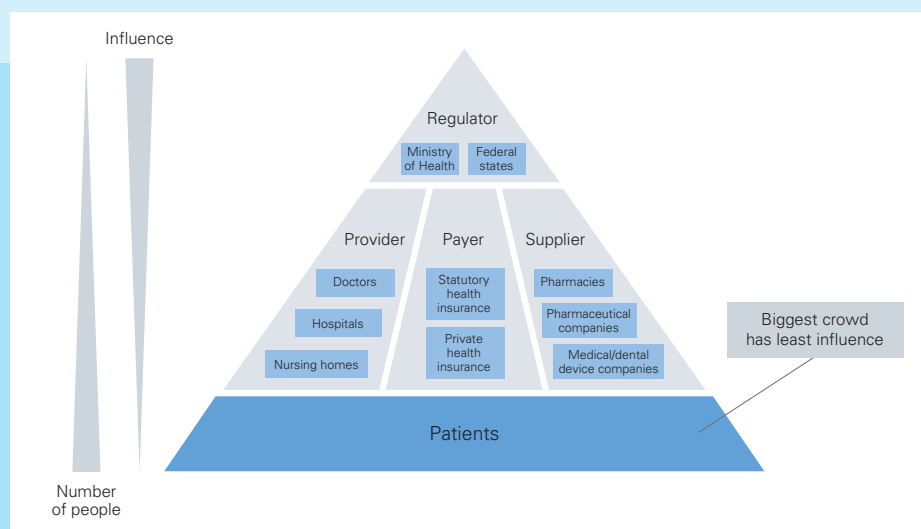


players in the healthcare system

The healthcare sector as a whole, which represents about \$5.5 trillion or 8% of the global economy, is certainly one of the industries made up of a very diverse set of players representing a wide range of interests. In fact, five major groups can be distinguished here (see figure 3):

- **Regulators**, e.g., ministry of health, national or regional committees who set regulatory guidelines
- **Providers**, e.g., doctors, nurses, other health professionals and medical experts who provide care in hospitals, doctor's surgeries, nursing homes, and others
- **Payers**, e.g., statutory health insurance, private health insurance, and government agencies
- **Suppliers**, e.g., scientific institutions, pharmaceutical and medical technology companies, who develop new products and treatments and heavily invest in research and development; pharmacies and wholesalers, who mostly do resale
- The **patients** as beneficiaries of care and, increasingly, as a knowledge base for their disorders

Figure 3: Healthcare landscape is traditionally dominated by five types of players



Purely quantitatively, in terms of number of people involved, patients are the largest group. They have gained enormous experience, either directly through their own health records, or indirectly through the suffering of relatives or friends. As a result many patients have developed ideas of how to make the process of care more efficient, of how to improve a medical device, or how to test new ways of treatments in the case of patients with life-changing conditions. Nevertheless, health suppliers and other stakeholders have been reluctant to absorb the patient's ideas into their processes. This is surprising, as from an innovation perspective, patients can serve as valuable knowledge resources.

In the case of the UK National Health Service (NHS) a combination of complex drivers is creating the conditions that will cause the current systems to fail. Increasing life expectancy means more people will require support for longer – and many will suffer from chronic diseases which are age-related, such as diabetes and stroke, which are particularly expensive to treat.

Other lifestyle-linked problems such as growing obesity levels put further pressure on a system which already consumes around 10% of GDP – yet this burden will have to be borne by a shrinking taxpayer base as the population distribution ages. Expectations have risen since the inception of the NHS in 1947, but continuing to deliver a broad-based package of care, free at the point of delivery, and without incurring crippling financial costs, is likely to become impossible in the years to come. The problem is not amenable to simple single point solutions like a new drug or therapy – instead it requires *system*-level intervention involving patients, carers, drugs and other treatment regimes across a broad therapeutic range, healthcare funding, etc.

The NHS is already a huge and complex organisation – the largest employer in Europe with the biggest purchasing budget. There is a complicated web of actors within the system – clinicians, managers, associated service providers, etc. – and it interacts with a very wide range of stakeholders – patients, carers, relatives, medical suppliers, funding agencies, local and national government, for example.

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Innovation in this system involves both the diffusion of improvement innovations and also radical new treatments and approaches, such as new equipment or surgical techniques. But it is likely that the fundamental shifts and rising complexity facing the NHS will mean that there is increasing pressure towards completely different models which require reframing, and the emergence/co-evolution of radically different alternatives.

