SCENE SETTER

The importance of taking a systems approach to person centred care

Since the end of the second world war healthcare has changed greatly. Advances in treatment mean that the average life expectancy in the UK, for example, has grown by 20 years. But this has come at a cost. Health systems are significantly more complex with care becoming ever more subspecialised.

Increasing numbers of health and social care professionals are involved in each patient’s journey through the system—reflecting the changing needs of populations that are ageing and living longer with co-morbid chronic conditions. Within this complexity the service user risks getting lost as different parts of the health and social care system struggle to coordinate with each other. Too often services are delivered in ways that fit with abstract processes (including how they connect within and between organisations); thinking focuses on:

- Establishing policies that set clear and explicit goals and directions regarding quality (including defining what quality means for an organisation);
- Processes and identifying indicators to monitor those processes (including how they connect within and between organisations);
- Identifying and assessing risks to human, technological, and organisational safety and performance (including how these are distributed within and across organisations and who owns them);
- Creating pre-emptive and mitigation controls to deliver safe and consistently reliable results;
- Measuring process performance and monitoring the efficacy of controls; and
- Continuously improving through the analysis of performance and the adoption of necessary process changes to achieve results

Combining systems thinking with the co-creation of person centred care offers a powerful framework for redesigning healthcare. Healthcare can learn from other complex sectors where such systems based approaches have resulted in significant improvement: capitalising on the potential of person centred care and systems thinking will provide a significant step forward in addressing the health challenges of today and tomorrow.

KEY MESSAGES:
- There is a growing demand for co-created PCC—both as a preferred way of experiencing care and as a means to improve quality.
- Despite this and examples from around the world, it is not yet a reality for all.
- Systems thinking offers a framework to change as it enables local practitioners, providers, policy makers, and service users a way to map and tackle risks to quality care distributed along the patient journey.

DNV GL is a world leading certification body. We help businesses assure the performance of their organisations, products, people, facilities, and supply chains through certification, verification, assessment, and training services.

We support over 2200 healthcare providers around the world to apply systems thinking to address their risks and ensure the care they provide is quality focused and person centred. We do this through healthcare accreditation, managing infection risk certification as well as other management system certification and training.

The DNV GL Group operates in more than 100 countries. Our 16 000 professionals are dedicated to helping our customers make the world safer, smarter, and greener.
We must harness the energy, insight, and expertise of patients, carers, and the communities that support them to help drive change.

Patient centred care is central to the mission of healthcare, yet traditionally neither patients nor the public have had the power to shape the services they use and pay for, or define their value. As a result, many patients find services difficult to navigate, disempowering, burdensome, and seemingly designed to frustrate.

There have been repeated calls to enlist patients’ help to reform systems poorly geared to meet current health challenges, subject to political meddling, and permeated by competing interests that fuel overdiagnosis and overtreatment. UK and US policy supports person centred care and shared decision making, and the World Health Organization champions it. We know it improves the quality of care and promotes appropriate use of services. There is broad agreement on what it is, and guidance on how to deliver it. The challenge remains one of overcoming “system” inertia and paternalism.

This Spotlight series, developed in partnership with members of The BMJ’s patient advisory panel and enlivened by a roundtable debate and interviews with discussants in the US, India, Uganda, Equador, and mainland Europe, seeks to inform, inspire, and spur change.

There is wide support for measuring and incentivising person centred care (p 4). In New South Wales districts are competing to provide it, with promising results (p 7). Robert et al describe how to codesign services with patients and carers (p 24). And the familiar message that strong leaders who ensure that all staff are responsible for patient partnership and person centred care can transform failing services fast is repeated in a podcast on thebmj.com.

It’s agreed that feedback from patients and their families should be more rigorous and used to inform practice, not merely collated for research. Nelson illustrates the value of systematically collecting information on patients concerns and priorities at the point of care and using outcome measures that they identify (p 16).

The rising number of people living with long term conditions, multimorbidity, and frailty requires services to be radically redesigned, and Eaton and colleagues highlight new approaches (p 13). These have to be based on a better understanding of what people need from health and social services, and patients can be crystal clear about this (p 15).

People who live with long term conditions are already in charge of their own health and if given the chance, willing to take on even complex management tasks. But it won’t happen without development of the science of care and support planning, better training of front line clinical staff, and inclusion of patients and carers in multidisciplinary teams (Frosch, BMJ 2015;350:g7767. See p 15).

Tailored support reduces dependency and can help the disadvantaged most. All services should keep the burden of treatment on patients as low and “minimally disruptive” as possible.

We also need to find better ways to listen to patients and ensure their voice is included and heard in medical forums. Better conversations are also core to realising shared decision making based on individual priorities and preferences. The quality of the information on which joint decisions are based needs to be improved too, and innovative decision aids hold promise (p 27).

The democratisation of health information, use of social media, rapid growth of networked patient communities, and new technologies have changed the landscape and provide new opportunities to harness the energy and expertise of patients. Clinicians and medical educationalists must catch up. Empowered, engaged e-patients are growing a social movement and spearheading a shift in roles “as profound as women’s liberation,” says deBronkart (p 19), who suggests we need a new science to understand and optimise the patient’s role.

Although the global flow of information has transformed many aspects of our lives, it has bypassed chunks of the health sector and it is still hard to get full access to personal health records. But there is welcome news on how the international move to open notes to patients is gaining momentum (p 10). However, it needs to go beyond giving people “viewing rights.” Montori emphasises (p 12) that indigestible records must be made more useful to patients (and doctors) and foster communication, not substitute for it.

In an unequal world the issue for billions of people is not whether care is patient centred but whether it is available at all, its poor quality, and its high cost. Anger and disillusionment are spurring change, however, and Jain provides illuminating examples of how patients’ rights are being advanced by effective advocacy in India, and local communities are holding the health sector to account (p 22).

It’s time to get real about delivering person centred care. It’s not a panacea for all of medicine’s ills, but we should not underestimate its contribution to tackling them. Working collaboratively and sharing decisions about care, services, and research is challenging. It requires a sea change in mindset among health professionals and patients alike. But its rewards are rich and reaped mutually.

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How can we get better at providing patient centred care?

Participants in our discussion on person centred care in January agreed that a change in culture and better use of technology could benefit both patients and doctors. Emma Parish reports

When the news is filled with stories of overflowing emergency departments, understaffed hospitals, and long delays in timely treatment for patients, where is the focus on providing care which centres on people’s needs and priorities?

We have been talking about the importance of person centred care for decades, and frustration at the slow pace of change on the ground was tangible among the patients, clinicians, and patient advocates invited by The BMJ to discuss the topic.

Angela Coulter, from the Informed Medical Decisions Foundation, acknowledged that, “most nurses, most clinicians do their utmost to treat people with dignity and respect and to listen to them,” but underlined that in person centred care “we’re talking about something that’s more ambitious than that.” Alf Collins, clinical associate in person centred care at the Health Foundation, pointed out that all medical care must show people “dignity, compassion and respect.” But for it to be person centred services must also be well coordinated and structured in a way that supports and empowers people to take charge of their health and long term conditions.

Providing people with the support they need to cope with illness and manage their health is not a luxury but a necessity, participants agreed, and it cannot be fully achieved without restructuring traditional models of healthcare.

“Physician centred models” that have subverted patient centredness must be abandoned, said Rupert Whitaker of the Tuke Institute. Major reorganisation of services needs patient engagement and involvement, and this means a cultural change.

Sara Riggare, who has Parkinson’s disease, made the point that she (along with millions of others who live with long term conditions) is already in charge of her health. “I spend one hour per year with my neurologist and 8765 hours in self care.” The system must recognise what patients do for themselves, she said, and all agreed that inflexible paternalistic systems must change if they are to successfully support self care.

There was consensus that culture change is well overdue and that strong leadership of clinical teams and reform of medical education is essential. Coulter acknowledged the “major advances in undergraduate training” but emphasised that the “problem comes in postgraduate” education. She called on the royal colleges to take responsibility for leading change to ensure the principles of person centred care were implemented. Reaching a point where clinicians can feel able to admit “they can’t and don’t know everything” is, it was suggested, fundamental to changing the perception of how people participate in their own care.

The inflexibility of the current structure of healthcare is a problem that both patients and doctors struggle with, said Michael Seres, who has Crohn’s disease. Many people are left navigating the system alone. “If you want to manage your complex conditions, you do it your way and your healthcare providers have to work round you.” Ben Meams, a consultant in acute care and elderly medicine, agreed: “If we’re truly going to be person centred I think we’ve got to move away from primary and secondary and tertiary [care] . . . you have to put the person in the centre of the process and then allow all of our systems to [provide the] resource the patient or the person

AT THE ROUNDTABLE

Fiona Godlee (chair), editor in chief, The BMJ
Tessa Richards, senior editor, patient partnership, The BMJ
Rosamund Snow, patient editor, The BMJ
Navjoyt Ladher, clinical editor, The BMJ
Angela Coulter, director of global initiatives, Informed Medical Decisions Foundation (www.informedmedicaldecisions.org)
Paul Wicks, vice president of innovation, PatientsLikeMe (www.patientslikeme.com)
Michael Seres, founder, 11 Health (www.11health.com)
Alf Collins, clinical associate in person centred care, Health Foundation (www.health.org.uk)
Jeremy Taylor, chief executive, National Voices (www.nationalvoices.org.uk)
Dave deBronkart, cochair, Society for Participatory Medicine (www.participatorymedicine.org)
Amir Hannan, general practitioner and member of clinical commissioning group board
Alexander Silverstein, past president, International Diabetes Federation’s young leaders in diabetes project
Paul Hodgkin, founder, Patient Opinion (www.patientopinion.org.uk)
Ben Meams, consultant in acute care and elderly medicine, Surrey and Sussex Healthcare NHS Trust
Sara Riggare, PhD student in health informatics, Karolinska Institute
Rupert Whitaker, founder, Tuke Institute (www.tukeinstitute.org)
Stephen Leyshon (observer), DNV Healthcare
The current “factory-style way of processing patients” has been to the detriment of good person-centred care, he argued.

**Change the medical culture and create new models of care with patients**

Ideally, each contact with healthcare would be with the providers best suited to meet an individual’s needs. One example cited was people who have behavioural or mental health disorders and social problems. Whitaker, proposed, “you need to have a team which includes nurse, psychologists, clinical social worker so that those issues are addressed fully and competently because they’re key to helping a person get well and stay well and not need to come back.”

Amir Hannan, a general practitioner, said we should question why emergency departments seem to be the first choice for people seeking care. Jeremy Taylor, from National Voices, suggested that it was not just a question of being unable to access care elsewhere. It reflected people’s genuine concern about their health, and knowing more about their worries and their expectations would help shape the delivery of services. Several participants at the roundtable made the point that an underappreciated part of a clinician’s role is to reassure. Rosamund Snow, The BMJ’s patient editor, said, “If you’re seeing a worried but well person, you’re doing your job.”

Coproduction of healthcare was widely seen as a positive step, with patients and clinicians “sharing the work.” Some argued that “patients are on the team but just not recognised.” Seres spoke of the “real role and great responsibility” of patients. As a patient, he said, it is “easy to pass the buck onto the clinicians and the professionals,” but if you do “you don’t have a partnership, and you don’t have a relationship unless both parties work at it.”

Alex Silverstein, past president of the International Diabetes Federation’s young leaders in diabetes project, referred to the “enormous disconnect” between patients and clinicians and...
agreed with the need to determine “active shared goals.” Determining these goals, recording them, and measuring whether they have been reached is important. Hannan discussed an initiative used in his practice where patients pledge their own health related goal as part of NHS Change Day. This is recorded in the medical notes and revisited in future consultations. Doing this provides a sense of “ownership” and promotes a “partnership of trust,” he said. He also urged greater patient involvement in commissioning services.

Taylor spoke of the value of harnessing the collective patient voice to push for new and better designed services. Rigaree agreed. All patients, she said, stand to benefit from the advocacy of patient groups and the efforts of individual patient leaders.

An important warning note was sounded by some that any advances in patient empowerment must ensure the less vocal and more vulnerable are not excluded. Too many people, Coulter warned, still feel that they are on their own and they “don’t belong to patient support groups.” Participants agreed that clinicians should see it as a priority for “everyone to be empowered.” The default position is recorded in the medical notes and revisited for the next consultation. Doing this provides a sense of “ownership” and promotes a “partnership of trust,” he said. He also urged greater patient involvement in commissioning services.

New technologies, better relationships

The use of new technologies to engage and empower people was discussed. A show of hands around the table found many people were using wearable activity trackers and mobile technology to monitor their health. Paul Wicks, from PatientsLikeMe, drew attention to the fact that many people now use the internet as “pre-primary care.”

The academic community need to realise “that’s where the action is,” agreed Paul Hodgkin, a former general practitioner and founder of Patient Opinion. “Patients have a voice now, and it’s a public voice. They’ve got Twitter, they’ve got Facebook...PatientsLikeMe, support groups” and so “they’ve got solidarity.” If more clinicians were to see the benefit of these already available resources for patients, including peer to peer support, and direct people to them, it might give more time to focus on those who need immediate attention.

Amid talk of system change and mindset shifts, participants were encouraged to come up with practical things that could be done now to advance person centred care. The list was long and included letting patients email clinicians, get results of routine blood tests texted to them, and using teleconferencing more widely (box, previous page). However, participants agreed that we should guard against moving to a “consumer” focused system.

Knowing about ways that promote person centred care is important, and so is incentivising them. “We’ve got measures to determine if person centred care is delivered. We just need to use them,” emphasised Coulter. There was broad agreement that following the principle “what gets measured gets done,” doing this for person centred care would enable it to be prioritised by healthcare providers.

But ultimately, participants agreed, “healthcare is about relationships.” If we want to improve the quality of healthcare, and people’s experience of it, we need to manage expectations and bridge the divide between physicians and patients. As Silverstein said, “we’ll only get to a partnership model when we reach a common position that what patients want and what GPs [and other doctors] want are actually the same thing.”

