

THE PATIENT WILL SEE YOU NOW

REBALANCING RELATIONSHIPS
BETWEEN PEOPLE WHO USE SERVICES
AND THOSE WHO PROVIDE THEM



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A new interaction

We know the consequences of a care system that treats communities as units of need and leaves passive patients waiting to be told what to do. It is inefficient and ineffective. It is also unsafe and leaves whole communities with poor access. It is time for a radical rethink of how we design and deliver services.

What do we need to do? First, we need to move from a healthcare service to a health support service, where the mutual desire to support and enable overrides the paternalistic desire to care; a move from seeing heroic medicine as the paradigm for the NHS to just a part of health services.

Such a person focused NHS has compassion at its heart and dignity and respect as its values. It supports people with the tools, confidence, competence and self-efficacy to make decisions and to manage their own health. It provides people with treatment and care when it is needed. And it meets people's psychological and emotional health needs as well as physical.

We need to engage with communities as the assets they are. Communities can bring knowledge on the "how" as well as "what". They are routes to engagement; their leaders provide role models. This means having wider community participation over and above individual representation.

We need to recognise people's vulnerability and support them to protect and manage their own health. We need to move beyond care pathways that create silos around conditions, to person centred pathways.

All this will mean letting go of control. Imagine making a decision about buying a house without having access to your utility bills or bank statements showing your past income and expenditure transactions. So why does the NHS make it so difficult for me to access my health record?

We need to make feedback the cornerstone of improving quality and a culture of compassionate learning. Contrast this with our present model, built around a bureaucratic process of complaint, which reinforces a culture of blame and distancing from responsibility.

Above all, we need

managers to see themselves as liberators not regulators. Clinicians need to be enablers who use their expertise rather than experts who dispense it. Passive patients need to become activated people. We need true mutuality, partnership and co-production.

The voluntary sector has grown up to fill the gaps in services – so it too is condition focused – and as individuals we have accepted our dependency.

As the commentators in this supplement highlight, we need to change the way we see ourselves, our mindsets and our roles, our behaviours and the culture of healthcare.

This is not a consumerist model. It has to happen within the social contract of the NHS, where I contribute to the cost of my health support as a citizen not as a consumer.

As leaders in the health service, it is our responsibility to hold the vision and support our staff in putting in place the solutions that will make the difference. Scotland has taken the first brave steps: its quality strategy puts mutuality at its heart and person centred health services as its goal. It is time for the other UK countries to follow.

The Health Foundation wants to help catalyse the transformation. We want to use our strengths to build your strengths; our capacities to catalyse and unlock your capacities; to work together to learn and demonstrate how to make improving person centred quality the heart of the NHS of the tomorrow that starts today. ●

Stephen Thornton is chief executive and Adrian Sieff is assistant director of the Health Foundation.



OUR MUTUAL TRENDS

Transforming relationships between people, clinicians and the health service will improve outcomes and the patient experience and reduce cost

Imagine a health system in which much more emphasis was given to supporting, educating and informing people about how to live better quality lives. One in which people with complex and long term conditions were more equipped to look after themselves. And one which placed a greater focus on customer care, valuing people and treating them with dignity and respect.

Such a system would be characterised by more information, more dialogue, and a different mind set about the expertise both patients and clinicians can bring to the party.

There is little argument over the desirability of that vision; the barrier is how to make it happen on the ground. One way of thinking about how to make the change is to explore the relationships through the lenses of three different interactions.

One is the dynamic between people who use services and individuals who provide them. Another is the dynamic between people and health systems. And the other, the dynamic between communities and health systems.

The first includes thinking about shared decision making and a more equal partnership between clinicians and people. Clinicians bring their technical knowledge to the consultation, patients bring their knowledge about themselves, and together they devise and agree the goals and actions to be taken – such as an activity plan, taking medication or having an operation.

But in addition to being expert technicians, doctors and nurses must be good with people, be educators and team players and have a holistic sense of people's needs, says National Voices chief executive Jeremy Taylor. The "doctor knows best" paternalism is eroding and a new generation of clinicians are emerging with different attitudes, but more needs to be done.

Mr Taylor says: "Our sense is that clinical training and standards and regulation still don't focus sufficiently on the human side of what clinicians do."

The second and third dynamics require easier ways for patients to give positive and negative feedback, and better involvement in major service change. Service change will become increasingly important during a period of cost cutting. Organisations ignore the public at their peril and risk huge amounts of public dissatisfaction and distrust.

Mr Taylor says: "There's a real need for a greater degree of exchange and honesty, particularly now, because what managers and commissioners are faced with is having to make huge savings and not being able to please everybody."

Co-ownership

The Scottish government introduced the notion of mutuality in healthcare in 2007 in the document *Better Health, Better Care*.

"Mutuality recognises that people who own the NHS in Scotland are the people of Scotland, and that we ought to really be thinking of them as co-owners rather than as service users," says Scottish government health directorate director of healthcare policy and strategy Derek Feeley.

"That brings with it a range of rights and responsibilities," he says.