imperative for open innovation

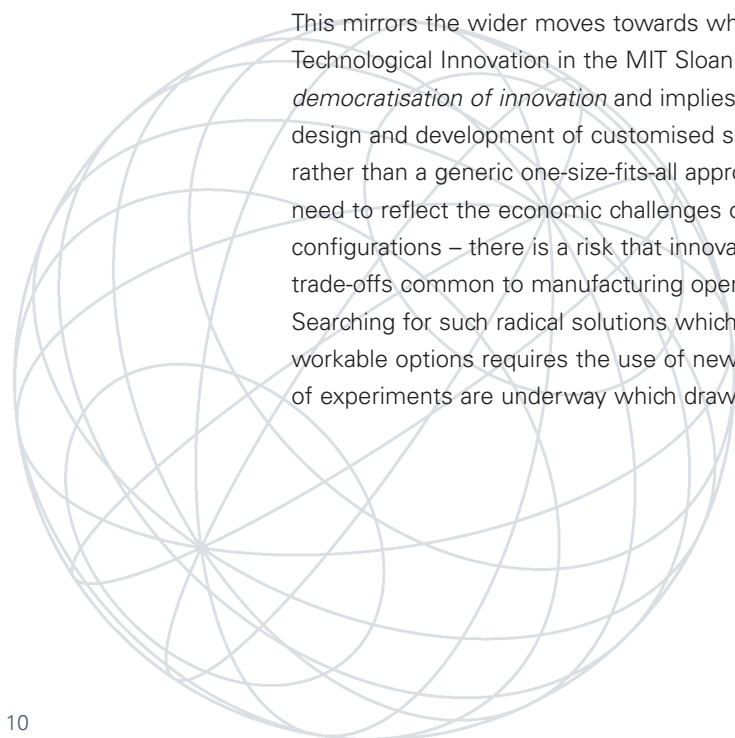
The need to manage such change is widely recognised – the NHS itself has recently concluded a 10 year reform programme – and there is growing recognition that existing perspectives, methods and approaches (and the underlying theories that drive them) cannot be relied upon to deliver the required change in the time and on the scale required. A key theme in the exploration of such radical alternatives is the need to incorporate new elements and perspectives and in particular to find ways to engage users much more actively.

One approach, advocated in the 2002 Wanless report, placed considerable weight on the role of the patient as a key architect in developing healthcare systems for the future. It emphasises that better access to information can help patients to be fully involved in decisions, not just about treatments, but also about the prevention and management of illness. With user involvement gaining more importance, the role of the patient is moving beyond an ‘informed consent’ to an ‘informed choice’.

As a report by Leadbeater, 2004, put it, *“current approaches to public service reform are reaching their limits... a wide range of prominent issues, including the environment, crime, and public health concerns such as smoking and obesity, cannot be adequately addressed by traditional services. Effective responses must encourage new norms of behaviour within society, developing approaches in which those who use services become involved in their design and delivery... we need a radical transformation and a new approach: co-created services”*

Co-created services of this kind require mobilisation of knowledge and resources which are distributed across communities and an active engagement of members of those communities – rather than central and unilateral supply driven solutions. This raises the issue of user-led innovation again. Co-design also helps deal with the customisation argument – rather than trying to design one size fits all, work with diverse users allows configurations which bring their particular set of needs and wishes into the equation.

This mirrors the wider moves towards what Eric von Hippel, Professor of Technological Innovation in the MIT Sloan School of Management, calls the *democratisation of innovation* and implies much higher levels of user-engagement in design and development of customised solutions matched to local and specific needs, rather than a generic one-size-fits-all approach. At the same time, such alternatives need to reflect the economic challenges of delivering high quality care in such specific configurations – there is a risk that innovations will revert to the traditional cost/quality trade-offs common to manufacturing operations management during the last century. Searching for such radical solutions which engage users and which also deliver workable options requires the use of new tools and techniques and a number of experiments are underway which draw on design approaches.



Related to the increasing need for innovation in healthcare, there is a paradigm shift in managing innovation. Often referred to as *open innovation*, this approach is about achieving and sustaining a higher degree of innovation by opening up the traditionally closed innovation process. It suggests that the process of product and service development should better integrate and leverage external knowledge resources provided by a wide range of external actors, such as customers and users. These external actors enable the innovating organisation to learn more easily about their needs, and to benefit straight away from their solution proposals for specific problems they might already have in mind.

Unlike traditional methods of market research, which are typically applied before the innovation process starts, open innovation allows external actors to be involved all the way along the entire innovation process. Customer integration is feasible during earlier stages of the process, such as idea generation and conceptualisation, as well as later stages, like development or prototyping.

Clearly there is considerable potential in approaches which mobilise a wider community, including patients and carers as a part of the 'innovation front end' in healthcare.

Related to the increasing need for innovation in healthcare, there is a paradigm shift in managing innovation.



One powerful set of tools, already widely used in industry to enable *open innovation*, are those which mobilise the enormous reach of the internet to create platforms on which shared exploration of healthcare challenges can take place involving a wide community. The emergence of interactive capabilities in the online space can be an effective source of jointly constructed and shared knowledge through the participation of patients, caregivers, health professionals, researchers, and others.

Patient engagement in service design at Luton and Dunstable Hospital

Improvement collaboratives – where members of multidisciplinary health teams work together both within and across organisations with a commitment to improving services – have emerged as a popular method for change within healthcare. Their impact includes significantly reducing waiting times and streamlining services. Typically such approaches – deployed for example in improving outpatient care – involve a range of staff including, nurses, clinic clerks, diagnostic services staff, doctors, secretaries and managers. Whilst they try to collect and integrate user's views into the redesign of services, there are fewer examples where patients and staff are jointly and equally involved in a *co-design* process.

Work at Luton and Dunstable hospital involves using design methods to create a user-led solution to the challenge of improving patient care amongst neck and head cancer sufferers. The approach involves patients and carers telling stories about their experience of the service; these stories provide insights which enable the team of co-designers to think about designing *experiences* rather than designing services. Importantly the role of designer includes all of those involved in the collaborative process: patients, staff, researchers, improvement leaders as well as design professionals.

By identifying the main areas or 'touch points' where people come into contact with the solution, where their experience is shaped, it tries to identify where the desired emotional and sensory connection needs to be established. Then, by working with people in the front line – doctors, nurses, and hospital administrative staff – the team can begin to design experiences rather than just systems or processes.