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PUSHING FOR CHANGE AND THE POWER OF PATIENT ADVOCACY:

Perspectives from international discussants from the US, mainland Europe, India, Uganda, Equador

The following are extracts from a podcast on thebmj.com. To listen to the complete podcast, visit www.bmj.com/patient-spotlight

Dominick Frosch, associate professor, Patient Care Program, Gordon and Betty Moore Foundation

“Despite the wealth of research and evidence on how to advance patient centred care we are still not seeing it. But I am optimistic—access to information plays a role and so do levers such as incentivising and rewarding doctors to provide it; and engaging patient and families in organisational decisions”

Maggie Breslin, US researcher, Mayo Clinic, Patient Revolution

“We asked people if they wanted to participate more in decision making with their physician and they said yes. But when we asked how likely they were to question or challenge their doctors they said they would never do that because they were fearful that their doctors would not [then] provide the best care for them”

Cristin Lind, patient advocate, rare diseases, Sweden, and carer of a child with complex special needs. “My journey towards advocacy followed many, many years of being kind of passive. It took me a long time to understand my role and to see that I was in the driving seat. What helped me acquire the confidence to do this was fellow parents, not health professionals”

Corine Jansen, chief listening officer, Radboud University Medical Centre, Hospital, Netherlands

“How can you treat patients without listening to them and knowing their health story? The 10 minute consultation is not long but if you ask the right questions it’s long enough. But for physicians to be of maximum help the patients themselves must be better prepared for consultations and be able to get their story across concisely. Then the consultation can focus on care not merely treatment for disease”

Rakhal Gaitdonde, chair, community advisory board of the National Institute for Health Research on TB

“In India the public health sector is still weak and not the dominant one and the cost of seeking care can be very high. But we see public groups, NGOs, and civil society, supporting patient and victim groups and challenging the health sector to look beyond the issues of access and availability and focus also on its quality and the broader determinants of health—and the relevant research agenda”

Robinah Alambuya, president of the Pan African Network of People with Psychosocial Disabilities, Uganda; Daniel Iga Mwesiwa, executive medical director, Mwesigwa Medical Centre, Uganda

“When I escaped from the mental hospital I had no [formal] identity and I was almost killed by soldiers as a result”

Robinah: “The problem [for me] was that no one identified that I had mental health problems. But advocacy by people with mental health conditions in Uganda has made a difference. Through speaking up for ourselves we can [and have] reduced stigma and we have hope now for we are being consulted”

Jonas Gonsseth, chief executive, Gaerente Hospital de Especialidades Guayaquil, Equador

In the reform of a failing hospital where there had been widespread public demonstrations against the poor standard of care, corruption, poor governance, and failure to treat patients with dignity and compassion it was essential to involve patients and members of the local community from the start. To give them an oversight role in clinical and managerial decision making”
New South Wales mounts “patient based care” challenge

The Clinical Excellence Commission in New South Wales is driving person centred care by stimulating districts to compete to provide it. Karen Luxford and Stephanie Newell describe the integrated approach, its uptake, and encouraging early evidence of change.

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Stephanie Newell chair, partnering with patients advisory committee, Clinical Excellence Commission, 227 Elizabeth Street, Sydney, New South Wales, 2000, Australia
Correspondence to: K Luxford karen.luxford@cec.health.nsw.gov.au

The principles of patient centred care and the mantra of “nothing about me without me” have gained broad support, but it’s proving hard to adopt and embed them in routine practice. New ways of thinking and tackling resistance to change are needed, and a range of initiatives are being pursued. We describe the approach being taken in New South Wales, Australia’s most populous state, with 7.4 million residents and 1.66 million public hospital admissions a year. This has focused on the development of a “patient based care challenge” aimed at spurring system-wide integrated change to promote patient centred care. The term patient based care was introduced with the aim of making patient centred care more broadly recognised as everyone’s responsibility—from the executive through to frontline clinicians and staff—with care systems included as well as bedside care. We discuss how the health districts have responded to this challenge.

Strategic and organisational change

Healthcare services that have taken a strategic patient based approach to change have witnessed benefits for patients, clinicians, and managers, with improved staff satisfaction and retention rates and decreased absenteeism. A 2013 systematic review highlighted the importance of taking an integrated organisational approach, noting the positive association between patient experience, clinical outcomes, and use of resources—for example, length of hospital stay.

Achieving patient centred care at the organisational level entails moving beyond the traditional focus of quality improvement on clinical measurement and audit.

Putting the challenge to New South Wales

The Clinical Excellence Commission was set up in 2004 to promote and support improved clinical care, safety, and quality across New South Wales. The commission monitors state-wide incident reporting and implements quality improvement initiatives to address key safety and quality problems identified. In 2010, a consumer adviser panel was established to actively involve patients, carers, and community members in all aspects of the commission’s work. In 2011 the commission developed a “patient based care challenge” for district healthcare services in collaboration with a partnering with patients advisory committee, which comprised patients, clinicians, managers, and policy makers. Patients and families highlighted the importance of engaging with patients in care at the bedside but also in health service governance and strategic decision making.

The 26 strategies included were grouped under nine domains drawn from evidence of effective strategies used by leading patient based health services (box 1). Although some strategies are specific to hospital settings, most can be used across a range of healthcare settings. We framed the overall strategy as a challenge to health services to reflect the difficulties of making system-wide change and to infuse a competitive aspect into the process.

In 2012, the commission issued the challenge to all 15 local health districts across New South Wales. Each district

![Uptake of challenge strategies among districts in New South Wales, Australia (number of strategies at sign-up and progress at October 2013 and October 2014)](chart.png)

**Fig 1** Uptake of challenge strategies among districts in New South Wales, Australia (number of strategies at sign-up and progress at October 2013 and October 2014)
is governed by a board appointed by the minister of health. To gain senior executive commitment and promote sustain-
ability, boards were invited to sign-up to the challenge.
Initially, we recommended that districts focused on up to
three priorities from the 26 strategies in the first year. This
was to ensure that change was seen as manageable
and to promote ongoing commitment by creating short
term progress. The decision was also pragmatic because
a shift towards patient based care tends to be incremental
and typically takes 5-10 years. Flexibility was also seen as
important so that districts could respond to local concerns
identified by patient survey data.
We developed an online guide to the challenge and com-
mission staff helped districts by providing advice on build-
ing staff capacity (such as learning what quality care means
from the patient perspective and patient based communica-
tion skills) and programmes to support specific areas such as
systems that allow patients or family to escalate care for
deteriorating patients (see box 2). With guidance from the
commission, districts established multidisciplinary teams
that included patients, carers, and community members to
identify local priorities and coordinate strategy uptake.
Response so far
Thirteen of 15 local health districts committed to the chal-
lenge in the first year. The two remaining districts wanted
to complete new district-wide strategic plans before com-
mitting. Most districts focused on two or three strategies,
although six adopted more than three. The most common
initial strategies selected were: start each board meeting
with a story of patient care from your service (six districts),
arrange for board and executive members to visit wards
regularly (five), involve patients, families, and carers in
governance through participation in committees (five); encour-
age staff to view patients, family, and carers as core
members of the healthcare team (four); and implement
processes to support patient or family activated escalation
care for deteriorating patients (two). By October 2014,
the 13 districts had adopted an average of 19 (range 13-25)
strategies (fig 1). Box 2 gives examples of improvements
implemented.
How the challenge is being assessed
Evaluation of the challenge will include comparison of
quantitative and qualitative data from before and after its
introduction. Data will come from:
• State-wide patient experience surveys
• Annual staff workforce surveys (NSW Your Say
Workplace Culture Survey including a validated
workforce/yoursay/2013/Documents/nsw-health-full.
pdf)
• Patient complaints data (collected locally and through
gov.au/clinical-incident-management)
• Annual safety and quality culture audit (NSW Quality
Systems Assessment conducted in health care
services)
Audits of clinician attitudes conducted in 2011 (before the
challenge) and again in 2012 and 2013 show an increase in
the proportion of clinicians who think that patients, families

<table>
<thead>
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<th>Box 1</th>
<th>Patient based care challenge</th>
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<tr>
<td>1. Leadership commitment</td>
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<tr>
<td>• Start each board meeting with a story of patient care from your service—told by a patient or carer face to face, recorded, or read by staff</td>
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<td>• Spend more than 25% of the board’s meeting time on quality—eg, put quality of care first on the agenda, create a quality dashboard for review</td>
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<td>• Arrange for board and executive members to visit wards regularly to talk with staff and patients—eg, conduct regular executive rounds and implement a process for the board to consider frontline concerns about patient care</td>
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<td>• Provide training to senior leaders to promote recognition of their critical roles as opinion leaders and champions of patient centred care</td>
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<td>• Engage patient advisers in strategic planning processes—seek patient, family, or carer input through focus groups, committees, or electronic methods to help set future priorities for the organisation</td>
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<td>2. Communicate the mission</td>
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<td>• Develop and promote an organisational mission statement that embodies the values of patient based care—eg, “The patient at the centre—every patient, every time”</td>
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<td>• Communicate the mission to new staff at orientation—eg, get the chief executive to speak at staff induction sessions about the importance of all staff in creating patient based care</td>
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<td>• Share senior leaders’ personal stories to engage staff in patient based values—eg, training sessions in which senior clinicians or executives tell stories of where care could have been better for their patients, their loved ones, or themselves</td>
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<td>3. Engage patients, family and carers</td>
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<td>• Engage patients, families, and carers in governance through committee membership, including quality and risk management and advisory committees</td>
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<td>• Engage patients, families, and carers in design of processes, new facilities, and staff interview panels</td>
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<td>• Implement a patient based visiting policy—consult with patients, families, and staff on current policies and consider more flexible approaches that recognise family and carers as integral team members</td>
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<td>4. Support engagement to transform care</td>
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<td>• Encourage staff to view patients, family, and carers as care team members—eg, implement techniques that promote recognition of patient goals for care</td>
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<td>• Implement processes that enable patients or family to seek urgent care if they have serious concerns about the status of the patient</td>
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<td>• Conduct handover at the bedside and include patients and carers</td>
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<td>• Engage patients in medication management and review—eg, conduct medication reconciliation processes with patients and carers to help avoid omissions and errors</td>
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<td>5. Use patient feedback to drive change</td>
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<td>• Use patient feedback from a range of sources (surveys, focus groups, anonymous shoppers) to gauge service quality and inform all staff—eg, get patient and family advisers to survey current or new patients in waiting rooms or work with junior medical staff to conduct a patient shadowing project</td>
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<td>• Review data on patient care experience at each meeting as an indicator of quality—eg, patient survey reports</td>
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<td>• Implement processes to provide real time feedback to staff to enable patient concerns to be resolved during care—eg, bedside electronic systems or “patient friend” models (where a former patient talks to ward patients and alerts management to concerns)</td>
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<td>6. Focus on work environment</td>
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<td>• Regularly assess work culture and staff satisfaction—eg, conduct an annual staff survey to monitor staff engagement and use findings to identify areas for improvement</td>
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<td>• Celebrate staff successes visibly—eg, introduce a patient nominated award for staff member of the month</td>
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<td>7. Build staff capacity</td>
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<td>• Implement organisation-wide training in patient based values and associated communication skills techniques—eg, focused on effective patient and carer engagement techniques</td>
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<td>• Involve patients and carers in staff training, including sharing stories of good and poor experiences of care</td>
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<td>8. Learning organisation culture</td>
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<td>• Enable staff to identify problems with delivering care and solutions, focusing on priorities identified by patients</td>
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<td>• Ensure processes are in place to enable ongoing patient and family engagement in open disclosure after adverse events</td>
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<td>• Share the learning from tragic events to improve quality of care—eg, provide forums for staff to openly discuss key lessons from incidents where patients have been harmed</td>
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<td>9. Accountability</td>
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<td>• Include accountability for patient care experience in all job descriptions and provide feedback in performance reviews</td>
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SPOTLIGHT  PATIENT CENTRED CARE

Box 2 | Examples of change resulting from the challenge

Building staff capacity through training

Several districts identified staff training as fundamental to long term success. This focus also supported compliance with new national government standards for health service accreditation.

For example, one district held training for all clinical leaders and managers, including board chairs, executives, senior clinicians, and safety and quality experts. Training focused on research evidence, local success stories about patient engagement, and communication skills. Patients and carers shared their stories (both good and bad) firsthand. Participants consistently identified these as a key motivator for change, with patients who had spent long periods in hospital and clinical staff who had become patients providing the greatest influence.

A training film was made available for use by local champions and other districts. Changes put in place after staff training sessions have included involvement of patients and families in design of new facilities and governance committees, moving nurse shift handover to the bedside, and including patients in medication reconciliation.

Changing visiting hours policy

In one district the board endorsed 24/7 patient directed visiting after a survey showed that patients, families, and carers found visiting hours too restrictive and wanted further recognition by staff that they were key members of the care team. Staff, however, soon expressed reservations about loss of devoted patient rest time and potential patient safety and privacy problems. A webinar was held in collaboration with the US patient centred organisation Planetree and the CEC to find out how other healthcare facilities had introduced patient directed visiting.

The final agreement, reached in collaboration with local clinicians and patient advisers, was to allow patients to nominate carers who will have 24/7 access as part of the formal care plan. Equally, some patients may want to have “no visitors” recorded in the care plan. Evaluation indicates 100% satisfaction of patients and visitors and 99% satisfaction of staff with the changes. Patient comments included: “I feel like doctors and nurses are more interested in what my family and I think is important” and “Excellent. My daughter was visiting me last week and noticed I was being given the wrong medication and was able to tell the nurse.”