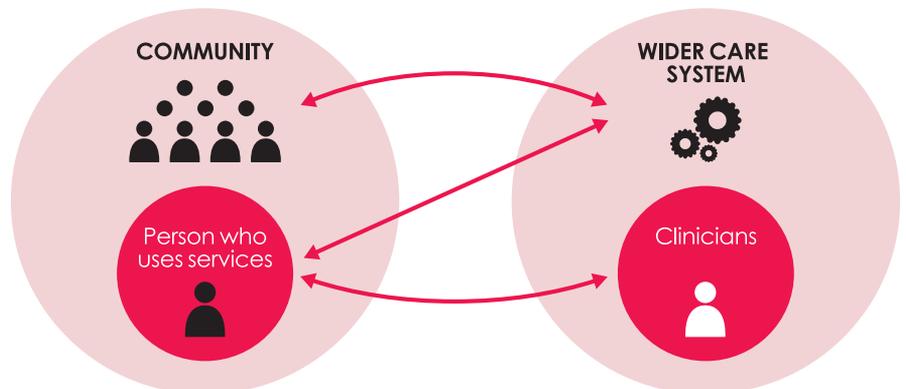
The initial focus of the mutuality work has been about engaging people in the planning and delivery of health services.

That has seen the introduction of a patients' rights bill and a participation standard which applies the rigour of clinical standards to the way boards interact with their populations and enable people to participate. The first pilot elections to directly elected boards in Scotland took place this month.

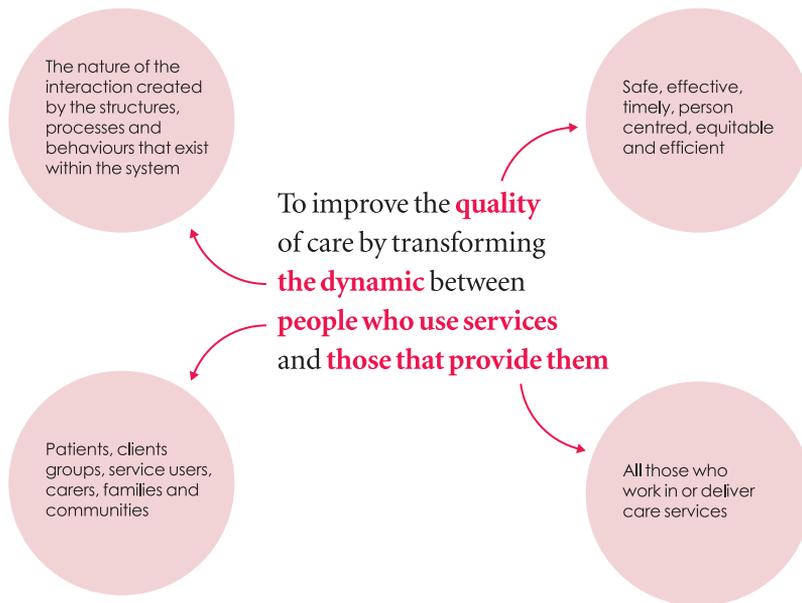
The next phase, outlined in the Quality Strategy, will concentrate on embedding the concept of mutuality in interactions between clinicians and patients in Scotland. The focus will be on person centred care and enhancing patient experience. There are plans to introduce patient reported outcome measures and shared decision making tools, and to measure clinical empathy.

Transforming the nature of the relationship people have with their own health is the emphasis of the regional Darzi vision, *Healthier Horizons*, in the North West.

NHS North West believes that transformation could be achieved by changing the relationship people have with the health service. People would be asked to think about their own health and get more involved in their own care, and in return be



'The NHS would be a very different type of service if power was devolved to frontline staff and to patients'



given more influence over setting service priorities and over managing their own care.

NHS North West chief executive Mike Farrar likens the transformation to the one that has occurred in the world of IT.

Technology has moved from the mainframe computer to the personal computer, the laptop and the handheld computer. But it is not those advances that have transformed people's lives. The internet changed the relationship users have with the system and now sees people shopping and banking online.

It is that kind of transformation that is needed in healthcare.

"It's not just reorganising stroke services or primary care services," says Mr Farrar. "The real transformational change will come about when we engage differently with our own health and the health services we use."

But how best to engage? At the individual clinical level that means patients holding their own clinical data. At the commissioning level it means patients having a say on priorities for services and medications.

People power

The big one in terms of who runs hospitals is foundation trust governors. They have the power to elect people onto the board and can start to run services in a way that is much more supportive of their own local views.

Mr Farrar argues that the biggest contribution towards meeting the Department of Health's quality, innovation, productivity and prevention challenge is to "unlock the power of the people" to think about how they use resources and to think about their own lifestyles in terms of health.

The health service should not fear that empowering others will result in its own loss of power.

"If you empower the patients and the public it creates more power, it doesn't take you and your power away," says Mr Farrar.

Radical, patient centred services and more effective approaches to public behaviour change will make it more likely that the NHS will achieve the required savings, says Jonathan Kestenbaum, chief executive of the National Endowment for Science, Technology and the Arts.

If the aim is to halve the £163bn annual deficit and save £15-20bn in the NHS over the next three years, that "can't possibly be found from what Whitehall traditionally calls efficiency", he says.

Long term conditions place the greatest single cost pressure on the NHS, with 15 million people costing the NHS £69bn a year. Traditional Whitehall efficiencies will be necessary but insufficient to attack those kinds of numbers.

Mr Kestenbaum believes the road to financial savings will travel through imagination and ingenuity, but services will have to be radical and different in their delivery if those savings are going to be achieved.

NESTA's work shows that other sectors are placing much greater reliance on customers, clients and staff to provide new ideas and testing grounds. This approach leads to the development of better products and services at less cost.

A NESTA survey shows that 57 per cent of FTSE 100 companies plan on increasing their level of user driven innovation for new products, even during recessionary times. Its paper *The Human Factor* outlines how patient and community led approaches have the potential to generate savings of between 5-20 per cent.