In the Luton and Dunstable Hospital such co-design has led to changes – for example patients and carers have changed project documentation so that it better reflects their needs, and clinic staff and patients have worked together to redesign the flow of outpatients in the consulting room. Various methodologies were used to encourage patient involvement in the process, including patient interviews, log books and film-making. This enabled patients to show their experience of the service through their own lens, and bring their story to life for others.

The initial co-design group identified 38 different actions to be taken, all based on user experience. Great care is taken to explicitly link the experience to the action by using actual narrative as expressed by patients or carers; this helps to retain the 'story' that has influenced the change. Many of the changes requested by patients required relatively tiny actions, for example, staff moved the weighing scales out of sight of the waiting room; they hadn't noticed how embarrassed patients were to be weighed in front of everyone. However, the impact of such a small gesture is potentially huge when people's experiences of the service are mapped. Other actions, such as changing the way the clinic space is used, have required more thought or organisation, yet many of these have been achieved quickly and inexpensively while still resulting in a significant difference to the patient experience.

Based on: Bessant & Maher (2009)

The Bolton diabetes care prototype

One of the major health issues identified by the Wanless report in 2002 is the rising challenge of chronic disease. Around 12 million (approximately one in five Britons) suffers from a chronic disease. These numbers are likely to rise if factors influencing chronic conditions, such as diet, lifestyles, and smoking, are not addressed as the population ages. The incidence of diabetes for example, closely related to obesity, has risen to 1.8 million people in just eight years, costing the NHS £10 million a day. It represents a complex problem but also one in which a patient-driven approach might offer significant new opportunities. For example, the average person with diabetes spends about three hours a year with doctors, checking prescriptions and general health – but they spend thousands of hours a year self-managing their condition.

As the Wanless report argues, the future of healthcare in an era of chronic disease would turn on the ‘full engagement’ of people in their own healthcare. Whilst hospitals play a key role, there is scope for much higher levels of engagement across the user community. One experiment in this direction has been work towards co-creation/co-evolution of new diabetes services within the Bolton area of north-west England. At present an estimated 10,000 residents suffer from diabetes (almost one individual in every ten households) in the area. This absorbs 5% of NHS resources locally, and 10% of hospital patient resources, a pattern that is similar to that nationally, exemplifying the challenges of chronic disease management. In response, Bolton has already developed an impressive track record of ‘traditional’ innovation solutions to the problem but progress has been largely inspired by the professional managers and clinicians rather than diabetics themselves.

The RED project was a prototype which looked at the ways in which the interface between people with diabetes and a range of required services could be made seamless and at ways in which diabetics might co-support each other. The core idea was that a co-created service would entail both participation and change on the part of the diabetics themselves and the professionals currently engaged in delivering services. This would have continuing implications for the organisation of the service itself and for bottlenecks within it. In Bolton for example there is a two year waiting list for orthopaedic shoe fittings (cost £100) which can save the need for amputations (cost between £30,000 and £40,000). Such bottlenecks are far from unique to Bolton or to diabetes management and reinforce the need to maintain prevention as a founding principle in the approach to co-creating services.

Having advertised the project in GP surgeries in the area, the team found a group of 20 willing participants, all diabetes sufferers ready to share their experiences of living with the condition. The first stage of the project involved focusing on the group’s individual lives not just their disease, and building up an in-depth understanding of the real issues that affect sufferers’ ability (or inability) to manage their diabetes effectively from day-to-day. Over time, common patterns began to emerge within the group, and it became possible to identify three profile categories based on how individuals approach and manage their condition; ‘knowing struggler’, ‘determinedly naïve’ and ‘able knower’. Further work with these different groups and their carers involved extensive prototyping and experimentation.

Based on: Bessant & Maher (2009)

A set of economic, social, and technological trends led to the next generation internet which is characterised by user participation, openness, and network effects.

The term *Web 2.0* was initially introduced following the O'Reilly Media Web 2.0 conference in 2004. It summarises the changes that had happened on the internet and the way its users deal with it. A set of economic, social, and technological trends led to the next generation internet which is characterised by user participation, openness, and network effects. Compared to Web 1.0, the so-called first generation of the internet, the difference with Web 2.0 is foremost about user interaction. While Web 1.0 was mainly about unidirectional information retrieval, users can create and add information and content to the Web. For that reason the amount of user-generated content has increased enormously. Since then online communities, in which users can participate and share content, have become very popular.

While other big industries have adopted the advantages of the information technology age since the 1980s, the healthcare sector has been quite slow to do the same, especially in support of coordination and cooperation between institutions. Now the influence of technological advance on healthcare is likely to increase further. This recent trend has also had an impact on healthcare related online offers which are then described as health 2.0 or medicine 2.0. Both terms cannot be separated distinctly, and are sometimes used synonymously. They are subsumed in the broader term e-health which was first introduced in 2000 in the context of telemedicine. According to the existing definitions of health 2.0, there are seven leading themes:

- 1 Web 2.0 as the underlying technology for communication and information sharing
- 2 Increased participation or empowerment of patients or consumers of healthcare
- 3 Apart from patients only, increased participation or empowerment of health professionals or other stakeholders, e.g. payers, providers, researchers
- 4 Emergence of online communities and social networking in health 2.0
- 5 Improving collaboration between patients and health professionals
- 6 Stronger focus on health information and content, one that is patient-driven or user-generated
- 7 Positive impact or change on the healthcare system in terms of higher quality and efficiency in healthcare

Recent studies show that the number of internet users worldwide that go online for health-related purposes is growing significantly. Over the past few years, many online platforms for patients have arisen to give information about disorders and to facilitate networking with like-minded sufferers. These websites help patients to better understand and manage their individual health status. The implemented functionality ranges from simple information distribution and general health advice to highly active patient communities specialising in rare conditions. Also, some of the platforms integrate elements of open innovation – if it is bringing people together who have not exchanged ideas and knowledge before, or solution-oriented discussions around users' problems.