Empowering patients and family to escalate care

Several districts implemented a process to support patient or family escalation of care for deteriorating patients. Thirteen hospitals introduced REACH (Recognise, Engage, Act, Call, Help)—a stepped process that provides a safety net for patients and families with serious concerns. The model was developed and implemented with the involvement of patients, families who had experienced serious incidents, clinicians, and managers. It encourages patients and families to initially engage with their treating doctors and nurses while providing a route for action (“request a clinical review”) or call for emergency help (“call this number for a rapid response”) if still worried. CEC worked with each hospital to decide on the local escalation process and responders (such as medical emergency team or intensive care outreach nurse). Education sessions for all staff highlighted benefits and allowed clinicians to discuss concerns (such as fear of inappropriate use).

If long term evaluation shows success our system-wide approach may also be applicable in other countries

index of 82% (state average 67%). Qualitative information about barriers and enablers for implementing the challenge is being collected to provide insights for future uptake.

We will also look at the effect on length of stay in hospital and patient mortality and financial implications of the implementing of specific strategies. Outcome reporting for REACH will include the costs and benefits to hospitals of averted patient deaths and decreased transfers to intensive care because deterioration is detected earlier.

Although the cost effectiveness of the challenge is not yet known, so far the resources spent are modest and include the salary of 3.5 full time CEC staff (1 director, 2 program coordinators, 0.5 project support officer). Ancillary feedback suggests costs to the districts have been minimal because the strategies have mostly focused on improving communication, with staff attending education sessions that are already part of their normal development activities. One area flagged as having potential future resource implications is employing staff to support sourcing and briefing increased numbers of patient and family advisers participating on local committees and quality initiatives.

Lessons learnt and policy levers that will promote change

The role of clinical leaders and executives as champions of change seems pivotal. Health services have responded positively to the flexible and incremental approach used to improving care and the competitive nature of rising to the challenge. Key supporting factors seem to include broad acceptance of patient involvement by Australian clinicians and health services because of a long history of health agencies and national policy development. Uptake has been helped by the inclusion of patient directed care as a key national goal for safety and quality in health care. The introduction in 2013 of mandatory accreditation standards for health services, which stipulate that consumers should be engaged in organisational governance, has driven further interest in partnership approaches to change.

As uptake of the challenge strategies is in the early stages it is hard to judge whether it has been a success. Introduction of new policies (such as patient directed visitation) by participating districts indicates some benefit. Some improvements in areas such as patient experience feedback and staff satisfaction have also been reported. One district has noted patients reporting high levels of engagement in care decisions (93% vs state average 60%) and a high staff engagement and carers are integral members of the healthcare team (from 79% in 2011 to 92% in 2013). As of February 2015.

Although these factors may have facilitated the local response to the challenge, if long term evaluation shows success our system-wide approach may also be applicable in other countries. Comparison with other approaches such as reimbursement and incentives may shed light on what contributes to effective, sustainable change.

Cite this as: BMJ 2015;350:g7582

ONLINE COMMENTARY

“Our research has shown the benefits of person centred care plans. Use of jointly agreed care plans is associated with a reduction in the length of hospital stay after hip fracture and chronic heart failure, reduced patient anxiety and uncertainty, improved pain relief, reduced medical complications after surgery, and cost savings”

Inger Ekman and colleagues on the work of a dedicated unit at the University of Gothenburg, which is leading and evaluating Sweden’s approach to implementing person centred care (BMJ 2015;350:h160)
For decades clinicians have experimented with making medical records available to patients. Now electronic medical records and associated secure internet portals provide patients the opportunity to view test results, medications, and other selected parts of the medical record online. But few patients are offered full access to their records; clinicians’ notes are rarely visible. After a demonstration project showed the acceptability of OpenNotes (www.myopennotes.org) in the US, several prominent healthcare providers decided to make clinicians’ notes available to patients online before further formal evaluation. We describe the OpenNotes movement in the US and how sharing notes with patients is spreading. We also underline the case for research to assess the long term effect of sharing notes and the potential to foster improved and truly collaborative care.

US OpenNotes initiative

The movement to share clinicians’ notes with patients in the US was spurred by the findings of a demonstration and evaluation project that included 105 volunteering primary care doctors working at three large and disparate institutions and 19,000 of their patients who were registered to use their patient portal (box 1 on thebmj.com). Most patients in the study chose to read their notes and reported benefits from doing so, with only a slight effect on primary care doctors’ workload. After 12 months, 99% of patients wanted to continue to have access to their notes online and none of the doctors decided to stop the practice.

In interviews, focus groups, and surveys, patients described how access to their notes gave them a new understanding of the importance of medications and more motivation to adhere to treatment. They reported that they were moved to change their behaviour after seeing words like “obese” in their notes. They reminded harried doctors about follow-up that had not been completed and shared the notes with family and caregivers when they could not remember the details of a visit. Elderly patients and those with little education were just as interested in reading their notes as young well educated people. In box 2 MM describes his experience.

Based on these results, the participating institutions decided to expand OpenNotes throughout their ambulatory services, including speciality as well as primary care. At Beth Israel Deaconess Medical Center, a large Harvard teaching hospital, 85,000 patients can now view their clinicians’ notes online, 220,000 patients have access at Geisinger, an integrated health system in rural Pennsylvania, and 128,000 patients in the University of Washington health system can review their notes.

Other US providers have followed their lead, including the Mayo and Cleveland Clinics, Dartmouth-Hitchcock Medical Center, MD Anderson Cancer Hospital, Kaiser Permanente Northwest, and Group Health Cooperative. The national Veterans Administration (VA) system now offers fully open records at all its centres, and a recent survey completed by 6800 VA patients reaffirmed results from the initial OpenNotes study. The Boston Children’s Hospital and Nationwide Children’s Hospital in Ohio have opened notes to parents and guardians and are looking at independent access for adolescents.

Sharing notes is not restricted to doctors. Most institutions open notes written by nurse practitioners and physician assistants, and some open those signed by other health professionals, such as clinical pharmacologists and occupational and physical therapists. Teaching institutions usually open notes written by registrars and fellows in the specialties, and by medical and nursing students. As part of the treatment process, some providers are also beginning to share notes written by specialists in mental disorders.

By December 2014, almost five million US patients had been provided with online access to their notes. Parallel developments in US health information technology have supported this spread, including government funding to increase use of electronic medical records. The Blue Button movement, initiated by the White House Presidential Innovation Fellows programme, encourages consumers to view and download their health information (http://healthit.gov/patients-families/your-health-data) and products such as HealthVault, a free Microsoft service, enable people to aggregate their health data in one online location.

The OpenNotes movement has attracted extensive media coverage, including publication of personal stories about benefits to patients and debate about the impact on
Box 2  Patient’s perspective

I was part of the original OpenNotes study so I have been reading my doctor’s notes for five years. Reviewing, downloading, copying, or sharing a note in your medical records isn’t a prescription. It’s an option. I can access the information or not, read and respond, or simply take it in. What is important is that the notes written by medical staff are understandable to patients, accessible, and accurate.

When the practice was in an early testing phase I provided information to my primary care physician as he typed his notes; the conversation about the proper terms to describe my current health sharpened our mutual understanding of my condition. Later I shared the note with family and was able to answer their questions in a way that would have been impossible without the text before me. Clarity about drug doses almost certainly enhanced my adherence, and I was also able to have a longstanding reference to a drug allergy I did not have removed from my record—something I had failed to achieve before by speaking to healthcare support staff. Reading the notes—and in my case jointly creating them—levelled the playing field, facilitated questions and comments, and deepened my already strong sense of trust in my doctor.

For notes written by specialists, I more often needed to clarify technical language by emailing questions. Several times I pointed out errors concerning my family history. Miscommunication between doctors and patients isn’t going to end with open notes, but it will help, and I think it will encourage people to take more responsibility for their health. It has provided me with better information and greater confidence that my doctors and I are on more equal terms and on the same page.

I know that some patients worry about privacy, but particularly if we are ill, I think few would dispute that full communication among all interested parties is far more important than limiting access.

Big bang versus an incremental change

Some providers have taken a “big bang” approach. Others have rolled out open notes sequentially as individual clinicians and departments decide to participate. Some have done “quiet” implementation with minimal communications or fanfare. Others prefaced patient access to notes with announcements in local media, informed patients through multiple channels, conducted portal registration campaigns, and used automated email messages to invite patients to read each new note as it is made available.

Most doctors want to understand how open notes will work, but beyond suggestions for ways to manage potentially sensitive or obscure terms few seem to want much teaching about it.

Clinicians adapt readily, and once open notes are switched on, few express ongoing misgivings. We have no reports of doctors turning back from sharing notes once they have started

| clinicians.11-13 The movement has also been endorsed by prominent clinical organisations, including the American College of Physicians, and by consumer organisations.14 15 There is also a growing call by patients for access to records, and suppliers of electronic medical record software, such as Epic (www.epic.com), are starting to build open clinicians’ notes into their products.

The US movement to share notes with patients is part of a global movement. Internationally there are many examples of initiatives enabling people to access their full medical records. Estonia launched a nationwide electronic record system in 2008 designed to include “transparent” access to doctors’ notes. Since 2009, “all healthcare providers have an obligation to send [an] agreed number of standardized medical documents to the electronic health record.”16 Taavi Lai, who was involved in developing the system, says there is “increasing pressure [from patients] to upload an increasing volume of data to the portal, as well as expressions of chagrin medical documents to the electronic health record.”16 Taavi Lai, who was involved in developing the system, says there is “increasing pressure [from patients] to upload an increasing volume of data to the portal, as well as expressions of chagrin and suppliers of electronic medical record software, such as Epic (www.epic.com), are starting to build open clinicians’ notes into their products.

The US movement to share notes with patients is part of a global movement. Internationally there are many examples of initiatives enabling people to access their full medical records. Estonia launched a nationwide electronic record system in 2008 designed to include “transparent” access to doctors’ notes. Since 2009, “all healthcare providers have an obligation to send [an] agreed number of standardized medical documents to the electronic health record.”16 Taavi Lai, who was involved in developing the system, says there is “increasing pressure [from patients] to upload an increasing volume of data to the portal, as well as expressions of chagrin, and that the rate of “hiding” notes declines as doctors gain experience with opening them to patients (unpublished data). Kaiser Permanente Northwest monitored email traffic between patients and clinicians for the first three months and found no change in volume (Monica Seidel, personal communication), echoing findings from the original OpenNotes study.6

Looking to the future

Face validity and growing evidence has convinced early adopters to embed open clinical notes into primary and outpatient specialty care. Although our experience suggests that open notes quickly becomes standard practice and requires little further attention, more evidence is needed to confirm whether transparent records help patients follow agreed care plans, medication regimens, preventive measures, or lifestyle changes. Do they respond more appropriately to referrals for tests and specialist care? As people gain better understanding of their condition, do open notes reduce or fuel their demand for investigations? How often are mistakes in documentation identified and corrected? Are there fewer missed appointments or fewer requests to be seen by a doctor? Are providers spurred to write more clearly or accurately? Does clinically important
communication and trust between patients and clinicians increase?

Open notes also provide a platform for further interventions. Emerging technologies will explain arcane medical language, link to educational interventions, and help those with poor health literacy. And inviting patients to co-author notes—essentially turning open notes into our notes—could enhance agreement on clinical priorities, reinforce patient engagement, and perhaps off-load some work from overburdened clinicians. Finally, full transparency will help clarify language, link to educational interventions, and help those with poor health literacy. And inviting patients to co-author notes—essentially turning open notes into our notes—could enhance agreement on clinical priorities, reinforce patient engagement, and perhaps off-load some work from overburdened clinicians. Finally, full transparency will help clarify

we worry the same trend may occur in patient-clinician communication: “Read the chart, and send me a message through the patient portal if you have any questions.” Ongoing access and review of their record and making sense of the information it contains could become yet one more task that “compliant” patients and caregivers must do. Open notes should reduce rather than exacerbate the burden of treatment. It should not replace the work of building trust between patients and clinicians or of seamlessly sharing information across healthcare systems. Patients are finally and eagerly gaining access to their records. How we reform the content of notes and deal with the unintended consequences to patient workload will determine the extent to which it proves a significant step towards patient centred care.

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MORE COMMENTARIES ONLINE

“We saw providing online access to medical records, seamless information exchange, the promotion of patient partnership, and peer to peer support as central”

○ UK general practitioner Farhan Amin on his practice’s aspirations to become a leading person centred surgery (BMJ 2015;350:h269)

“Our experience has shown that it is not sufficient to provide patients with viewing rights. They need to understand the content of their records too. This has been helped by an explicit consent model”

○ UK general practitioner Amir Hannan on moving to open notes to patients (BMJ 2015;350:h266)

“National e-health services in Sweden provide citizens with health information, contact details of providers, and interactive services where they can ask questions anonymously that are answered within seven days”

○ Maria Håglund and Sabine Koch on Sweden’s experience (BMJ 2015;350:h359)
SPOTLIGHT PATIENT CENTRED CARE

Delivering person centred care in long term conditions

Transforming care for people with long term conditions, including support for self management, requires comprehensive reform of health systems largely geared to provide acute care. Simon Eaton, Sue Roberts, and Bridget Turner explore the barriers to change, arguing that the success of new approaches will depend on whole system change and strong leadership.

Long term conditions are a major challenge to the sustainability of health services globally. Their increasing prevalence is associated with growing rates of preventable complications and premature mortality, resulting in soaring costs (box 1). These factors, coupled with higher expectations among patients and the public, create an urgent need to redesign health services, which are still largely geared to providing episodic acute care.

Definitions of long term conditions as “health problems that require ongoing management over a period of years or decades” fail to reflect the personal, social, and economic burden on the individual, their families, and wider community. Nor do they acknowledge that people with long term conditions spend just a few hours a year interacting with clinicians and healthcare services and more than 99% of their lives managing their conditions themselves. The challenges they face vary widely depending on their personal circumstances: the number, nature, and stages of their conditions; the need for lifestyle, specialist, and technical interventions; and their capacity to self manage effectively.

Individual priorities and goals also differ and may often extend beyond a condition specific or health focus, particularly for the increasing percentage of people living with multimorbidity or frailty.