Innovating in this way depends on giving genuine power to frontline staff, patients

and the public. If done in half measures it will not generate the required level of impact, and it will not be brought to scale.

Scaling up new ideas from users and communities is not just about financial investment. It needs commitment to the objective of replication and scale from the beginning, and a willingness from the health service itself to place new providers and new ways of doing things right at the heart of the service.

The old venture model is a wide funnel which shows that for every five ideas that have traction, 500 are needed at the outset. Innovation will not occur in the health service unless it is prepared to build sources of funding and structures which acknowledge that not every idea will succeed.

The NHS would be a very different type of service if power was devolved to frontline staff and patients to develop a more responsive, person centred model of care. Therein lies the key to improving patient experience and outcomes, while reducing cost. ●

THE HEALTH FOUNDATION'S PLANS FOR THE FUTURE

The health service is under intense pressure. As an independent foundation, it is more important than ever for us to create the space for those working in the service to step back and look at ways to meet the present challenges.

We have expanded our research and development programme and we are testing new ideas in a wide ranging portfolio of award schemes.

Our approach to inspiring improvement is to:

- Identify. We provide the evidence and highlight the success stories to show that improvement is possible
- Innovate. We help people to take a step back, to innovate, and to plan the practicalities of change
- Demonstrate. We put ideas to work, share our learning and turn demonstration into accepted practice
- Encourage. We work across every level of the healthcare system to create advocates for our approach

For further information about the Health Foundation's plans visit www.health.org.uk/our_plans

THE DO BETTER DYNAMIC

A roundtable of health leaders agreed improvements in quality will be most far reaching where driven co-creatively by both service users and service providers



Participants at the Health Foundation roundtable event all believed change is possible

Taunton and Somerset Foundation Trust chief executive Jo Cubbon.

Starting now

But changing the dynamics of the NHS is not a simple task. Good ideas are often turned into a bureaucratic process which then misses the point. The chasm between good policy intent and demonstrable improvements on the ground remains largely unbridged.

One reason is that relationships start from a basis of inequality: the Goliath of the institutions and professions of healthcare; the David of communities and individuals. Some managers and clinicians believe they have the responsibility to empower communities, while others fear that this will diminish their roles.

But clinicians and managers do not need to release power in order for patients to have more power, said Patient Opinion chief executive and GP Paul Hodgkin: "There isn't a zero sum game."

Another factor is that action is driven by a narrow definition of evidence – the weight of a billion pound industry producing evidence, guidelines and protocols bearing down on the individual GP. Professional behaviour is incentivised through the quality and outcomes framework and payment by results. But these reward treating the condition, not healing the person.

Our measures of success are based around the organisations that provide services, not the needs of those who use them. The need to deliver short term targets crowds out the space to innovate for long-term goals.

"I've yet as a chief executive to be measured at being really successful at not delivering some of the care and enabling other parts of the health system to deliver that," said Jo Cubbon.

Real transformation of health service dynamics requires changing incentives and freeing managers to manage.

There have been plenty of examples of new ways of delivering, procuring, outsourcing and commissioning, but all too often such efforts are short lived.

"You get something started in the NHS and before you've even allowed it to breathe, you've started another system," observed roundtable chair and chair of the Patients' Council Paul Mainwaring. "No one system is

What happens when you get a group of leading health thinkers together for a revolutionary discussion? Not about the usual themes of strategy or planning; not what we should measure or how we should measure it; but the very purpose and ethos of health services themselves? When the Health Foundation brought together a collection of people who design, manage, deliver and use the health service which offers so much but still falls so far short of our aspirations, there was a sense of energy and a belief that change is possible.

Vision for quality

The idea is simple but profound. Improvements in quality will not go far enough if they focus on looking inwards, not outwards, and if they only follow the usual path of looking at organisational and professional boundaries, changing service architectures and increasing clinical skills.

Real change in outcomes and experience will be achieved only when people who use health services are active partners, at the heart of the NHS, determining the services that are responsive to their needs and taking the lead role in their health. In short, a transformation in the quality of health services will only come from changing the relationships that underpin the manager driven, professional led NHS.

There was an early consensus that the Health Foundation's vision was impressive and that achieving it depends on

'There is a correlation between ownership, satisfaction and the clinical outcomes that can be achieved'

transforming the dynamics between individuals using services, communities, professionals and the wider healthcare system.

"People go into healthcare as professionals because they want to help, because they want to make a difference," said National Voices chief executive Jeremy Taylor. "How do they get diverted away from a set of motivations and an underlying philosophy of care which is probably not that different from what the Health Foundation is espousing?"

The vision holds many opportunities. When people are at the centre of service design they will feel greater ownership and are more likely to turn up for their appointments.

There will be greater concordance and reduced wastage.

"There is a real correlation between ownership, satisfaction and clinical outcomes that can be achieved," said



Jo Cubbon



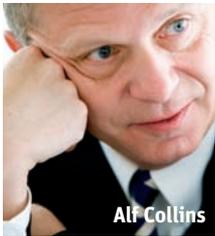
Jo Bibby



Stian Westlake



Jeremy Taylor



Alf Collins



Adrian Sieff



Jane Naish



Malcolm Alexander



Patrick Vernon

ever given the chance to mature and come to life.”

Constant changes miss the point. They do not address the relationships that are the heart of the problem and the solution.