It is claimed that the combination of innovation and health 2.0 is a powerful and radical way to change medical practice and the current role of patients.

Groups of Innovators

With the recent shift towards *open innovation*, innovation processes have to integrate three distinct types of innovators: core inside innovators; peripheral inside innovators; and outside innovators. Traditional research and development (R&D) departments, classified as *core inside innovators*, have a central role filling the innovation pipeline with promising ideas.

Employees from other departments than R&D are named *peripheral inside innovators*. This group is not directly responsible for innovation. Through their daily job, though, they gain relevant experience and knowledge that can be a valuable contribution to the innovation process.

Beyond the organisation's boundaries, *outside innovators* represent all external players like customers, users, retailers, suppliers, and competitors. When they participate in the innovation process, their heterogeneous backgrounds and the outside-in perspective can create enriching contributions. This typology of innovators can be applied to value-creating supply networks of multiple stakeholders with differentiating roles – as is the case in the healthcare domain.

Hence, one way to classify health 2.0 platforms is to look at the groups of innovators involved in healthcare. The patient stands at the end of a complex industry whose leading rationale is to improve healthcare. More strikingly, the patient is the source where health issues originate – or at least where they first appear. The patient's health status and diseases are the subject matter of the players involved in healthcare. In short, the patient is both actuator and receiver of all health-related efforts. Accordingly, the differentiation of the three types of innovators introduced before needs to be adjusted and led by a patient-centric perspective.

From the perspective of a patient, there are numerous relationships to problem solvers who can deal with the patient's health problems. In the first place, it is the patient's relationship to any sort of care providers, such as a dedicated general practitioner who typically has the best overview of the patient's health status. In the course of medical treatment, the GP might send the patient to medical specialists for further examination. In addition to the GP, the patient could consult other health professionals and medical experts on a one-to-one basis, ranging from technical encyclopaedia to health counsellors from industry partners. We consider the different instances of medical experts described here as *core inside innovators* – they all share a direct and very close relationship to the patient while acting as qualified problem solvers for the patient's health issues.

As a consequence of health 2.0, the traditional one-to-one relationship between doctor and patient is supplemented by a number of new relationships with like-minded people. Here, one major group consists of fellow patients who suffer from a similar disease pattern, and also their caregivers and family relatives who suffer indirectly. They all have acquired relevant experience and knowledge in the same field. As fellow sufferers are less familiar with the patient's detailed situation than the supervising GP but still can share relevant experience, this group could be considered as *peripheral inside innovators* from a patient-oriented perspective.

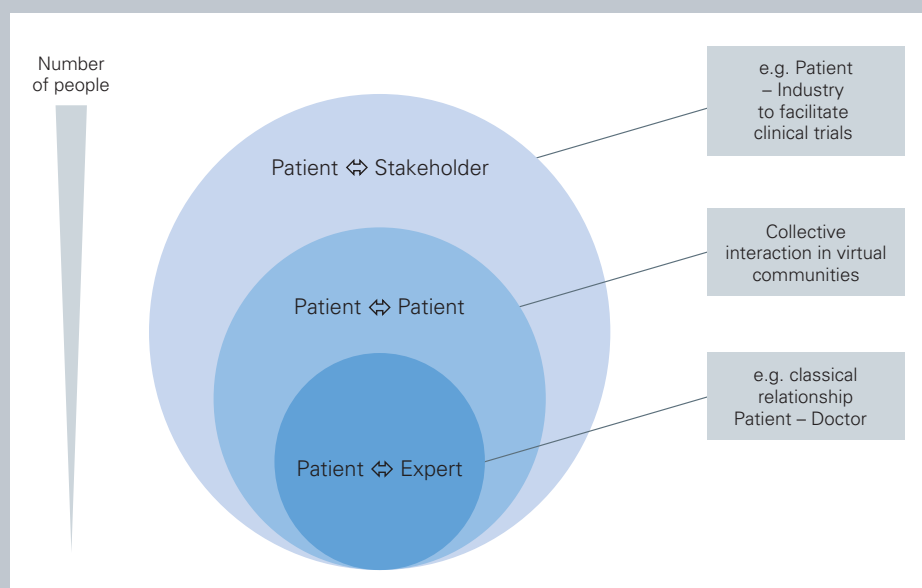
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Radical innovations account for only 6% to 10% of all innovation projects.

Other stakeholders who do not directly share disease experience with the patient make up a third type of innovator. They can contribute specific technical knowledge in order to solve, or at least facilitate dealing with, the patient's health problem. These could come from the side of suppliers, payers, and regulators. Typical examples are industry partners like medical device manufacturers or service businesses specialised in a particular aspect of medical care. According to the previous logic of patient-centric perspective, we consider this group *outside innovators*.

To conclude, one approach to classify health 2.0 platforms is about patient-related innovator groups consisting of three clusters: medical expert-to-patient relationships; patient-to-patient relationships, and other stakeholder-to-patient relationships. It is conceived as a shell model, which means that, for example, patient-to-patient relationships are consecutively based on expert-to-patient relationships (see figure 4).