It is widely agreed that person centred services for people with long term conditions should be coordinated; support self management; engage people in decisions; provide effective prevention, early diagnosis, and intervention; and offer emotional, psychological, and practical support. More needs to be done to realise the untapped potential of patient led care through increasing tailored information, education, and training; access to new technologies; and peer and community support.

Accumulating evidence and experience shows that people who are “activated”—that is, have the knowledge, skills, and confidence to manage their health effectively—are more likely to adopt healthy behaviours and have better health outcomes and care experiences. This may lead to better use of resources.

Thus, health services need to provide a comprehensive and coordinated range of interventions for populations but organised to provide a tailored response for each person. This requires fundamentally new ways of thinking about service delivery and relationships, recognising that whole system approaches are needed with support for self management as the central component, as set out in the chronic care model. Recent comprehensive programmes of care, such as TEAMcare in the United States and the Flinders programme in Australia, show that system wide organisational change can be achieved and improve clinical and personal outcomes.

Challenges and barriers

The barriers to introducing such whole scale change are, however, immense. A recent evaluation of a failed attempt to do this in the UK shows that the way change is introduced is vital. A top down approach, without clinical or management engagement and leadership, and failure to change attitudes from a biomedical and paternalistic approach, meant that support for self management was perceived as irrelevant and received little priority from staff or patients.

Clinicians’ mindset and approaches are important in effecting change. Many clinicians believe they already practise in a patient centred way, though patient surveys tell otherwise. Some don’t see support for self management as their responsibility or find the shift in the relationship and power dynamic uncomfortable. Guidelines and financial incentives focusing on disease specific biomedical approaches and misperception about lack of benefit support a climate of inertia. Limited consultation time and workload pressures also make it hard to explore new ways of working.

A further challenge is how services and clinicians respond to the diversity of individual needs and engagement in healthcare. For people already taking, or keen to take, a proactive and informed role, the traditional “clinician knows best” approach is frustrating. At the other end of the spectrum, around 40% of people report a poor understanding of their conditions or treatments, are lacking in confidence, or feel overwhelmed by the complexities of daily living.

Nevertheless, these individuals are still managing their health day to day and have the most to gain from additional...
**Box 2** Systematic care and support planning

**Preparation**—Most of us would feel uneasy about going into an important meeting and making snap decisions without having had a chance to think it through, yet we expect people to do this in the healthcare setting. Providing people with test results and prompts to list questions or things they’d like to cover beforehand may encourage greater participation.

**Discussion**—The subsequent consultation should enable the person to articulate what is important to them, identify needs and priorities, define their goals, and agree a plan for how these goals will be met. This should recognise the mutual expertise of the person and the clinician aiming to build self efficacy, promote problem solving, and support each individual’s self management efforts.

**Documentation**—The outputs of the consultation are summarised into a care plan that is owned by the person and also recorded in the clinical record and shared with other professionals as needed.

**Review**—Next steps should be agreed, including a date for review, follow-up plans, and clear guidance on whom to contact for support in the interim.

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**Box 3** Example of house of care approach to care and support planning

Whole health community—Tower Hamlets, London, UK

As part of a wider reorganisation, care and support planning was implemented for diabetes in 31 of 32 practices in Tower Hamlets, which has a disadvantaged, multiethnic population. Local community events, faith groups, and advocates supported people with poor health literacy, including through pre-appointment health education sessions. After patients attended for diabetes “tests and tasks” they were sent colour coded test results and prompts before a consultation with the GP or practice nurse around two weeks later. Over 90% of patients with type 2 diabetes had an annual care and support planning review and patient reported “involvement in care” rose from 52% to 82%. Diabetes outcome measures and staff job satisfaction improved. Extended appointment time for the care planning consultation was recouped through practice reorganisation and was cost neutral overall.28

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House of care. When used in the training programme, a blank outline of the house is provided and participants are asked to consider what needs to be in place to deliver and support the care planning process and then reflect on current local services. The examples shown here are those that have been consistently identified by teams across multiple diverse health communities.29

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Support11—colluding by continuing prescriptive approaches merely perpetuates poor outcomes and experiences.

Finally, we need to consider how change can be implemented at the pace and scale that is required. International evidence on the benefit of whole system approaches mainly comes from initiatives for specific conditions or within single organisations.16-16 22 However, in the UK people experience healthcare through multiple devolved teams facing conflicting incentives and drivers, with a focus on short term financial targets and surrogate outcomes rather than patients’ priorities. This encourages discrete, narrowly focused interventions rather than the whole system approaches that may have greater overall benefit.25

**Care and support planning**

Focusing on policy and culture is unlikely to lead to change unless there are practical approaches that clinical teams can understand and implement. The “house of care” has received prominence in the UK as a practical framework for a whole system population approach that can deliver a unique and coordinated response for each individual.26 27 At its heart is care and support planning—a “better conversation” that meets the demands of people to “plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.”28

Care and support planning is an ongoing, often annual, process to take stock, look forward, identify personal needs and goals, discuss options, and agree and coordinate a plan for how these goals will be met (box 2). A recent Cochrane review showed the benefits of such an approach, including the core components of preparation, goal setting, action planning and review.27 The authors underline that this is fundamentally different from, but embedded within, routine care.

Implementing care and support planning involves considerable organisational skills and attitudinal changes across the health community. The house of care provides a mechanism to achieve this (figure). It is not a fixed model to impose on clinical teams or organisations, but has several defining properties. As a metaphor, it emphasises the importance and interdependence of each element, with care and support planning at its heart. As a checklist, it can stimulate reflection on the “building blocks” available locally, areas needing improvement, and components that are missing. Finally, as an organising framework, it also provides a reproducible and flexible tool to engage clinical teams and local communities with the principles of the chronic care model14 in a way that both feels achievable and enables them to see their role within the change process.

The house of care was initially tested in diabetes by primary care teams as part of the year of care programme,30 but increasing experience suggests it can improve the care of people with multiple conditions (www.yearofcare.co.uk). The clinician training curriculum, which explores attitudes, behaviours, and clinic infrastructure changes simultaneously with skills, has shown that complex transformational change can occur in UK general practice enabling care and support planning to become the norm for large numbers people with long term conditions (box 3).

**Moving forwards**

Transforming support for people with long term conditions makes sense from every angle: improving wellbeing, developing a more positive sense of control, achieving better health outcomes, and potentially lower healthcare costs. It now seems possible to envisage this as the norm but substantial barriers and challenges exist. We need clinical and patient leadership to help navigate these challenges, along with system drivers and incentives, and practical support to encourage these new ways of working. People with lower activation levels, poor health literacy, and difficult social circumstances need specific and tailored support but have the most to gain.11 We believe that the success of any clinician, team, or organisation should be defined by their efforts to tackle these disadvantages and to ensure a person’s goals and priorities are always at the centre of his or her care.

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**COMMENTARY**

What I need to self manage my care

Managing my health has, and always will be, a partnership. I had type 1 diabetes diagnosed at age 18 months and I am now 27. Along the way my diabetes has been managed in a partnership between family (mainly my mother), friends, school, college, the workplace, the charity sector, health professionals, drug companies (who provide insulin, test strips, etc), the patient community (through peer support and online resources), and, most importantly, me, the person at the centre. As I have grown older, the responsibilities and level of involvement of each of these have changed, and I now feel confident in managing my health. These are the things that help me.

**Medical devices and repeat prescriptions**—I order these through an app and website installed by my general practice. I can choose which pharmacy my repeat prescription goes to or they can deliver to my house, similar to internet shopping. The app also lets me book appointments and look at my medical records when it suits me. My insulin pump has a programme to upload all my blood test results and carbohydrate and insulin intake, and I can access and analyse these at home on my laptop.

**Multidisciplinary healthcare team in secondary care**—I trust the team to provide me with the best advice and technology available, and the team trusts me to lead and advise them on what my care should look like.

**Education**—As I self manage for more than 99% of the time I need to understand how to treat my diabetes, and this requires ongoing education. The first self management education I received about diabetes was a week’s course with my nurse and dietitian when I was 18. I then also had a three day course for my pump. For me this was too little, too late. Healthcare professionals should provide age appropriate education for those responsible for the day to day management of their care (be that a carer or the patient themselves), at the time of diagnosis or signpost patients to appropriate education from charities or websites. I get my ongoing education, especially about the latest research, from patient communities on Twitter, Facebook, and other websites, without the need to visit health professionals. If we are to reach 385 million people with diabetes worldwide, this is the only sensible method. But patients should have access (and be directed) to approved online courses to ensure quality.

**Empathy**—The first step to regaining control in your life after being diagnosed with a long term health condition is to recognise the normality of shock, anger, and grief that you, or your carer, will immediately feel. You then have to slowly learn what positive steps you can take, from others that have been through the same experience. If people are to manage their health successfully we must recognise as a whole system that this support is generally found within patient communities rather than in a clinic. Health professionals should therefore be able to inform people about patient communities and online resources.

**Engagement**—This is different from compliance. It’s about finding opportunities for experiential learning and spending time to educate yourself about your condition through finding or providing peer support.

**Integrated services**—General practice and secondary services should be integrated and provide friendly personalised guidance, so that patients are keen and motivated to access all the avenues open to them. Luckily for me, my mother, my nurse, and my previous employers (Diabetes UK and the International Diabetes Foundation) as well as many of the fellow patient leaders I have met along the way have guided me to find and use the different services on offer.

I now feel I can manage my health independently except in a crisis. However, I don't think this is recognised: I am still requested to go to the hospital once every six months for an appointment that may not be needed, to take tests that I could access locally, and to look at healthcare data that are requested, delivered, and stored by my hospital—not by me. This is not person centred care, and health professionals should instead be focusing on patients that need more support than me.

For me the next logical steps are to create my own care plan, containing goals set and measured by me and accessible at a time and location that suits me (online or offline), and to work with the stakeholders I choose, from the list mentioned above, so that I can achieve and update my care plan.

What I don’t want is to be given routine outpatient appointments. People don’t want to spend time in clinics to manage their health; they want to do it at home in a way that suits them, like their banking or shopping.

**MORE COMMENTARIES ONLINE**

"The current focus on person centred care runs the risk of overemphasising independence and interdependence—which are facts of life for many older patients"  
Adam Gordon on the needs of frail older people (BMJ 2015;350:h370)

"Shared haemodialysis care does require flexibility in units where traditionally services have been set up to ‘do things to patients’"  
Martin Wilkie and colleagues on supporting patient independence in long term haemodialysis (BMJ 2015;350:h252)

"I want to be recognised as the most important member of the team: the one who know most about living with this disease."  
Dominick L Frosch, who has type 1 diabetes, on his bid to be treated as an equal in managing his disease (BMJ 2015;350:g7767)

People don’t want to spend time in clinics to manage their health; they want to do it at home in a way that suits them, like their banking or shopping.
Patient reported outcome measures in practice

Scores of tools to measure outcomes that matter to patients have been developed over the past 30 years but few are used routinely at the point of care. Eugene C Nelson and colleagues describe examples where they are used in primary and secondary care and argue for their wider uptake to improve quality of care.

Clinicians’ understanding of the effect of disease and treatment on patients’ daily lives is poor.1 In response to this problem, over the past three decades, hundreds of standardised measures have been developed to capture patient reported outcomes, including symptom status, physical function, mental health, social function, and wellbeing. However, the patient reported outcome measures (PROMs) movement has largely been driven by the agenda of researchers or service payers and has failed to focus effectively on improving the quality of care from the patient’s perspective (box 1). We use two examples to show how the use of PROMs in everyday practice has the potential to narrow the gap between the clinician’s and patient’s view of clinical reality and help tailor treatment plans to meet the patient’s preferences and needs.2

Barriers to routine use

Evidence shows that the systematic use of information from PROMs leads to better communication and decision making between doctors and patients and improves patient satisfaction with care.3 7 There is also evidence that patients report better outcomes—for example, improvement in depression.8 However, research on attempts to embed measurement of patient reported outcomes into routine practice has revealed many technical, social, cultural, legal, and logistical barriers to successful adoption.4 11

Clinicians are often reluctant to use PROMs routinely because they fear it will add to their workload rather than make them more efficient and effective. Furthermore, many clinicians who do spend time talking to patients contend that they already understand their patients’ problems and do not need additional information from them.

Patients generally welcome systems that routinely use PROMs. However, they say that patient reporting systems must be used well and not misdirect the focus of the clinical encounter, burden patients, or focus only on factors that have value to clinicians (box 2).

Any system designed to assess and respond to patient reported outcomes must include relevant and validated measures. These must be analysed and reported appropriately and the response to them made explicit in the notes. Identifying the best way to incorporate PROMs in pre-existing medical record systems while safeguarding privacy is challenging. The best design will vary for different patient populations, practice types, and clinical settings.

Below we present two cases from Sweden and the United States that show routine use of PROMs in primary and secondary care. Both systems were developed by experienced, practising physicians and share similar objectives but the design differs.

Swedish rheumatology quality registry

The Swedish rheumatology quality registry was established in 1995 and contains data on over 66 000 patients, about 85% of people in Sweden with rheumatoid arthritis.14 Data generated by patients is fed into a user friendly “dashboard” and used to support care. Patient reported outcome measures are tracked over time in relation to ongoing treatment. Patients input information on both disease specific and general measures of function and health, helping clinicians to provide more appropriate and patient centred care. The dashboard displays trends and is used to guide treatment, shared decision making, and self management. Experience suggests that the registry dashboard helps engage and empower patients and increases their confidence that they can manage and control their condition.15

Karin A, who has rheumatoid arthritis, says: “Nowadays I work together with my doctor and the computer for every change in my treatment. I can check my disease at home between visits. Before I go to see my doctor I report on and measure my own health. It’s easy; I just click on the screen and enter how I feel now.”