Achieving the vision

Despite the myriad of obstacles, there was a clear sense in the room that there is a way forward; that we can learn from successes of the past and from outside the health field. We can seize the opportunities of new technology and social media; harness the

INSPIRING IMPROVEMENT: CLOSING THE GAP

Showing people genuine improvements in health services is the best way to convince them that change is achievable. So the Health Foundation puts ideas to work and shares learning. By showing ideas being implemented on an ever larger scale, we create excitement about improving quality, and turn demonstration into accepted practice.

Closing the Gap provides the opportunity for teams and organisations working in partnership to make demonstrable improvements in quality by tackling known gaps between best practice and routine delivery of care.

This year, eight partnerships will be awarded up to £400,000 each to test and demonstrate approaches to transforming the dynamic between people who use health services and those who provide them. For more information visit: www.health.org.uk/closingthegap

knowledge and skills of the voluntary sector, community groups, professionals and managers. We can recruit on the basis of attitude and behaviour alongside academic success. We can incentivise person centred care and disincentivise siloed organisational and professional working and put the new dynamic at the heart of training and development.

Understanding communities

There was agreement about the Health Foundation’s vision that efforts to transform the dynamic between communities and the wider healthcare system need to start with communities rather than individuals. The temptation is always to interact with individuals, when the focus here should be on supporting communities as a whole.

At the heart of this shift in dynamics is the need to engage with communities to understand the services they want to use, rather than merely to encourage them to use the services the NHS wants to provide.

In reality, it is the NHS, the state, clinicians, drug companies and the media that hold the power. It is important this doesn’t get in the way of co-producing and engaging with communities.

“If we ignore it, we ignore it at our peril,” said Department of Health national director of patient and public affairs Joan Saddler. “[When thinking about co-production with our communities] we have to factor in all of those power relationships because they’re real.”

There was a strong consensus that we need recognition that our structures favour dominant culture attributes, and that a

deeper understanding of communities is required. Passive resistance to the MMR vaccine and 19th century opposition to immunisation both demonstrate the power of communities and the risks of not engaging with them.

It is one reason why the Tesco consumerist model doesn’t fit the NHS – service users need to have a broader level of control.

“Co-production is a different approach not only to the conventional model of healthcare but also to a consumerist model,” noted the national clinical lead of the Health Foundation’s Co-creating Health programme, Alf Collins.

Everyone agreed that the health system will only work well if there is a collaborative effort between all the players: the NHS, community groups, the third sector and the people who use services. In letting go of power, the NHS needs to allow those who know communities to participate in determining what services are needed and how they are best provided. In this way, the wasted effort of poorly used services would diminish.

Interacting with individuals

A second focus of the Health Foundation’s vision is about changing the nature of the interaction between people using services and the wider healthcare system. It is not as if we don’t have examples of changing relationships. Director of the King’s Fund Point of Care programme Jocelyn Cornwell highlighted the transformation that has occurred with HIV/AIDS services since the 1980s. And we were reminded of the

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transformation of children's services from a largely paternalistic model to a family centred one.

What can we learn from these examples? People who used these services demanded and campaigned for change. Their demands were heard by enlightened professionals and organisational self interest supported by effective championship. There was also time and money. Both of these are in shorter supply today. But today there is also more evidence of the effectiveness of change. The roundtable was clear: we need to build on the will, use the resources we have more wisely, and provide the leadership for change.

Burning question

One burning question was why don't people own their health records? It was agreed that this would be the foundation stone of a truly person-focused service culture. Again, there are examples of success, such as the maternity record held by pregnant women.

A move towards instant feedback, rather than waiting for a complaint, would also provoke change. There are new opportunities using new media. The future will see patients blogging about their experience in hospital and posting photos of the dirty toilets on Flickr.

Paul Hodgkin commented: "This dynamic has completely changed the music, travel and banking industries, it just hasn't changed us yet."

Service users and service providers

The third focus of the Health Foundation's vision is the dynamic between staff and the

people they support. This interaction often takes place in a space which is uncomfortable and alien to the service user. People often arrive at hospital not knowing what to expect and leave without understanding what has happened to them. Improving that scenario is just one aspect of transforming the third dynamic, that between people who use health services and the individuals who provide them.

Being a health professional is a huge responsibility. The job comes with emotional demands which can become so excessive that staff switch off and stop seeing the person in the patient.

But Health Foundation director of improvement programmes Jo Bibby said: "The emotional side of the work is a burden people need to carry if we're going to have high quality care."

Milton Keynes Hospital Foundation Trust head of cancer services Jane Naish gave a simple but inspiring example of how small changes can make a big difference to staff and to people. A busy outpatient ward. Little time. Hard pressed staff. Disenfranchised patients. Staff observed what was happening. They designed the change and implemented it. Chairs were put in a circle. Photos of staff were put on a board. Nurses introduced themselves at the start of a clinic. A leaflet, approved by non-medical people, is sent to all new outpatients so people know what to expect and includes the sister's telephone number.

These changes improve the staff experience also; outpatient staff and receptionists feel more in control and happier.

Economic models focus on the consumer and professional models look to education and training. But it is in the relationships between patient and professional carer that health is delivered.

Dynamics are about these relationships as well as transactions. We need to turn to sociology, psychology and anthropology for our models of change.

Jo Cubbon pointed out that improving staff engagement is the way to drive patient centred care.

Moving forward

People recognised that there are severe challenges ahead: "We've got to be careful as we go through the next four to five years because this whole urgency on productivity and efficiency is not necessarily recognising the psychological support time that teams and individuals need to be able to continue to provide safe patient care," commented one participant. "We're getting a bit fixated on allotting every moment."