Figure 4: Classical relationship patient-doctor enhanced by relationships created in virtual communities



Degree of Innovation

An important aspect of innovation is the *degree of novelty* involved. Obviously, upgrading minor details of a product like improving medical care through new ways of servicing is not the same as finding a formula fighting an HIV infection or a rare disease. There is a continuum extending from minor, incremental improvements to discontinuous, radical changes. The latter can be far-reaching, potentially changing the basis of society, as the impact of today's information and communication technologies has shown in recent years, for example.

Incremental innovations are more widely seen in practice than 'new to the world' products. The cumulative gains in efficiency which come with incremental changes are often larger over time than gains from occasional radical innovations. Unlike incremental improvements, *radical innovations* change the rules of the game and challenge the boundary conditions (technology, markets, social, regulatory, etc.), they enable a new opportunity space for innovation. Radical innovations account for only 6% to 10% of all innovation projects.

These differences are important when it comes to managing the innovation process. Certainly, day-to-day, incremental changes need a different management approach than those applied occasionally to control radical step changes in products, services or processes. Yet it is important to note that it is the *perceived* degree of novelty which matters.

Another way to classify health 2.0 platforms is by the outcome focus of health 2.0 platforms. The online platforms currently available in the health 2.0 space differ widely in their mission statements. When we look at them from a dedicated innovation standpoint, we narrow the focus down to the impact such a site can have on the emergence of innovation. More specifically, due to the relative novelty of a number of sites, the focus is on the anticipated outcome. Classification may be done through declared intention by platform operators as well as assessment by innovation researchers.

On the one hand, there are online sites which do not, or at least not to a recognisable extent, have a dedicated innovation focus but which still operate successfully in the health segment. These are mostly sites characterised by unilateral information dissemination, e.g., on general health advice, or sites providing basic functionality on managing personal health records electronically (without connecting to a community).



...day-to-day, incremental changes need a different management approach than those applied occasionally...

On the other hand, online platforms with a clear innovation focus can be classified by the degree of change an innovation is likely to cause. The change can be incremental or radical. For example, a typical online self-help group with forum certainly has the potential to create incremental innovations. In contrast to that, rewarded innovation contests like the Archon Genomics X Prize¹, are more likely to produce radical innovations.

Finally, another approach to classify health 2.0 platforms relates to the outcome focus of health 2.0 platforms. It consists of three clusters: focus on information; focus on incremental innovation; and focus on radical innovation.

¹ <http://genomics.xprize.org>

exemplary health 2.0 cases

CureTogether

*CureTogether*² is a type of social network which attempts to solve medical challenges through the collective knowledge or experiences of the patient crowd. The site which started in 2008, and counts over 22,000 patient members (as of October 2011), is organised around support groups on specific conditions. The most popular support groups with more than 5000 members deal with anxiety, depression, and back pain. Smaller groups discuss topics such as heartburn, adrenal fatigue, and stomach pain. In total there are over 500 medical conditions supported.

It is different to other general support disease communities in that there is not a lot of social, story-sharing on the site. The focus is on anonymous patient profiles and their experiences shared as data. Data is recorded through a structured questionnaire that is available for every supported condition. Survey questions ask for patients' experience on symptoms, treatments, side effects, and causes. The list of symptoms or treatments can be supplemented by user's input if the desired answer is not in the list. Accordingly, the more patients participate, the more comprehensive the survey becomes. Despite the lack of some 'social networking' elements such as discussion boards, patients are able to privately and anonymously contact others who suffer the same combination of conditions that they do, and exchange experiences.

The most popular support groups with more than 5000 members deal with anxiety, depression, and back pain.



²www.curetogether.com

Analysis of the given data is anonymously provided straight on the platform. Users can instantly compare their individual disease experience with data shared by others. First, survey results of all respondents are presented in an aggregated form, detailing absolute and relative numbers about, for example, the most common symptoms and most popular treatments. Second, a two-dimensional matrix compares treatments by popularity and effectiveness.

Equipped with these preliminary results at hand, *CureTogether* strives to provide the patients' data for research purposes. There are active partnerships with universities and research organisations which have led to a series of publications and on-going studies. Research findings have to be seen in the context of its limitations as it is based on patient-reported data only and there may be a potential bias in patient self-selection and recall. Yet it serves as a stimulus for discussion and further research. *CureTogether* illustrates how the engagement of patients is changing. The website is not only empowering patients to share experiences with each other, but to develop their own evidence base and to generate new knowledge from it.

...users are encouraged to write a journal about medical and psychological treatments they have undergone.

DailyStrength

*DailyStrength*³ is a social networking site that focuses on the development of patient communities. The platform, founded in 2006, has approximately 400,000 registered users (as of October 2011), and addresses people with a wide variety of medical, psychological and life conditions ranging from general health to chronic disorders. Its users are mainly health seekers, patients, or members of self-help groups, but also include care givers, supporters and medical professionals.

The main function of *DailyStrength* lies in its 500 plus communities which focus on conditions such as autism, infertility, smoking addiction, and several types of cancer. Discussion boards help users to talk about their struggles and treatments, to exchange knowledge, and to give and receive emotional support from people facing the same circumstances.

Outside of the discussion boards, users are able to ask questions to find quick answers and straight-forward solutions through other experienced users. Another highlight is that users are encouraged to write a journal about medical and psychological treatments they have undergone. That information is then aggregated by condition and treatment and it becomes easy to see what a large number of people have done in response to a condition.