Clinical outcome measures seem to improve after patients start measuring, reporting, and sharing responsibility for the management of their condition with their physician. Patients in one region (Gävle County) that implemented routine use of PROMs in clinic visits had less disease activity, as measured by C reactive protein, than patients in regions where structured communication with doctors was not necessarily part of routine care.43

Patients have a personal identifier to access the registry, and the system is easy for patients to use and input information. The system also contains all the usual data used by medical staff to track outcomes (blood test results, inflamed joint counts, etc) so staff do not need to spend extra time inputting data or to move from one screen to another. Because patients track their outcomes between office visits and can communicate electronically when there is a change, the timing of appointments (urgent care for flare-up or routine follow-up) and their duration and content can be pre-planned by the office staff and guided by patients’ needs and priorities. Registry data can also be aggregated to examine population health, improve quality of care and provide transparent public reports on patient outcomes at the county level.

US primary care model: HowsYourHealth.org

Developed in 1994 and disseminated on the internet since 1999 without charge to primary care practices, the HowsYourHealth system provides an immediate and standard source of information about patients’ function,
diagnosis, symptoms, health habits, preventive needs, capacity to self manage chronic conditions, and their experiences of care. Patients enter all the data themselves, mainly using tick boxes in response to questions. For practice improvement the system also provides a summary of all patient data (with national benchmarks) and a secure registry to target interventions at groups of patients with similar needs (such as those with diabetes, emotional problems, or low confidence to self manage health problems). The system is used by hundreds of practices in the United States and Canada, and initiatives to increase uptake are under way in Iowa, Massachusetts, and British Columbia. The system is endorsed by several medical specialty organisations.

Patients usually access HowsYourHealth from home or within the doctor’s office. They have the opportunity to share their “check-up” data with the office staff, receive information tailored to their needs, and create a personal health plan for tracking and sharing their health status and behaviours. They can also access tools to help build confidence and skill in self management and better understand the risks and benefits of treatment. The system collects generic patient reported outcomes, including COOP/WONCA measures on pain, mobility, mental health, age and sex specific preventive health needs, and self management capacity for common risks and conditions. Patients control their HowsYourHealth information and its security, and it doesn’t require a personal identifier or password.

A controlled trial involving 45 primary care physicians and 1651 patients aged ≥70 years found that the HowsYourHealth system significantly improved patient ratings of overall care quality and their understanding of important risks (such as falls and advance planning of care). Patients also reported that it helped with daily activities, emotional issues, and social support. Another controlled trial involving 47 primary care physicians and 644 adults with pain and emotional problems showed sustained improvement when HowsYourHealth was combined with a problem solving intervention supported by a nurse educator. Patients also reported that it helped with daily activities, emotional issues, and social support. Another controlled trial involving 47 primary care physicians and 644 adults with pain and emotional problems showed sustained improvement when HowsYourHealth was combined with a problem solving intervention supported by a nurse educator. Patients also reported that it helped with daily activities, emotional issues, and social support. Another controlled trial involving 47 primary care physicians and 644 adults with pain and emotional problems showed sustained improvement when HowsYourHealth was combined with a problem solving intervention supported by a nurse educator.

For most patients there is no systematic or effective method for communicating what happens outside the clinical encounter, such as perceived needs, symptoms, response to treatment, undesirable side effects, effect on function, and what matters to patients and their families. Like clinicians, patients want better outcomes for individuals and communities, and better professional development and system performance, although we might not use those same words to describe them. PROM systems have the potential to enable improvement by providing information that can bridge the gap between the clinical reality and the patient world, triggering learning as well as the right next action. PROM systems must be codeveloped by patients, the public, and professionals to obtain maximum value. They should be integrated with the rest of the patients’ healthcare information and patients should be able to use the information when and where they choose, including for research to benefit others with their condition.

Box 1 | Uses of PROMs

- Health system
- Performance assessment
- Value for money
- Healthcare provider organisation
- Benchmarking
- Quality improvement
- Clinical trials
- Screening
- Treatment outcomes
- Clinical practice
- Diagnosis
- Monitoring progress
- Information for patients or clinicians
- Choice of provider
- Choice of treatment

Box 2 | Views of patient advocates

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Measuring what matters: the case for patient generated PROMS

When I started researching amyotrophic lateral sclerosis (ALS) in 2002 I was trained to interview patients and administer a 12 item scale assessing their ability to walk, speak, and breathe. It yielded a score between 48 (healthy) and 0 (incapacitated). This functional rating scale (ALSFRS-R) was developed to support clinical trials and correlates with survival and markers of neurodegeneration. In contrast to the shared notes schemes Nelson and colleagues describe, we were not allowed to tell patients what their score was. The scale was seen as a research tool to describe groups, not the progress of individuals, so would it help or harm patients to know they scored 23 or 35?

Subsequent validation studies showed the measure was just as reliable if administered by caregivers, by telephone, or by patients themselves. In November 2005 patients were given access to an online self reported version of the scale and visualisations of their progress compared with that of other patients on PatientsLikeMe.com. This website was built by a family affected by ALS who wanted to learn more about the progression of the disease and manage it effectively. Self reported data submitted to the website were validated against clinical measures and used to help understand the effect of treatments. Crowdsourced models of ALSFRS-R scores recorded by clinicians have been used to predict outcomes, and patient reported scores might achieve the same goal. Tellingly, the predictive algorithms designed by mathematically minded solvers who were non-experts in the disease substantially outperformed the predictions of ALS expert clinicians.

Regrettably, few other groups of patients have such well developed patient reported outcome measures (PROMs) for their particular conditions. Done well, such tools can serve so many purposes: identifying treatment effects, mapping to pathology, supporting predictive modelling for researchers, guiding clinical care, and offering feedback to support self management. In the absence of a common framework to systematically evaluate PROMs against these purposes many who develop them continue to produce tools that fulfill only a subset of these ambitions. Part of the problem is that clinicians often lack psychometric expertise or the time and funding to develop more useful tools. As a result, many PROMs are sponsored by the pharmaceutical industry, in line with Food and Drug Administration guidelines, to support label claims for the added value of their medicines to improve symptom relief or quality of life. Some claim that an unintended consequence of this has been the development of a “cottage industry” of companies developing measures with the needs of pharmaceutical sponsors primarily in mind. Furthermore the sharing of such tools may be restricted through licensing because the measurements are considered to offer a competitive advantage.

Alternative paths to systematically developing PROMs are, however, being explored. The PROMIS initiative, a group of academic researchers, develops measures that use computerised adaptive testing (CAT). Unlike traditional measures, which use a fixed list of items, CAT adjusts the level of questions according to the patient’s previous answers. CAT shows good performance against traditional measures, but understanding responses requires digital administration and new skills, and, crucially, no PROMIS instrument has yet been used as an endpoint to support an FDA label claim.

From the patient side, “patient powered research networks” such as PCORnet (www.pcornet.org/) offer the opportunity for large online registries of patients to contribute to the psychometric development of new PROMs. On another network, PatientsLikeMe, the Open Research Exchange (www.openresearchexchange.com) lets researchers rapidly create and validate measures with substantial patient input by combining an engaged patient network with online software that guides researchers through the process of developing PROMs with constant patient feedback.

Instruments developed on the Open Research Exchange are licensed under Creative Commons, meaning they are free for use and adaptation, and work is under way to understand how PROMs developed online might meet FDA guidelines in a reliable and resource effective manner.

Measures that are more patient centred might frame questions in a more positive and aspirational manner, use the patient’s own language, and harness CAT to be brief and responsive, automatically honing in on relevant domains across comorbidities to reduce the survey burden. Patients using technology to take the lead in methods for measuring their diseases could be a cornerstone of the learning health system—tools developed by patients for patients that align what’s measured to what matters (box). Measures optimising the priorities of patients, clinicians, and researchers that are then overlaid on patient portals that integrate with clinical practice could improve clinical care and self management and fuel better predictive modelling, pragmatic trials, n of 1 trials, and comparative effectiveness research. Now is the time to measure what matters.

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Patients codeveloping PROMs
Cathy Wolf worked as a psychologist at IBM for 25 years before ALS prevented her from working. Although she is quadriplegic and dependent on a ventilator, her intellect remains. When she came to meet the ALSFRS-R she was frustrated that despite her ability to speak, and breathe. It yielded a score between 48 (healthy) and 0 (incapacitated). This functional rating scale (ALSFRS-R) has been developed to support clinical trials and correlates with survival and markers of neurodegeneration. In contrast to the shared notes schemes Nelson and colleagues describe, we were not allowed to tell patients what their score was. The scale was seen as a research tool to describe groups, not the progress of individuals, so would it help or harm patients to know they scored 23 or 35?

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From patient centred to people powered: autonomy on the rise

Following in the path of feminists and civil rights leaders, informed patients are building a progressive social movement to improve medical care. Dave deBronkart says medicine should let patients help improve care, share responsibility, and think for themselves.

The practice of medicine is intellectually demanding; it requires specialised skills and decades of training and experience. Understandably, the accepted model that has guided us for centuries is “doctor knows best.” As recently as 2001 the American Medical Association proposed this new year’s resolution to patients:

“Only your physician has the necessary experience and expertise to diagnose and treat medical conditions. Trust your doctor, not a chat room.”

A decade later pronouncements from the Institute of Medicine, the Mayo Clinic, the World Health Organization, and others suggest that patients—individuals without specialised training—should be treated as genuine, value contributing partners in the work of medicine.

If the American Medical Association in 2001 and the Belgian government (which ran a paternalistic “Don’t google” your health problems campaign last year) are right, then the Institute of Medicine and WHO have gone mad. But I believe the opposite is true and that our thinking must change.

Inclusive approach

I have recently been appointed the 2015 visiting professor in internal medicine at the Mayo Clinic, simply on the basis of my experience with my disease and my subsequent work to change medicine’s thinking so others might benefit. I don’t reject physicians (they saved my life), and I don’t assert that patients know everything. I do know first hand that patients can truly add value, and explain why in my book, Let Patients Help.

A growing movement, exemplified by the Society for Participatory Medicine (www.ParticipatoryMedicine.org) and the annual Stanford Medicine X conference (http://medicinex.stanford.edu/), asserts that patients and clinicians must collaborate. Central to its belief is that whereas the physician brings training and clinical expertise, patients bring their life experience, their deep investment in the outcome of their case, their skills and resilience, and a unique perspective on needs and priorities. The movement recognises patient autonomy as a valid priority and patients’ hearts and minds as essential contributions to the best possible care. We believe that medicine cannot achieve its potential if it ignores the voice of thinking patients.

This movement is not anti-physician, it’s about partnership. When I had cancer diagnosed, “I received the very best care I could find, but I didn’t sit back and expect to be saved: I joined an online patient community, and my oncologist says that members’ practical advice may have helped me to tolerate the treatment that saved my life. What if I’d followed the AMA’s advice and stayed away from chat rooms?

The internet has let many such “e-patients” (empowered, engaged, equipped, enabled) be heard by other patients, physicians, and policy makers (box). Dozens have served as “e-patient scholars” and advisers to MedX and other forums. In so doing they are growing a new reality, contributing to improved care for themselves and others. They are creators of a social movement, a shift in roles as profound as women’s liberation, racial equality, gay rights, and disability rights.

The internet has changed the infrastructure of information flow

Thomas Kuhn’s masterpiece The Structure of Scientific Revolutions showed that when too many cases arise that cannot be explained by a profession’s model, a crisis develops that leads to revolution. This may be what we are seeing in medicine. Clinicians’ skills are obviously essential, but something has changed in the environment—the flow of knowledge—and it is altering what’s possible. Because of it, we may be on the verge of needing a new science to understand and optimise the role of the patient—a science of patient engagement.

Value in medicine depends on knowledge, and in the past two decades the flow of knowledge has undergone a state change, from closed system to open network. Not only is it possible today for patients to see (and tell each other about) the same information that clinicians see; they can also connect with patient peers near and far to discuss topics they care about. They have eyes, ears, and a voice that they’ve never had before. These are the precursors of autonomy, emancipation, and self determination.

The change is illustrated by a visual model created five years ago by Lucien Engelen at Radboud University Medical Center in the Netherlands and Marco Derksen (figure). It
suggestions that knowledge is like a nutrient that enables a more robust response, with the internet as its capillaries (figure). Ultimately, knowledge flows through a network of networks, which makes it far easier to obtain optimal information on any clinical case and thus get optimal outcomes.

This doesn't make patients oncologists. It does mean patients can truly know things they couldn't in the past—even things some clinicians don't.7 The clinician's response to this change can be decisive: forward thinking doctors, such as those who treated Janet Freeman-Daily,6 welcome such contributions and share them with colleagues; by contrast, outdated attitudes can lead to informed patients being treated as near criminals, as happened in the Ashya King case last year.9

A crisis in confidence can be caused by a clinician who asserts, “Nothing could have changed that I haven't heard of,” because that itself is unscientific. The much praised book The Half-Life of Facts notes that current truth changes faster in medicine than almost anywhere else,10 but overworked clinicians can hardly afford to spend more time reading. It makes sense to let patients help be bloodhounds for information. I speak from experience when I say that a person in trouble can be highly motivated. To have that urge discouraged throws into question the clinician's priorities.

When an oppressed class learns to think for itself, people start wanting autonomy as individuals, then self-determination for their peers. That is the start of a social movement, bringing with it cries for justice.

Towards a new model
If “doctor knows best“ is no longer reliable for predicting the best outcome for patients, it can no longer serve for planning the future. The e-patient communities are already at work exploring new models in collaboration with providers who welcome them. Together, can we be scientific, and research this? Can we probe, analyse, and explore the extents and limitations of patient contributed value, and the mechanisms by which it can improve care?

Regina Holliday, Maryland (reginaholliday.blogspot.com/)
When her husband died at 39 from renal cell carcinoma Regina (@ReginaHolliday) learnt about medicine’s weaknesses and then about social media’s power to give people, especially those who are disadvantaged, a voice. A skilled storyteller in paints and words, she painted a mural of her husband’s death (www.bmj.com/bmj/section-pdf/186330/0 page 3). She has gone on to paint medical stories on jackets and encourages others to do the same. Her “walking gallery of healthcare” (http://vimeo.com/80009527) has become a patient advocacy movement.