But caution was not the final word.

There was a palpable energy in the room to move from ideas to practice.

There was clear agreement around the importance of values based care and the need to share power and control; that we must hear the voices of communities who have been modelling a different dynamic for years.

As Alf Collins said: "The story for me is 'Butch Cassidy and the Sundance Kid'. The only way they were going to save themselves was to jump into the water, and the way they did it was they held each other's hands. They trusted each other." ●

DRIVING WITH DUAL CONTROLS

Consultation models in which the patient is seen as an active information resource are not threatening to the health professional but empowering on both sides



The consultation between a patient and clinician is one of the fundamental building blocks of the NHS. But these interactions are often characterised by an imbalance of power, control and information.

In research conducted by Martin Fischer and Gill Ereaut for the Health Foundation they describe how clinicians have a single model for the consultation that is not complex or sophisticated enough to cope with the variety of situations they encounter. Doctors take their step by step process for granted, but it is invisible to the people they serve.

Fear drives the relationship

They also found that the dynamic of the doctor-patient interaction is driven by three categories of fear on both sides.

For patients that manifests as: “if I’m ill and don’t go to the doctor I might die” (existential anxiety), “will I be able to say what I need to say and ask what I need to ask?” (interaction anxiety) and “am I sick enough to be using the health service?” (entitlement anxiety).

At the same time doctors are afraid they will miss something critical (existential anxiety), worried that once they ask a patient a question the patient won’t stop talking or will bring up something that is beyond the doctor’s abilities (interaction anxiety), and worried they might get into trouble if they refer too often or prescribe things that are not evidence based (entitlement anxiety).

The anxieties come together in an “opening up and closing down” dynamic. The clinician knows they have to open up the patient to find out what is wrong or they might miss something, but because they fear the patient will have insatiable demands, won’t stop talking or will bring up an unsolvable problem, they close them down.

Patients feel confused and find they have reached the end of the consultation without communicating what they wanted to say.

There is also a mismatch of energies

during the consultation. Because doctors' anxiety is about getting the diagnosis wrong, their energy drops the moment they make the diagnosis, which is the moment the patient's energy rises.

Doctors don't feel their fear because the system and consultation model have evolved to reduce and manage their anxiety. As we transform health services dynamics to support people in managing their anxiety, we also need to recognise the hidden anxieties of clinicians and other staff and ensure they too are supported.

Invisible structure

From the patient's point of view the structure of the consultation – welcome, history taking, etc – is a glass maze that they are only aware of when they bump into it.

Mr Fischer says: "The doctors completely deny the fact that they've got the map and they drive the vehicle."

Rather, they believe their tone is entirely set by the patients and they have different ways of consulting.

For patients, the consultation is part of a single conversation that they are having with

'The Care Quality Commission aims to shift the balance of power by making patient views core to its assessments'

the health service as a whole, whereas doctors see lumps of people they call the clinic. It explains the wrong footedness patients experience when their notes go missing.

Ms Ereaut says: "It's a bit like the frustration of having a conversation with somebody who isn't listening to you."

On the broader scale

On a broader scale, the researchers found that much of the NHS was structured around the patient-clinician dynamic. The same opening up and closing down dynamic can be seen in the consultation trusts have with patients and the public. The system asks the questions it wants to ask and then

closes down quickly to avoid moving into subjects it doesn't want to discuss.

The fact that the doctor-patient consultation occurs behind closed doors has disconnected the doctor from the organisation. Patients may wait six weeks for an appointment, then sit for three hours in the waiting room, but the doctor doesn't know there is a problem or see it as their responsibility. Equally, managers are separated from clinical work because they don't understand it. These separations diminish quality.

Staff find it difficult to relate to each patient as an individual because of the power imbalance, particularly on the ward when a patient is in bed, not wearing clothes and connected to tubes during the consultation.

"It's very hard for the relationship to start off in the right place unless there is an extraordinary amount of sympathy to that situation by the healthcare professional," says Heart of England Foundation Trust chief executive Mark Goldman, who is a Health Foundation governor.

Patients are upset when professionals speak to each other as if the patient were not there, but it is easily done.

At the bedside, doctors have a responsibility to communicate with the patient, their team and the nurses, and to teach junior doctors and students. Often the patient misses out.

Power imbalance

Getting that interaction right could have a big impact on outcomes by making people less reluctant to engage with the medical profession when they feel unwell.

That might lead to earlier diagnoses and resultant improved health outcomes that are more in line with those of other countries.

The Care Quality Commission aims to shift the balance of power by making patient views core to its assessments.

CQC chief executive Cynthia Bower says: "When we go out to inspect it won't be about going into the boardroom it'll be going onto the wards [and] observing patient-clinician interactions."

A new paradigm is needed for the patient-clinician interaction, in which trust goes both ways, says NHS Alliance Patient and Public Involvement Steering Group chair Brian Fisher.

"We consistently neglect the patient as a vital resource," he says.

CASE STUDY: CO-DESIGN

Amid numerous policy initiatives which have impacted on patient care, there has been no one in the system whose sole or main responsibility is to think about people in the round. That scenario kick started The Point of Care programme at the King's Fund, which seeks to improve patients' experience in hospital.

Experience based co-design, in which patients and staff work together to improve the experience of using services, is being piloted at the Integrated Cancer Centre at Guy's and St Thomas' Foundation Trust and King's College Hospital Foundation Trust. A new private space in outpatients for receiving results is one output.