DailyStrength relies on a board of medical advisors who are active members of the team. They contribute to feature design and community creation and also participate as community members or blog editors in their respective areas of expertise.

³www.dailystrength.org

Across the great variety of illnesses, patients and their families are often confronted with similar types of problems.

Gemeinsam für die Seltenen

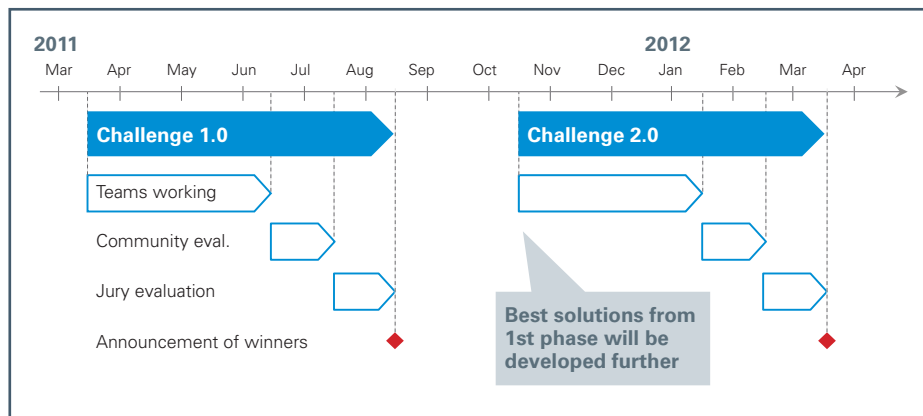
*GemeinsamSelten*⁴ allows users to initiate and participate in finding ideas and solutions that help sufferers of rare diseases. The site, which has added over 1000 members since its launch in March 2011 and addresses a German-speaking community, has three main functional components: an innovation initiative based on a series of contest-like challenges; a social network; and a marketplace for exchanging problems and ideas.

The platform strives to collect the problems of rare disease patients and, thereby, increase public awareness. The aim of the site is to develop innovative solutions for the patients' reported problems through innovation contests. Across the great variety of illnesses, patients and their families are often confronted with similar types of problems. The site targets people who know about the daily troubles of rare disease patients – whether that is the patient himself or other people connected to patients. These people might have thought about tricky problems, possible solutions and even practical implementations.

To become a participating member, people do not have to possess experience on rare conditions. The site's intention is to bring people from diverse backgrounds together – whether that is caregivers, health workers, physicians, nurses (i.e. core inside innovators); family members, friends, fellow patients (i.e. peripheral inside innovators); or researchers, engineers, product managers, civil servants (i.e. outside innovators).

The research group behind the platform organises *challenges* in which participants can compete for the best ideas (see figure 5). During a challenge, which lasts for approximately three months, participants can present unsolved problems, submit solution proposals, and collectively work on refining ideas and concepts. At this point, the social community features of the site enable members to create a personal profile, connect to others, discuss ideas, and comment on others' contributions. Proposals for solutions on *GemeinsamSelten* can cover descriptions on technical aids and products, medical and caregiving services, medical-technical services, or housekeeping and social services.

Figure 5: At „Gemeinsam für die Seltenen“ innovation contests take place in so-called challenges



⁴www.gemeinsamselten.de

After the closing date of each challenge, a jury of experts assesses the most innovative concepts. The multi-disciplinary jury consists of researchers and practitioners from clinical as well as commercial organisations. The jury members evaluate each solution proposal along a predefined set of criteria such as novelty, usefulness, feasibility, market potential, and degree of elaboration. Not only do final winners of the contest collect prizes, but they are also supported in innovation workshops to develop concepts for prototypes.

GemeinsamSelten is part of an initiative from the German Federal Ministry of Education and Research, which has defined priority projects of which one is the 'development of local service concepts especially in the field of rare diseases'. The term 'Gemeinsam für die Seltenen' can be translated as 'jointly fighting rare diseases'. It illustrates the point that the many are collaborating to support the few.

In summary, the platform has three distinctive features; it organises a series of innovation contest-like challenges to find solutions for improving the quality of life of rare disease patients; collects patient's problems and needs in a central place; and creates a community with people from diverse backgrounds to promote knowledge exchange and collaborate on innovative concepts.

PatientsLikeMe

The platform *PatientsLikeMe*⁵ is a health information system that looks, at first glance, similar to patient chat rooms and support groups. The site, which has been operating since 2006, is specifically designed for patients to meet and discuss their ailments with other patients. With a clear focus on patients facing life-changing and rare illnesses, the 116,000 or so registered patients (as of October 2011), mainly from the UK and the US, are organised in disease-based communities, such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), fibromyalgia, acquired immune deficiency syndrome (AIDS), depression and anxiety. It has been recognised by Fast Company, a monthly magazine in the US, in its 2010 ranking of the world's 50 most innovative companies. In an industry-specific ranking it ranked as second most innovative in healthcare.

On *PatientsLikeMe*, patients provide a detailed record about their health information and then make it public to the community. The record contains a combination of structured and unstructured data about symptoms, severity, progress, medication and their side effects. Health data is neatly represented using standardised metrics and clear graphical displays. Once shared with other patients, they can enter into active dialogue via the web platform and learn from collective knowledge and experience.