**COMMENTARY**

Social media provide patients with support, information, and friendship

Amanda Greene lupus activist, Los Angeles, USA lalupslady@gmail.com

When I was diagnosed as having systemic lupus erythematosus 32 years ago, aged 15, social media did not exist. After months of diagnostic tests, I was happy to find out that my condition had a name. Six months after diagnosis, I attended my first lupus support group, where the topic for discussion was funeral planning. Questions posed included “what prayers and flowers do you want?”

For me dying was not an option. My mother and I looked at all the treatment options. We told the doctor that I was going to be a long term lupus survivor. My doctor took my mother aside and suggested that was unlikely. Shortly afterwards I found a different rheumatologist. Patients have the right to change doctors, and I did.

My new doctor had a good understanding of the spectrum of illness that lupus can cause. He also knew that when he suggested any change to my treatment that my mother would say, “If your daughter had lupus, would you give this medication to her?” Our doctor-patient relationship lasted 30 years and was one of mutual respect.

When he retired I used social media to find a new rheumatologist and an internist open to respecting patients’ views and exploring alternative therapies as well as conventional medical treatments. Social media not only enabled me to find new doctors, it was also the way I met Tiffany Peterson. Only 48 days after she had lupus diagnosed, Tiffany searched “lupus” on Twitter, and my Twitter profile (@LAlupusLady) appeared. Soon, we were sharing the latest research and our excitement when the first drug specifically designed for lupus was approved by the FDA, and supporting each other through disease “flares.” Having had the disease for many years, I was able to offer her the insight and support that her doctors and other healthcare professionals simply could not.

In 2011, I spoke at the #140 “State of Now” conference in New York (where speakers share stories on how Twitter has changed their world) on “Lupus Awareness is fun, Lupus is not.” It was there that I met and hugged Tiffany in person for the first time. A lifetime friendship had started. We are “lupie sisters.” Lupus may have brought us together, but it’s our passion for sharing and supporting lupus awareness that has made us friends.

As patients, we realise that many health professionals have yet to embrace the powerful tools that Twitter, Facebook, Instagram, and other social media platforms have created. Most doctors’ offices are busy, understaffed, and view social media as a distraction. If only they took a moment to realise the benefit of offering a “patient portal” or posting a monthly blog. Supporting patients with information online would result in healthier patients and could reduce their workload.

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Kuhn documented that many sciences have evolved as our powers of observation expanded, and, often, established theories (for example, Isaac Newton's) turn out to be constrained cases of a more universal rule (relativity). It now seems that “doctor knows best” exemplifies a more general rule: “Those with skill and useful knowledge know best.”

Generations ago it was largely only physicians who had current knowledge. Today that is not a given, but even the most emancipated patient cannot deny the value of clinical experience. One of the first tips I got from my patient community was to find a specialist centre that’s dealt with a lot of similar cases to mine.

So perhaps a new draft of the model of care would be: “Useful knowledge plus clinical experience plus what the patient wants leads to best care.”

Let patients help share the work
A person who knows nothing must necessarily be cared for by wise people providing paternalistic care. But as with the growth of a child, at some point not only does autonomy increase; so does ability to comprehend. If a person is kept in the dark others underestimate their potential, and they can never share the responsibility that comes with emancipation.

As Hugo recently said in the Society for Participatory Medicine blog:

“Autonomy is true empowerment. It promotes patient responsibility and holds the promise to lead us to more engagement and better health. We must move beyond participatory medicine and focus on educating, enabling, and equipping patients with the tools necessary to master autonomy and the art of self care.”

Patient powered healthcare is no insult to clinicians any more than home thermometers insult paediatricians or home glucose tests insult endocrinologists, nor any more than a drowning swimmer insults a lifeguard by climbing onto a raft. Independence is a good thing, and we applaud the many who welcome the new world. Join us.

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A few times a week, I put a small device into a pocket on a wristband and measure my sleep pattern. I use the results to set my smart watch to wake me up at the optimum time (when I start moving and I’m not in deep sleep any more). That way I wake up energised. When I go out for a run I collect data with activity trackers and wear a chest strip to chart my heart rate to motivate me to improve my performance. Once a week, I measure my blood pressure, and I can do an echocardiogram at home. From home I also access the peer reviewed literature and look at information sourced from my curated social media channels. For relaxation I use a device that gives feedback about my brain activity, and I improve my cognitive skills by playing neuroscience validated online games. Once a month I check if I am eating too fast with a smart fork (www.hapi.com/product/hapifork). Does it sound obsessive? My lifestyle is not even at the end of the scale.

Chris Dancy, described in Businessweek as possibly the most connected human on earth, has hundreds of sensors on his body and a smart home that can dim the lights and start playing classical music when he is getting stressed. There are people living with augmented reality cameras in their eyes and magnetic implants in their fingertips that allow them to remotely unlock a smart phone or a garage door. These examples are among myriad new technologies and innovations coming on stream that collectively will not only enable people to manage their health but are set to tear down the ivory tower of medicine too.

To prepare for the future, doctors and patients must change. All need to acquire digital literacy skills, get to grips with new technologies, and use new channels of communication. Doctors will need to develop their role as guides for patients struggling in the digital jungle. Digital methods are available for all of us to tackle information overload, from subscribing to RSS feeds to using Twitter for crowdsourcing (www.youtube.com/watch?v=x756caaU2w).

Another task for health professionals is to ensure rigorous evaluation of new technologies and ensure patients are aware of their risks and limitations as well as their potential benefits. For their part, patients must meet physicians half way and take more responsibility for their own health and managing their conditions. For both, the quality of the doctor-patient relationship will remain central. Innovations will increase the quality and affordability of care, but this should not be at the expense of maintaining the human touch.

Enabling people to own and understand their health data is important. It is outrageous that many hospitals and practices still don’t have joined up e-records and doctors are not equipped to handle new streams of data. When I brought my smart phone with infographics about my vital sign measurements to show to my general practitioner, he did not know what to do with the data or how to transmit the otherwise useful and quality data to the medical record systems. Young doctors are learning new skills, however. At Semmelweis Medical School in Hungary they have been taught about the use of social media, mobile devices, and wearable gadgets for health and medical purposes since 2008.

If the waves of change from disruptive technologies and a restructured medical ecosystem hit us unprepared, which is the situation we are in now, there is a risk that medicine will become even more of a technology based service. To prevent this, we should be consciously and purposefully redesigning health systems by preparing for the now.

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Patient communities reform healthcare in India

Public disillusionment with health service provision has led patient advocates in India to mobilise and push for change, Anita Jain reports

India presents a classic paradox. At one end patients receive the best of advanced medical care, and at the other millions lack access to basic services. The public health sector is neglected, and patients have to rely on a private sector that is commercialised and unregulated. Corruption is pervasive, resulting in exploitation of patients and irrational care. Yogesh Jain, a public health advocate, puts it plainly: “With the discourse on primary healthcare hovering around access, cost, and sometimes quality, patient centred care seems like a futuristic thing in this country.”

Disillusionment with the status quo has given rise to vibrant examples of patients mobilising to safeguard their right to health. A vision for a better future is driving communities to organise so that they can collectively influence health outcomes, as the following examples show.

Action by people with HIV

Recounting her experience living with HIV, Kousalya Periasamy, founder and president of the Positive Women Network in India, says, “I was able to buy the medicines because I was well-off. Rather than shout for changes in the system, I could have sat back. But I saw people around me dying without medicines. Our friends are no more.”

At the 14th World AIDS conference in 2002, Periasamy and other HIV/AIDS activists demanded that the Indian government provide free antiretroviral drugs. Their persistent efforts were successful, and free access through the national HIV programme was established in 2004.

“You have to make a noise, else you will not get anything,” says Periasamy. Information about treatment options and solidarity among patients are vital to the movement, she says. Advocacy organisations such as Lawyers Collective have a key role in educating the community on their rights to consent for testing, treatment, and confidentiality; the social and legal implications of stigma and discrimination; and intellectual property provisions that limit access to medicines.

Last year, HIV activists from across the country staged a protest outside the Ministry of Commerce against intellectual property provisions being negotiated in a regional free trade agreement. A similar movement in 2011-12 resulted in the Indian government rejecting provisions in the EU-India free trade agreement that might have restricted production of affordable generic medicines. The HIV community has also challenged proposed patents on antiretroviral drugs such as tenofovir that could prevent production of affordable generic versions until 2018.

“The HIV movement in India is premised on the right to health approach, which promotes participation of affected populations in all levels of health related decision making,” says Lorraine Misquith, senior research officer at Lawyers Collective. “This is an exemplary model for a community led and driven campaign, where the community is empowered to respond to actions, laws, and policies that negatively impact their right to health.”

Patient groups improve care for chronic illnesses

A transformative approach to empower and support patients with long term conditions to manage their illness has been pioneered by Jan Swasthya Sahyog (www.jssbilsapur.org), a non-profit organisation providing health services to rural and tribal communities in central India.

Jain, one of the founding doctors of JSS explains, “Treatment continuation rates for most chronic conditions were poor even if the drugs were free. Hospital centred care just does not work in these illnesses. Not enough time can be spent with each patient to ensure good follow-up care. A platform was needed where patients with the same illness and their families could get together and discuss the disease and its treatment.”

JSS has established patient support groups for chronic conditions, including sickle cell disease, epilepsy, type 1 diabetes, and alcohol dependence. Currently, 13 patient groups have been set up with over 300 patients from 85 villages. They meet regularly, with the venue rotating between villages so members have to travel equal distances.

Community health workers trained in disease management and group facilitation skills steer the meetings. Information on the disease and its treatment is shared with participants. The health workers encourage discussion of challenges and concerns and identify topics of common interest. “Topics like drawing a family tree to understand the inheritance pattern of sickle cell disease, and managing pain were discussed more than once in the sickle cell disease groups. Among epilepsy patients, topics like structure and function of the brain, mechanism of seizures, and pregnancy and anti-epileptic drugs evoked lively discussions,” shares Jain.

“We were sceptical whether people would join because of the little time they can afford given the sheer burden of eking a livelihood in rural areas. But the idea has been a runaway success,” says Jain. Mutual motivation has resulted in greater
adherence to recommended treatment. “From a dismal compliance rate of 40% in epilepsy and sickle cell disease, it has reached high 90s. Alcohol abstinence rates are well over 70%. People can see the effect of compliance with treatment in terms of freedom from seizures and being able to return to school in epilepsy, and fewer crises in sickle cell disease. Many patients feel this is the only support they are receiving. Family members are encouraged to participate and are trained to provide care. Some groups have initiated monthly savings by members to help out with small and urgent needs.”

People in rural areas often follow traditional beliefs or visit unqualified healers rather than seeking appropriate medical care. Sharing information with many people at a time helps spread knowledge. “We have observed a sisterhood of people with a common illness in rural areas. People with an illness often know a few others with the same illness. We have used this technique to identify and reach more patients with care,” says Jain.

**Public hearings hold health officials to account**

Self reliance and self determination of people in planning health services is a fundamental tenet of the international conference on primary care’s Alma-Ata declaration of 1978.¹ Jan Sunwais or public hearings, also referred to as mass social accountability events, put this into practice.

Traditionally, most people in India have not been empowered to voice their opinions and concerns with the health system. Channels to facilitate their participation and address grievances have been nearly non-existent. The Right to Healthcare campaign by Jan Swasthya Abhiyan, the Indian arm of the People’s Health Movement (www.phmovement.org/), devised a framework for community based monitoring and planning of health services that was incorporated in the National Rural Health Mission in 2007.

The process has flourished in Maharashtra, where around 1000 villages across 13 districts participate.² “Regulation of health services is a public function, the responsibility for which cannot be limited to a distant bureaucracy,” says Abhay Shukla, a physician and health activist from SATHI-CEHAT, a non-governmental organisation that steers the programme in Maharashtra (www.cbmpmaharashtra.org/). “Even so, having these provisions on paper is a first step. Community engagement with health services needs to be actively facilitated by community based organisations through a series of interlinked processes and mechanisms from villages to the state level.”

The process starts with community meetings to make people aware of their rights and entitlements. SATHI-CEHAT has set up a system where people in each village get together annually to rate provision of services at the local government health centre. The ratings are collated on a report card that is displayed at the health centre.

The process culminates in public hearings where the findings from the report cards are shared. People also voice their experience of the health services and instances where they have been denied care. Government health officials attend the hearings and are expected to respond to the concerns raised. An independent panel of judges, which includes professionals such as teachers, doctors and lawyers, mediates the dialogue.³ “Over 2-3 years, most issues that can be resolved locally such as staff absenteeism, overcharging, rude behaviour, and non-provision of essential services, are addressed through public hearings. An improvement is observed in the functioning of primary health centres. Some issues related to inadequate staffing, infrastructure needs, and shortage of drugs require approval at the next level of administration, and are taken for discussion in a public forum there,” says Shukla.

Over 450 public hearings have been held so far across the state, and they have proved popular and successful in fostering accountability and transparency in public health services. A qualitative evaluation of these hearings documents improved community engagement and greater health awareness and use of services.⁷ Hearings in some areas have evolved from a fault finding exercise to a participatory dialogue between communities and health officials to plan health services in line with their needs.

“Making the public health system responsive is a huge challenge,” says Shukla. “Resistance from bureaucracy and inadequate funding has stalled the process in several states.” Community monitoring of the availability and quality of health services should be a non-negotiable and mandatory component of the health programme, Shukla suggests.

People’s participation in regulation of the private sector is equally, if not more, critical.⁸ The Jan Swasthya Abhiyan in Maharashtra is pushing for a formal charter of patients’ rights to hold private healthcare providers accountable for emergency services, quality of care, information provision, privacy, and autonomy for patients.