Schwartz Center Rounds are being piloted at the Royal Free Hampstead Trust and Gloucestershire Hospitals Foundation Trust. During the monthly one-hour rounds, staff discuss difficult emotions arising from patient care.

Director of the programme Jocelyn Cornwell says: "They're talking about the nitty gritty [of] what staff confront in trying to deliver compassionate care."

Staff feel supported and it reconnects them to why they went into a caring profession in the first place.

The next phase in the health service will be about shared decision making (see article on page 13), supporting patients in looking after themselves better, and setting up systems and environments which facilitate that.

The consultation would be transformed from a paternalistic exercise to a meeting in which clinicians offer technical expertise, patients offer expertise about themselves, and together they work out a plan of action.

A new professionalism

Doctors are trained to be problem solvers, not to help patients become confident and capable of looking after themselves.

The old inward model of professionalism provides a narrow definition of the professional's role. When it comes to quality, doctors say "providing high quality care is what we do".

But striving to improve what they do "is more of an improvement philosophy and much more compatible with a person-centred service", says Health Foundation clinical director and director of research and development Martin Marshall.

There are different dimensions of quality beyond clinical effectiveness which health professionals have a responsibility to address, including safety, patient centredness, efficiency and equity.

Professor Marshall is working on a new model of professionalism which shifts clinicians' orientation from the individual patient and clinical effectiveness to a wider definition of quality and a wider responsibility for the system.

That would see clinicians' decisions take into account the benefit to individual people as well as the implications for other patients and the system. ●

CASE STUDY: ACCESS TO RECORDS

A patient sits in the GP waiting room looking at his medical record on an iPhone. He is reviewing the last few consultations and his test results. On entering the consultation he knows more about his record than the doctor, which shifts the power base.

There are three experts in the consultation – patient, clinician and computer (which holds information) – and they need to work together.

A champion of patients accessing their medical records and map of medicine pathways, Hyde GP Amir Hannan, who is a member of the Record Access Collaborative,

believes such access leads to a partnership of trust between clinicians and patients. His patients can see both on the practice website, www.htmc.co.uk.

He says: "If you explain to a patient where they are – that's what accessing their records is about – and then explain what they could have – evidence based pathways – plus what services are available, that patient might figure out what they need."

That will become increasingly important as patients live longer with more long term conditions.

INTERACTION WITH THE PUBLIC



Participation in service design and access to health records will improve people's relationship with the NHS

SO WE ALL KNOW WHERE WE ARE

USE OF LANGUAGE

When people start a job with a new organisation, for the first few weeks they notice its language and at a semi-conscious level “clock” the priorities.

“After a few weeks you can’t hear them anymore because you’ve had to start living it in order to function within the organisation,” says Gill Ereaud, managing director and founder of Linguistic Landscapes.

Her job is to make that language visible to people again so they can decide if it is working for or against the organisation’s objectives.

Hospital doctors commonly talk about patients being poorly or sick, which in the outside world means a bit unwell, but to them is reserved for people at death’s door.

In medicine, patients are spoken about as passive recipients – they are “seen”, “looked at” – rather than being consulted or helped. They “wait” in the waiting room.

She points out: “The status quo of any organisation in its habitual language is a product of the past and in many cases it was a very sensible past.”

But it can become an anchor that slows or stops change. Changing language can be “a very effective tool for accelerating change”.

Scotland’s Quality Strategy talks about improving person – rather than patient – centred care because feedback revealed people want to be viewed in terms of their whole lives and not just their medical condition. The terminology shows they have been listened to, but also suggests a different kind of relationship to staff.

The Scottish government asked the Long Term Conditions Alliance Scotland to write its self management strategy.

“They wrote it in a very different language and in a very different style from how we would have written it,” says Scottish Government Health Directorate director of healthcare policy and strategy Derek Feeley.

That includes the document’s title, *Gaun Yersel*, a Glaswegian rejoinder to galvanise yourself, which has caught people’s attention.

Mr Feeley says: “What you’re doing in policy and strategy needs to be backed up by what you’re doing in relation to language. You can’t separate those two things if you want to have something that’s coherent and meaningful to people.”

The relationship between people who use health services and the health system has been a policy focus, with choice and integrated care pilots just some examples. But the impact of these initiatives has been limited because they have concentrated on following a process rather than fundamentally changing the relationship.

The Health Foundation has identified other areas with the potential to drive more radical change and improvements in quality. These include using feedback to continually improve services; and patients accessing their health records.

Using feedback

Research from Picker Institute Europe in 2008 shows that just 9 per cent of patients in hospital were asked for their views on the

quality of care. Picker Institute Europe chief executive Penny Woods says too often feedback is centred on complaints, while trusts are increasingly interested in relaying positive comments to staff.

Health Foundation research finds that the complaints system is perceived as adversarial and inhibits constructive feedback.

Making the most of patient feedback requires a shift in mind set, seeing it as an opportunity for improvement rather than a mode of communicating complaints.

Democratic or participatory processes need to be systematised across the NHS to ensure that patient and public views become part of the commissioning process, says GP Brian Fisher, chair of the NHS Alliance Patient and Public Involvement Steering Group. That means care pathways would not be designed without these views.

Accessing health records

The NHS guards information, and the health record is a means of controlling patients’ care, while reinforcing their dependency.