⁵www.patientslikeme.com



Another outstanding characteristic of *PatientsLikeMe* is the philosophy of openness within the community – in addition to their privacy policy towards non-members. For most online users, protection of private and personal data is an imperative that platform operators must adhere to. For patients with incurable and life-changing diseases who are looking for ways to prolonging their life, the case might be different. The makers of the site assume that open collaboration on a large scale with real-world data enables change, and possibly new treatments.

Apart from patients, there is collaboration with several nonprofit groups as well as pharmaceutical companies. It is an essential part of the business model. *PatientsLikeMe* is very clear in stating that aggregated anonymous data is sold to drug, device, and insurance companies – all with the consent of its members. For example, *Novartis* and *Avanir*, both research-based pharmaceutical organisations, are partnering with the site to recruit participants for clinical studies. These firms can publish online pre-screeners on the site that help to select patients who are eligible for a clinical trial to test drugs, for example. In the case of *Novartis*, it is reported that the site helped to speed up an MS trial by several months. In brief, *PatientsLikeMe* offers: graphically enhanced personal health record for rare disease patients; open sharing of personal health data in social network; and matchmaking between patients and researchers.

Apart from patients, there is collaboration with several nonprofit groups as well as pharmaceutical companies.



List of further examples

Name	Link	Type	Description
HealthGrades	www.healthgrades.com	Appraisal system	Healthcare ratings, information, and advisory services in the US
PatientOpinion	www.patientopinion.org.uk	Appraisal system	Feedback platform for UK health services
RateMyHospital	www.ratemyhospital.ie	Appraisal system	Hospital ratings by users in Ireland
Dossia	www.dossia.org	Electronic health record	Patient managed health record
Hello Health	www.hellohealth.com	Electronic health record	Patient managed health record and appointment booking system
Microsoft Health Vault	www.healthvault.com	Electronic health record	Patient managed health record
SugarStats	www.sugarstats.com	Electronic health record	Blood sugar tracker and diabetes management system
NHS HealthSpace	www.healthspace.nhs.uk	Electronic health record	Online personal health organiser integrating electronic medical records from the NHS
Cochrane Library	www.thecochranelibrary.com	Information aggregation	Library of systematic reviews of primary research in human healthcare and health policy
DocCheck	www.doccheck.com	Information aggregation	Password service for medical professionals and attached expert community
EverydayHealth	www.everydayhealth.com	Information aggregation	Information portal on everyday health and healthcare
Healthline	www.healthline.com	Information aggregation	Information portal on general health and healthcare
HealthMap	www.healthmap.org	Information aggregation	Information system visualising global disease outbreaks according to geography
MEDgle	www.medgle.com	Information aggregation	Information portal on symptoms, diagnoses, drugs, procedures
MedlinePlus.gov	www.medlineplus.gov	Information aggregation	Information portal on general health and healthcare by the US National Institute of Health
MSN Health	www.health.msn.com	Information aggregation	Information portal on general health and healthcare
MumsNet	www.mumsnet.com	Information aggregation	Information portal on parenting

List of further examples (continued)

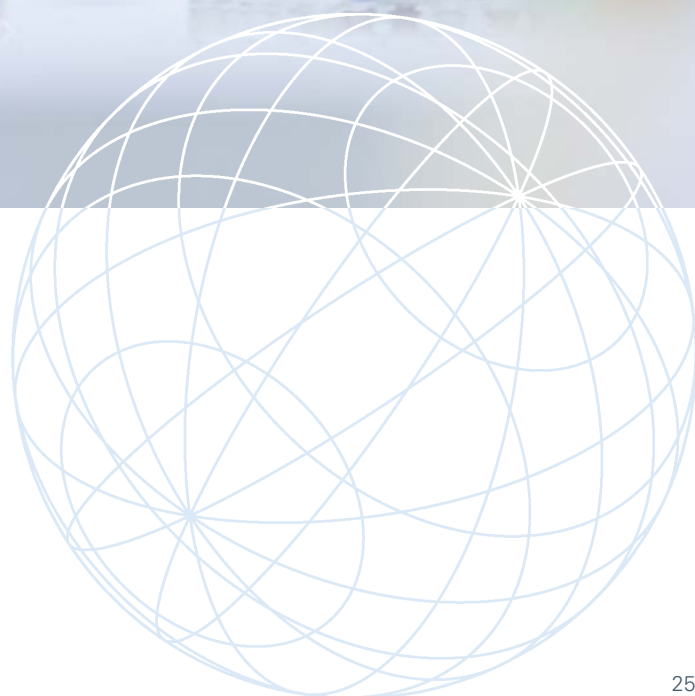
Name	Link	Type	Description
NetDoctor	www.netdoctor.co.uk	Information aggregation	UK-based information portal on general health and healthcare
NHS Choices	www.nhs.uk	Information aggregation	Information portal on general health and healthcare from the NHS
Revolution Health	www.revolutionhealth.com	Information aggregation	Health-related portal and social network
VisibleBody	www.visiblebody.com	Information aggregation	3D human anatomy visualisation
WebMD	www.webmd.com	Information aggregation	Largest health-related portal and social network in the US
Who is sick	www.whoissick.org	Information aggregation	Local sickness information
Yahoo Health	www.health.yahoo.com	Information aggregation	Information portal on general health and healthcare
Zygot Body	www.zygotebody.com	Information aggregation	3D human anatomy visualisation
PubMed	www.ncbi.nlm.nih.gov/pubmed	Search	Database accessing references and abstracts on life sciences and biomedical topics
ZocDoc	www.zocdoc.com	Search	Search for doctors and medical appointment booking service
Cure Together	www.curetogether.com	Social Network	Data-driven social networking health site
Daily Strength	www.dailystrength.org	Social Network	Social networking health site
Doctors.net.uk	www.doctors.net.uk	Social Network	UK-based social networking site exclusive to physicians
Gemeinsam für die Seltenen	www.gemeinsamselten.de	Social Network	Innovation contests for patients with rare diseases
Inspire	www.inspire.com	Social Network	Social networking health site
PatientsLikeMe	www.patientslikeme.com	Social Network	Data-driven social networking health site
Sermo	www.sermo.com	Social Network	US-based social networking site exclusive to physicians
Wiki Surgery	www.wikisurgery.com	Wiki	Surgical encyclopaedia