These glimpses into patient participation in healthcare in India highlight the crucial role of informed and empowered citizens. When access to basic care is uncertain, the discourse on patient centred care shifts from individual doctor-patient interaction to collective engagement and advocacy by communities to make the health system function and deliver their needs. The new national health policy in India proposes making health a fundamental right with the promise of improved access to treatment.⁶ This vision can be achieved only through active engagement and participation of people.
Patients and staff as codeesigners of healthcare services

Glenn Robert and colleagues describe an approach that aims to ensure that healthcare organisations realise the full potential of patients—the biggest resource they have for improving the quality of care.

Over a decade ago Don Berwick suggested that healthcare “workers and leaders can often best find the gaps that matter by listening very carefully to the people they serve: patients and families.” Health professionals are now familiar with a range of approaches—surveys, storytelling, focus groups, online feedback (to name a few)—that can help them listen. A minority use other techniques, such as shadowing patients and observing staff-patient interactions, to find out how and why services work well or not, and how they might be improved. But healthcare staff don’t routinely use such data to improve the quality of their services unless they have support. Often the patients are only given a passive role with staff making all the decisions about how to respond.

Here we argue that patients can and should take a more direct and ongoing role in identifying, implementing, and evaluating improvements to healthcare services. We discuss examples of projects in which patients and staff have worked together and suggest that codesign methods have the potential to make patient-centred services a reality.

Growing attention has been paid to the value of applying design thinking to improve public services. This is usually based on direct face to face user and provider collaboration to codesign products or services, and includes a focus on the aesthetics of a service—how it looks and feels. Though gaining in popularity, rigorous research is needed to determine how best to apply design thinking in healthcare. Here we argue that patients can and should take a more active role in identifying and implementing improvements to healthcare services.

The intervention, which became known as Take Care, was developed using EBCD. The design process began with 20 hours of non-participant observation, 20 semi-structured interviews with staff members, and 20 filmed narrative based interviews with carers. The carers and staff reviewed the themes arising from the observational and interview data, discussed these, and then worked together to codesign the intervention.

Take Care eventually comprised:

- A 19 minute supportive and educative DVD
- Accompanying booklet
- A 1 hour protocol guided group consultation conducted by one of two chemotherapy nurses trained in group facilitation

The consultation was provided before patients’ first cycle of treatment to groups of no more than five carers. During it, they watched the DVD and were given the opportunity to freely express concerns and ask questions. They were given a copy of the DVD and booklet and were encouraged to consult them when they needed information or support during the patients’ treatment.

In healthcare the term codesign refers to patients and carers working in partnership with staff to improve services. Here we focus on one particular approach called experience based codesign (EBCD), a six stage process that usually takes 9 to 12 months to complete (figure):

- Setting up the project
- Gathering staff experiences through observation and in-depth interviews
- Gathering patient and carer experiences through 12-15 filmed narrative based interviews
- Bringing staff, patients, and carers together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30 minute “trigger” film of patient narratives
- Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months
- Celebration and review event

Though filming patients is time consuming and resource intensive, our experience shows it is an important catalyst for improvement; seeing and listening to patient experiences helps connect staff and is a persuasive starting point for change. The films also set the process apart from other ways of capturing patient experiences in which anonymity and circumlocution can often hinder rather than enable quality improvement. The aim of the patient and staff interviews and observational work is to help patients and staff identify and jointly explore emotonal “touchpoints” on the journey of care, with a view to improving these experiences. Touchpoints are interactions between staff and patients, both positive and negative, that both parties perceive as crucial to the overall experience of receiving or delivering care.

One example is the surgical insertion of a percutaneous endoscopic gastrostomy (PEG) feeding tube to allow liquid feeding of cancer patients. Though staff perceived this as a major touchpoint because it occurred just when they thought the patient had “had enough” and had undergone a major intervention, patients identified it as a minor procedure compared with the major surgery and radiotherapy a patient has already had. Staff perceived this as a negative, that both parties perceive as crucial to the overall experience of receiving or delivering care.

Using codesign in healthcare quality improvement

EBCD was first piloted in an English head and neck cancer service in 2005. After a subsequent project in an integrated cancer unit an online toolkit was developed as a free guide to implement the approach.

Box 1 | Improving the experience of carers of patients receiving outpatient chemotherapy

Supporting someone through chemotherapy can be emotionally and physically demanding. This study tested the feasibility and acceptability of a complex intervention for carers that was codesigned by staff and carers.

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Debates about how it is best interpreted, applied, and evaluated in practice.

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This infographic explains Experience-based Co-design (EBCD), a six stage process that usually takes nine to 12 months.

**PROJECT SET-UP**

**GATHER STAFF EXPERIENCES**

**GATHER PATIENT AND CARER EXPERIENCES**

**IN-DEPTH INTERVIEWS**

**OBSERVATIONS**

Interviews and observational work help patients and staff identify emotional “touchpoints” on the journey of care.

**BRING STAFF, PATIENTS, AND CARERS TOGETHER**

**EDITED 30 MIN “TRIGGER FILM”**

Filming patients helps connect staff, by allowing them to see and listen to patient experiences.

**SMALL GROUPS WORK ON IDENTIFIED PRIORITIES**

**12-15 FILMED NARRATIVE INTERVIEWS**

Groups work on the identified priorities (typically four to six) over three or four months.

**CELEBRATION AND REVIEW EVENT**

**DEEPER, LONGER TERM CHANGES TO ATTITUDES AND BEHAVIOURS**

Although codesign projects typically bring about a series of incremental quality improvements, the partnership between patients and staff often leads to deeper, longer term changes in attitudes and behaviours.
Box 3: An intensive care patient’s perspective

For patients like myself and our relatives, being involved in such a codesign project is one of the most constructive ways of giving something back for the care shown to us during a very difficult period in our lives.

The developing of interpersonal relationships between patients, their relatives, and healthcare professionals was rewarding in itself and enabled the creation of a safe social environment in which to work. Such an environment allowed us as patients to reflect on aspects of our care which we had not been prepared to discuss before and for staff to explore and highlight ways in which their clinical procedures could be improved without fear of criticism.

It was apparent to us as patients during the smaller codesign team meetings that staff were inspired by what we had to say and it felt as if they were reconnecting to the beliefs and values they had when they first chose healthcare as a profession.

As the project moved forward my initial expectations of what to expect were far exceeded; everyone’s thoughts and ideas were discussed in full and then developed in a meaningful manner. In my own case rewarding outcomes were the creation of a leaflet to aid the understanding of the cause and effects of hallucinations and the development of new, more effective, and considerate procedures for the transfer of patients from intensive care. These issues can cause considerable stress to both patients and relatives.

Box 4: A clinical nurse specialist’s perspective on facilitating a codesign project

For me it was about creating an opportunity—a safe social space—for staff to tell their story of what they experience every day; acknowledging the awfulness of what we see was cathartic, empowering, and engaging. Our staff worked alongside the experts in the services we deliver (patients and relatives), who were willing to share such rich and deep reflections on their personal experiences; it was the commitment of our patients and relatives that became the driving force to deliver improvements to our services.

As the facilitator, when asked to provide evidence of outcomes I can demonstrate these through our codesigned information booklets, DVDs on experiences of being voiceless while ventilated, and of hallucinations, the room madeover, etc. However, these do not and cannot convey the changes in personal, professional, and work culture that I witnessed. I saw a paradigm shift in an intensive care consultant who changed from having no insight into the impact of critical illness on patients and relatives to championing the importance of striving to become a patient centred service at every opportunity. I saw a “light bulb” moment in patients when a consultant explained by a simple hand drawn picture why they had become voiceless when intubated. I saw leaders emerge within each codesign team—patients as well as staff. Because of what the staff had heard I saw changes in practice with immediate effect. I saw patients caring for staff in meetings, such was the rediscovered connection and humanity between them. I saw staff reconnect with their fundamental core beliefs and values, which has to impact not only on their wellbeing but on that of the next patient and relative they meet. Sometimes you cannot count what really counts.

Sought to enhance touchpoint experiences for patients in two breast and two lung cancer services.16 Fieldwork comprised 36 filmed narrative patient interviews, 219 hours of ethnographic observation, 63 staff interviews, and a series of codesign meetings involving patients and staff that were facilitated by trained quality improvement specialists. In total, 62 improvements were identified and implemented across the four services.17 Table 1 shows the 19 codesigned improvements implemented and sustained over two years in one of the breast cancer services.

An international survey of EBCD projects in healthcare services identified 59 projects implemented in six countries (Australia, Canada, England, the Netherlands, New Zealand, and Sweden) during 2005-13 and a further 27 projects in the planning stage.18 Boxes 1 and 2 (on thebmj.com) provide case studies of the outcomes resulting from initiatives to codesign services and products with patients and carers.

As these two case studies show, the original blueprint for EBCD can be adapted and tailored to suit different types of healthcare services as well as local and national contexts. A notable adaptation is an accelerated approach that used existing archive of patient narratives to create the trigger films (www.healthtalk.org/peoples-experiences/improving-healthcare/trigger-films-service-improvement). The approach was evaluated in two lung cancer services and two intensive care units in England.17 The use of national trigger films meant that the project took half the time of a standard EBCD project and at only 40% of the cost; the films can be used across NHS settings. Improvements that staff and patients identified and implemented together include redesigned lighting systems, appropriate clocks to aid patient orientation, tablet computer applications to assist ventilated patients communicate, redesign of discharge summaries, v-shaped pillows for postoperative patients, and a new process for effective transfer of patients’ belongings from theatre to recovery ward.

A trial is currently under way in six Australian community mental health teams to evaluate the effect of codesign on psychosocial recovery outcomes (such as willingness to ask for help and personal confidence and hope). Although evaluation is important, reliance on relatively broad and insensitive outcome measures such as patient satisfaction may overlook the real value placed by patients and staff on changes in the personal behaviour, attitudes, and culture of healthcare teams and organisations (boxes 3 and 4).

Of course, implementing codesign in healthcare settings is not without challenges. Professional service designers can feel frustrated at the pace and scale of change when working within healthcare organisations.19 And conflict and tension—often relating to issues of power11 13 14 24—can emerge between patients and staff. This may be especially true if patients find it difficult to express their views because of a previous experience of very poor care. In such circumstances a highly participative codesign process may not always be the best option for that individual patient.

Looking forward

Patients provide insight, wisdom, and ideas, and we urgently need to include them more creatively as partners in change. Although there has been substantial investment in refining methods for collecting data about patient experience and satisfaction, we need to better understand how these data can be used locally to improve the quality of care and the culture of health services.1 Although stronger evidence is needed to justify disinvesting from current practices and shifting some resources to novel ways of using patient experiences to drive up quality, the opportunity costs of current practices are substantial. These costs need to be made clear and the practices formally evaluated against alternative approaches.

We believe that mainstream approaches to improving patient experience place too much emphasis on metrics, lack critical reflection about the insights provided by survey methods (or knowledge of how to enact improvements on the basis of those insights), and are hindered by a deeply engrained perception of patients and families as passive sources of data rather than active partners in implementing change. Rather than marching relentlessly onwards to capture more patient experience data, we should be embedding codesign practices and values in our healthcare organisations. Experience with codesign projects shows that they can enable patients and staff to come together and jointly reflect on their shared experiences of a service in meaningful and sustainable ways. And given the increasing evidence in support of a link between staff wellbeing and patient experience, it is not only patients who may benefit from such a shift.

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Decision aids that really promote shared decision making: the pace quickens

Decision aids can help shared decision making, but most have been hard to produce, onerous to update, and are not being used widely. Thomas Agoritsas and colleagues explore why and describe a new electronic model that holds promise of being more useful for clinicians and patients to use together at the point of care.

Many, perhaps most, important decisions in medicine are not clear cut. Patients and clinicians need to discuss the options using the best available evidence and make informed joint decisions that take account of patients' context, values, and preferences. But implementing shared decision making is not easy. Doctors need the skills and tools to do it and to build trust; patients need information and support. Patients also need to have a greater role in developing strategies to improve the process.

Access to best evidence is another key ingredient. Until now the production and dissemination of clinical practice guidelines and summaries of evidence have largely been tailored to meet the educational needs of clinicians. They are seldom provided in a format that supports shared decision making. Patients, meanwhile, struggle to find reliable and accessible summaries of evidence, although plain language summaries and patient versions of guidelines are being developed.

In this article we highlight the limitations of current decision aids and discuss how the generic production of electronic decision aids designed for use in the clinical encounter, linked directly to trustworthy summaries of evidence from systematic reviews and guidelines, may help in the long march to realising effective shared decision making.

Challenge of shared decision making
Shared decision making depends on a good conversation in which clinicians share information about the benefits, harms, and burden of alternative diagnostic and therapeutic options and patients explain what matters to them and their views on the choices they face. It should follow the principles of patient centred care, promote informed choice, and result in care that patients value. Many clinicians think they practice shared decision making, but evidence suggests a perception-reality gap because of misconceptions about the nature of shared decision making, the skills it requires, the time it takes, and the degree to which patients, families, and carers wish to share in decision making.

Each clinical encounter is influenced by many factors. These include patients' circumstances and medical needs as well as their beliefs, stemming from what they have read, personal experience, advice from family and friends, and the media. It is therefore important to provide patients with accurate, up to date evidence on the benefits and harms of alternative management strategies and their likely effect on outcomes that matter to them, although evidence may not always reflect the complexity and multimorbidity of individual patients and patients may choose to ignore the evidence. Good shared decision making requires clinicians to have access to detailed knowledge and ideally summaries of the latest evidence and the means to share it in a way that supports thoughtful deliberation, something that cannot be done on the fly.