Health Foundation research finds that people’s control over their health records can increase quality by improving relationships and communication with clinicians; promoting informed discussions; increasing people’s ability to contribute to decision making and manage their own health; reducing errors; and improving compliance in heart disease, hyperlipidaemia and depression.

But the health service tends to look at the point of greatest risk, says University Hospitals of Leicester Trust chief executive Malcolm Lowe-Lauri.

“[Staff] are worried that a particular individual might insist on having their records in order to act in a way which is unjustified, but that is rare,” he says.

The 60 per cent of UK general practices using EMIS can allow patients to access their full GP electronic record online, but only about 50 practices offer it (see case study, page 7). A culture shift is needed so that patient access to records is viewed as part of the infrastructure needed for better self management, says Dr Fisher, who is also co-director of software and hardware development company PAERS.

Fragmented care

All too often patients find that the care they receive is fragmented and the responsibility to join it up sits with them, rather than the health system.

Financial incentives in the NHS reinforce fragmentation, says Dr Fisher. Hospitals want to suck patients in through payment by results and practices want to keep people out of hospital by practice based commissioning. That makes it more difficult to get agreement between primary and secondary care about care pathways and make smooth interactions between different parts of the system.

Programme budgeting, in which a primary care trust and hospital share a budget, for example in cardiology, is one way forward. Personal budgets may also be part of the solution.

Mr Lowe-Lauri says the public are often ahead of the NHS, as shown in the NHS Plan consultation exercises 10 years ago, when it was patients rather than professionals who emphasised the need for clean hospitals.

“I think they accept and understand the need to change, for example, the traditional acute hospital model,” he says. “At the same time they know that there’s a case for getting a lot more done by GPs.”

Impact on quality

What impact will improving patient and public involvement have on quality?

“I think it will have a huge effect on process quality because there are lots of things we do in terms of our processes that are clearly a mystery to patients,” says Mr Lowe-Lauri. In addition, some hospitals are poorly organised and the miles patients travel suggest you have got to be fit to be ill.

He points out that professionals and senior managers in the NHS are “inexpert about how the NHS works” because when they are patients themselves they “shortcut the process on the basis of local knowledge”.

“We inside the NHS, at the top it, leading it, can often if we’re not careful be entirely ignorant of what it’s like to experience the NHS,” he says. “When you start to think like that you realise just how much your public has got to offer and just how inexcusable some elements of our process are.”●

CASE STUDY: FEEDBACK

Taher Mahmud, consultant physician and rheumatologist at Pembury Hospital, Maidstone and Tunbridge Wells Trust, started collecting patient feedback five years ago in order to improve performance on patient experience and increase compliance with treatment. Since 2008 he has asked for feedback at every consultation. Recommendations are put into practice before the next clinic.

“The clinic is not complete unless I’ve done the feedback at the end of the clinic,” he says. “If you say we’re interested in feedback and we’re going to act on that feedback you change the dynamic and the psychology of the whole team.”

Through his Centre for Patient Involvement, www.patientinvolvement.org he hopes to have 100 pilots doing patient feedback by the end of the year.

Ben Bridgewater, consultant cardiac surgeon at University Hospital of South Manchester Foundation Trust and chair of the Society for Cardiothoracic Surgery in Great Britain and Ireland database committee, has also been getting real time feedback on his consultations, using questions such as “did the doctor listen to you”.

“It keeps you focused and keeps you sharp,” he says.

Mortality rates for cardiac surgery have been published for several years and been well received by patients because they can access the information if they want it and feel reassured that there is a proper governance system. Clinicians see the data and that drives up quality; mortality in cardiac surgery in the

POPULAR IDEAS

It can be hard to find favour within PCTs for the concept of sharing some of their power with local communities, but it is vital to ensuring healthcare access for all

The first step to high quality care is equitable access. But across communities there are barriers for people who don't have the cultural expectations, knowledge and language that accessing services requires. People from disadvantaged, marginalised and excluded communities face many challenges in getting the care they need.

Those responsible for planning and delivering services need a deep understanding of the communities they serve so that they can make services equitable, and so that support and care can be effective, and user experience characterised by compassion and respect.

Difficulties with engagement

Primary care trusts have been struggling with how to engage communities in designing services. Community engagement is patchy and often based on models of individual representation. These treat communities as passive spaces where interventions take place rather than dynamic ones which can shape services.

There is a need to shift from representative to participative models which reach out to communities.

NHS North West chief executive Mike Farrar says PCTs have been unimaginative in their efforts to engage communities in designing services.

"We tend to engage patients at the point that we're making changes and we want their support," he says. "But we could have a much more proactive, systematic, ongoing high tech consultation, using texting, using internet polling, all kinds of things that we can do on an ongoing basis."

He adds that it is important to consult widely and avoid being captured by particular lobbies.

Deficit model

Leadership development consultant Allison Trimble argues that the approach to engaging with communities is a "deficit model".

It is epitomised by the phrase "hard to reach", which implies there is something difficult about those communities, that they are not able to access the support and care they need and lack the skills to engage.

Papers from government and local

authorities about how to engage communities use language that is "couched in the fact that it is all about enabling communities to start being able to play the game the way the statutory sector plays it". She says: "A lot of people, particularly civil servants who are writing [these documents], are still stuck in that deficit model."

PCTs need to channel resources into encouraging different thinking about communities, but thinking differently can mean letting go of power and resources.

Architecture for engagement

Before world class commissioning and quality accounts there was no health architecture to indicate that community engagement was important, says national director of patient and public affairs at the Department of Health Joan Saddler.