conclusion

We began this report by looking at the serious challenges in healthcare and the emerging need for innovation in this area. Put simply, the current trajectories for the delivery of reliable and high quality healthcare at a sustainable cost cannot be supported much further – and so there is a need for radical change across the sector. This is true irrespective of the underlying business model and level of state involvement.

The question then is how innovation across the sector might be accelerated – and there are valuable lessons here to take from the major changes seen elsewhere as a result of opening up the innovation process. Innovation has always been a collaborative, multi-player activity – but in today's knowledge rich environment even the largest organisations are recognising that *'not all the smart guys work for us'*. This drives a search to engage and employ a wide range of additional players – from inside and outside the organisation's boundaries in multiple ways which allows the innovation net to be cast much more widely. (We discuss some of these trends in an earlier AIM Executive Briefing, 'Open Collective Innovation: the power of the many over the few').

...the current trajectories for the delivery of reliable and high quality healthcare at a sustainable cost cannot be supported much further...



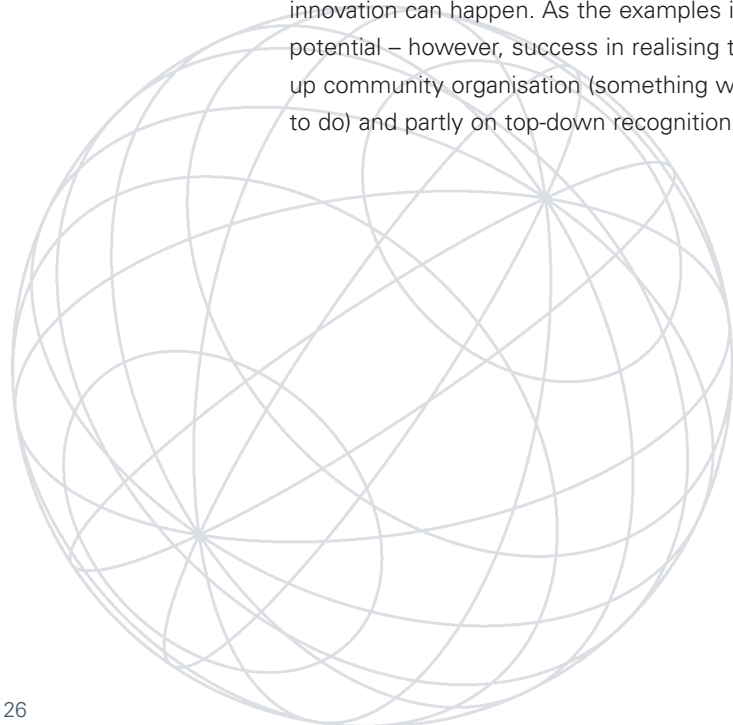
There are many examples where patients have played a key role in developing solutions to their healthcare challenges...

One fruitful direction for many public and private sector organisations has been to seek the ideas and involvement of their users – and the potential certainly exists for doing so within healthcare. There are many examples where patients have played a key role in developing solutions to their healthcare challenges – and there is evidence that this process is accelerating. In this report we have tried to focus on one of the new avenues along which such engagement might take place – the growing use of online and interactive platforms in the healthcare sector, often termed as health 2.0.

Health 2.0 platforms seem promising for two reasons. Firstly, Web 2.0 technologies offer a growing number of ways in which patients can acquire a voice on the internet, and that voice can be heard by others, with the conversations moving towards shared solution generation. Compared to the first generation of the internet, Web 2.0 offers significant advances in user participation, openness, and network effects. We know that community-based innovation in online communities works in other industries – and potentially healthcare can profit from it as well.

Secondly, patients obtain easier access to health-related information and are able to gain a better understanding of their health status. In peer-led patient communities, this means that patients (and their carers) can not only provide each other with knowledge and support – they can also enable one another to comprehend the necessary medical information and science in the context of the respective disorder. Such communities, characterised by a high degree of interaction between users, and reciprocal exchange of information, have been shown to be powerful engines of innovation.

As with so much of the information revolution, the technical possibilities outstrip our capabilities to use them to full effect. But there is evidence that we are learning, not least through powerful social networking approaches which are becoming so much more familiar with the widespread use of Facebook, Twitter and other platforms. Building interactive online communities and mobilising these towards meeting key needs and dealing with shared problems is of growing relevance – and in some ways offers one of the most concrete ways in which a ‘Big Society’ approach to social innovation can happen. As the examples in this report show, there is considerable potential – however, success in realising that potential will depend in part on bottom-up community organisation (something which patients groups have already learned to do) and partly on top-down recognition, support and user-education.



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