Limitations of traditional decision aids
For the past two decades enthusiasts have advocated decision aids to facilitate shared decision making, and over 500 have been developed. A systematic review of 115
randomised trials showed that their use was associated with a 13% absolute increase in patients’ knowledge scores and an 82% relative increase in accurate expectations of possible benefits and harms. Effects on clinical outcomes, adherence to treatment, and use of services have not, however, been consistent.15–17

Most decision aids have been designed for patients to use independently outside the consultation, either in the waiting room or at home.10 Although these decision aids promote understanding of the issues, they cannot guarantee that decisions in the consultation are shared,3,18 and there is insufficient evidence to determine how their use influences the consultation.19 Another problem is that use of decision aids in routine care is low,13 mainly because of poor design and lack of ready access to them. Furthermore, clinicians may find the format impractical to use in consultations and may be as unfamiliar with their patients with risk estimates and the inherent uncertainty associated with probabilities.19

Traditional decision aids are often not based on current evidence or rapidly outdated, at least in part because of limitations in funding after tool development—and may thus do more harm than good.20 A rigorous systematic review is needed for each important outcome, and such reviews are often unavailable. A recent assessment found that although around two thirds of decision aids are based on systematic reviews or guidelines, many of these sources are of questionable quality, and only 5% of aids included an “expiry date” or a stated policy about updating.20

Ensuring the quality and timeliness of decision aids is a daunting challenge. The work required to summarise evidence for a trustworthy decision aid is similar to that for producing a systematic review or a guideline, suggesting the potential for synergy between the worlds of evidence based practice and shared decision making.20–22

Harnessing the potential of recent developments

New decision aids

Some newer decision aids have been designed to facilitate collaborative deliberation in the course of the clinical encounter.3,10 Montori and colleagues pioneered a user centred approach to producing decision aids through iterative observations of discussions between doctors and patients.9,23 Their approach resulted in succinct, easy to use tools that provide graphic displays of the benefits and harms of different options organised around concerns that are important to patients (http://shareddecisions.mayoclinic.org). In contrast to traditional aids, which patients use independently, they are not designed to be comprehensive and do not include explicit exercises to help patients clarify their values (such as the relative values of avoiding a stroke versus a gastrointestinal bleed).23 Instead they rely on the unique conversations that take place between patients and clinicians, with clinicians providing just in time, tailored explanations and information.16
short tools (so far available for diabetes, statins, and antidepressants) promote dialogue and increase joint deliberation. They also shift the “body language” as patients and clinicians sit together to review the data.

Other short point of care decision aids include Option Grids (www.optiongrid.co.uk). These are one page summaries that provide answers to patients’ frequently asked questions, covering clinical outcomes and practical concerns faced in daily life. Their value in routine care is being evaluated.

Developments in appraisal and presentation of best evidence

The GRADE approach (Grading of Recommendations Assessment, Development and Evaluation) provides systematic, transparent, and explicit guidance for processing evidence from the medical literature, and has been widely adopted. Use of the GRADE approach results in standardised and succinct evidence profiles or summary of findings tables, which specify the absolute effects of an intervention on outcomes important to patients rather than surrogate outcomes and provide a rating of the certainty in these estimates (high, moderate, low, or very low). The recent international patient decision aids standards have emphasised the potential of GRADE for the production of decision aids, and it has been adopted by over 80 organisations (www.gradeworkinggroup.org).

Furthermore, clinical practice guidelines using GRADE now issue weak recommendations (in contrast to strong) when there is a close balance between desirable and undesirable outcomes among alternatives, low certainty in estimates of effect, or when there is large variability in patients’ values and preferences. Weak recommendations, which dominate in recent high quality guidelines, thus identify decisions where shared decision making is particularly important.

Use of new technologies

The not-for-profit MAGIC project (Making GRADE the Irresistible Choice www.magicproject.org) has developed an online “app” with potential to produce electronic decision aids for use in the clinical encounter. This MAGICapp (www.magicapp.org) allows authors of guidelines or systematic reviewers to write evidence summaries into a structured database and appraise them using GRADE criteria. The content can then be published on a web platform and presented in interactive formats on tablets, web portals, or electronic medical record systems.

In the SHARE-IT project, we use this authoring and publication platform for the generic and semi-automated production of a large number of decision aids. The aids can be used with the corresponding systematic review or clinical practice guidelines and the format modified and tailored to specific contexts—for example, published in different languages or adapted to national guidelines. The electronic format facilitates continuous updating because the data in the decision aids will change automatically each time the underlying review is modified.

Figure 1 summarises the methods of the SHARE-IT project. In collaboration with DECIDE (www.decide-collaboration.eu), we gathered an international team of experts in evidence based medicine and shared decision making, clinicians, guideline developers, and designers, and developed an initial framework and electronic prototype for the translation of GRADE summaries into decision aids. We then applied an iterative and user centred design, directly involving patients and clinicians facing real decisions. We built 10 decision aids on antithrombotic drugs and modified the prototype in light of observations of their use in practice and individual feedback from patients and clinicians.

The prototype shows that the approach is feasible, and preliminary experience suggests it is appreciated by both patients and clinicians (box). Across 16 clinical encounters, patients consistently reported high levels of satisfaction with the prototype in understanding risks and benefits and in enhancing their confidence in decisions (mean scores of 88.7 and 90.9 respectively (maximum 100) as assessed by COMRADE.

Conclusion

No decision aid is sufficient to guarantee that clinical decision making is shared. Undergraduate, postgraduate, and continuing education programmes must teach health professionals about the importance of creating and fostering a culture of shared decision making and the skills needed to communicate evidence, and its limitations, in a way people can understand. Furthermore, the challenge of producing evidence summaries that deal optimally with complexity, multimorbidity, and potentially limited applicability to the patient remains.

We are, however, now in a position to construct, test, and refine electronic evidence summaries for use in the clinical encounter for a wide variety of patient groups and clinical settings. Our prototype, built in the MAGICapp, demonstrates the feasibility of semiautomated production of decision aids from a large number of electronically published evidence summaries. We also plan to implement these formats in another similar platform, the GRADEpro Guideline Development Tool (www.guidelinedevelopment.org). We invite patient organisations, research groups, guideline developers, patients, and clinicians to partner with us (www.magicproject.org) and help us advance the science and art of truly shared and well informed decision making.

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Patient centred care has many evangelists but few practitioners. Doctors aspire to a state of grace in which their practice is truly focused on the individual, not on a passing stranger with a set of symptoms. But time is short, pressures great, and financial ligatures too tight.

So what could be done to advance the ideal a little faster? Can good teaching and training make the difference, or do healthcare professionals, including doctors, need incentives to succeed and sanctions if they fail? How would we even measure success and failure?

One problem is that patient centred care trades under many names, including participatory medicine, shared decision making, and support for self management, all with slightly different meanings. Proponents advance their own labels, diffusing focus and giving the impression of a circle of enthusiasts talking to each other but making a limited impression on the profession as a whole.

**Unblinding patients**

Many doctors, of course, claim that they already provide patient centred care. But this claim is hard to sustain given that doctors dominate in clinical encounters and hold most of the cards. A computer screen generally divides patient from practitioner, allowing one party to consult the record while the other remains a “blind” petitioner. Danny Sands, cochair of the US Society for Participatory Medicine, says that the first thing he does when training primary care doctors is to alter this time honoured arrangement. “I look at the screen and I turn it round so that the patient can see it, too,” he said.

Many people think that patient centred care is impossible without shared records. “It’s fundamental,” said Catherine Foot of the King’s Fund, lead author of a recent report, *People in Control of their own Health and Care*.1 “The idea that you are not allowed to access information about what is going on inside your body is ridiculous.”

Shared records may be necessary but they are not sufficient. Health professionals need to be taught and trained differently, and patients also need to change. Financial and other incentives may help but the greatest incentive to doctors, says Sands, is practising medicine better.

Jagtar Dhanda, head of inclusion at Macmillan Cancer Support, makes the same point. The cancer charity has been involved in training programmes that bring doctors and patients together to design new programmes of care. “There’s tension at the start, with doctors on one side of the room and patients on the other, but once you’ve broken down the barriers you can have a really rich conversation. Health professionals who’ve been involved become very strong advocates and they go and become champions of the ideas in their own peer networks,” he says.

Mohammad Al-Ubaydli, a clinician and information technology specialist who founded Patients Know Best,2 a system designed to allow doctors and patients to communicate securely online, says: “Everyone wants to do patient centred care, but on the ground nobody does it. The way we demonstrate it to professionals is to say that it’s in their personal interest to put the patient in control of the record. It’s a case of saying to the doctors that in your specialty, in this region, at this funding level, the more the patient has control the more you will benefit by saving time, saving money, improving outcomes—and the patient will be happier.”

**Updated training**

New technology and old ideas about patient centred care are converging.3 Ron Hsu of Leicester Medical School, who is using Patients Know Best as an adjunct to undergraduate teaching, says: “It’s absurd to have techniques of teaching and training that are based in the 1950s and 60s.” He points out that today’s students will complete their specialist training in the 2020s. “It’s inconceivable that the public by then won’t expect electronic communication with their doctors? So why aren’t we teaching our students to do it?”

Hsu devised a scheme in which lay volunteers, hiding behind “avatars” to protect their anonymity, communicate by email with groups of students.4 “I told the volunteers to behave normally not in a standardised way (the usual teaching approach),” he says. “That put the volunteers in control, because one of their concerns had been ‘Do I have to behave in a certain way?’ What are the rules and boundaries?” I said there are no boundaries, you can be racist if you want, you can be misogynistic if you want, but the students have to maintain their professionalism throughout.”

Richard Thomson, professor of epidemiology and public health at Newcastle Medical School, has developed training programmes for postgraduates to improve their skills in working collaboratively with patients through awareness training and role play. About 600 people have been through the workshops in the past year.

“What we really need to do nationally is to create that appropriate menu of skills in patient centred care and provide access for clinicians to develop their skills.

“What disappoints me is that nationally the main educational providers are not driving this agenda through. The General Medical Council says the right things about being a good doctor, the Royal College of Physicians has appointed a lead fellow in shared decision making—good stuff is happening but it’s not sufficiently coordinated.”

Dhanda agrees that there is a “lack of alignment” between the different bodies involved. “You’ve got the General Medical Council, the royal colleges, Health Education England, the NHS Leadership Academy, and so on, but they all have different views and starting positions on what they think leadership and development in this field means.”

Thomson says it proved hard to get patient centred care into the undergraduate curriculum at Newcastle, and “Nationally, it’s still not really biting on postgraduate training. I can’t see that people will struggle to pass royal college membership exams if they’re not person oriented.”

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The Royal College of Physicians expressed support for shared decision making in a position statement published in July 2013. It says that the professional attitudes and skills needed for shared decision making and support for self management needs “to be woven into physician training and assessment.”

But in a statement on the college’s website, Nick Lewis-Barned, a consultant in diabetes and endocrinology at Northumbria NHS Foundation Trust and the shared decision making clinical fellow, acknowledges patient involvement in the UK lags behind “almost all other developed health systems” including those in the US, New Zealand, and France.

Foot believes that training in motivational interviewing is important. This is a counselling approach, defined as “a collaborative conversation for strengthening a person’s own motivation and commitment to change.” Doctors can be trained in the technique and Foot says it works. “When you talk to doctors who’ve been trained to do this they report that it’s absolutely transformative,” she says. “They go in thinking that they do share the decisions with patients and come out realising they don’t.”

She is also enthusiastic about “value-based” recruitment policies which Health Education England plans to introduce.

Can incentives help to change practice?
Many suggestions have been made to encourage patient centred care, from the introduction of points in the Quality and Outcomes Framework, to the use of extra payments to hospitals under the Commissioning for Quality and Innovation Programme (CQUIN). But Foot has doubts. “A hospital inpatient is affected by every person they see—you can’t sum up your experience easily and that makes it hard to incentivise. It’s too far-removed from something that you can set a target for.”

Robin Hewings, head of policy at Diabetes UK, cites as a positive example the use of local enhanced services payments to encourage general practitioners in Islington to engage in care planning sessions with people on the diabetes register. GPs who have taken part often begin as sceptics but gain in enthusiasm later, he says. “They find it works really well, because what it does is to get people to have a strong sense of ownership of what they need to do. One doctor said: ‘I’ve spent 20 years telling my patients what to do, and now that I’ve helped them to find the answer themselves, they do it.’”

In Wolverhampton, patient centred care in diabetes has been encouraged by removing the incentives that often lead to fragmentation of care—principally, the payment by results tariff that encourages hospitals to admit and retain patients. A block contract was placed with Royal Wolverhampton NHS Trust for specialist care and a shared IT system enables specialists to identify people who need specialist attention without a referral from a GP. This is achieved through a central portal that extracts data from general practices and uses a locally developed algorithm to stratify patients by risk as red, amber, or green. This is used to determine how and where a patient should be treated. If a patient falls into the red band specialist treatment can be provided without having to wait for a referral. The trust also delivers community care services, removing another barrier to integration.

In the US, the Centers for Medicare and Medicaid have introduced financial incentives, under the Meaningful Use framework, for doctors to use modern technology to communicate with patients, although Sands says there is a lot of resistance to change.

“If doctors don’t go with it not only do they not get the financial incentives but over the years they will see a reduction in payments for visits. But I’m not optimistic that doctors are going to change their behaviour as a result of these incentives—they’re doing everything they can to adhere to the regulations without really encompassing the spirit. I’ve seen companies that offer to communicate with patients electronically so that doctors don’t have to.”

A different approach is to use professional interactions to drive a change in attitudes. Just as multidisciplinary teams improve quality of care, regular discussions among groups of staff about the human dimensions of care can too. So called Schwartz rounds (named after the Boston based Schwartz Centre for Compassionate Healthcare that devised them) usually take place once a month for an hour at a time, with the first 10-15 minutes taken up by a team telling a patient’s story or exploring a theme. The rest of the time is devoted to discussion guided by a facilitator. A King’s Fund pilot of Schwartz rounds in two acute trusts in England found that they increased empathy and understanding and resulted in a less hierarchical environment and a culture of openness. Schwartz rounds, with the support of the Point of Care Foundation, have spread to 87 health organisations across the UK.

Macmillan is a strong supporter of Schwartz rounds and has put money into 35 trusts to implement them. “We see real value in it because the whole idea of reflective practice is so important,” says Dhanda. “Health professionals need a safe space to discuss with colleagues when things go wrong and when they go right, and where they don’t have to come up with a ten-point plan.”

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