The regulatory architecture was there, but that meant that the driver for engagement was an external one.

"You now could argue that there's a measurement from the DH but the internal

driver for a PCT to get it right and to evidence that they're engaging towards better outcomes is stronger than it's ever been," she says.

Setting objectives

"The problem facing PCTs and commissioners is that they've been told that they must consult with and involve local communities and most of them are really struggling to do that," says independent consultant Angela Coulter.

One issue is that they are not clear about what they are trying to achieve with community involvement, she says.

In her report for the Health Foundation, *Engaging Communities for Health Improvement*, she suggests four different types of objectives: to determine local needs, to promote health, to improve the quality of services and service design, and to strengthen local accountability.

All are legitimate objectives for commissioners but may require different approaches, so it is important to identify which are applicable.

Barriers to engagement

Much is known about what works in terms of engaging people (see box). But too often the people in PCTs who find themselves responsible for community engagement feel they are low in the hierarchy and don't have a budget or the support of senior managers.

"PCTs have all sorts of other competing priorities but I don't think they're going to achieve any of their goals unless they do this well," says Ms Coulter.

She believes that NHS organisations need to take community engagement more seriously and that senior managers should be engaged.

She adds: "This is an area which is absolutely beset by woolly thinking. It needs a serious approach and just as much project planning as any other change in healthcare facilities.

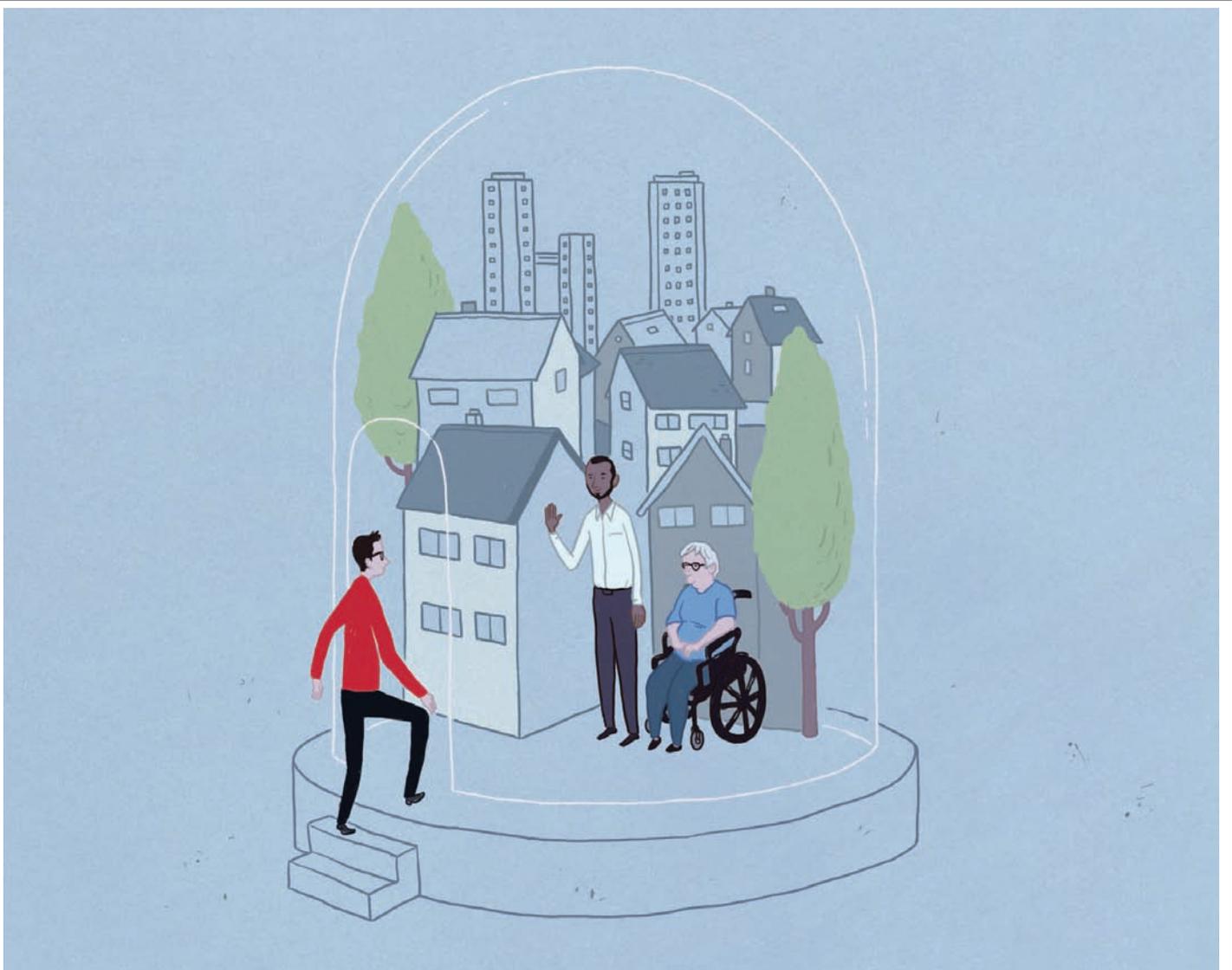
"It's not just something that can be left to the most junior person and nobody else needs to bother about it."

Michael Blomfield and Harry Cayton in *Community Engagement: a scoping report*, commissioned by the Health Foundation, highlight deeply ingrained organisational



HOW TO GET EFFECTIVE COMMUNITY INVOLVEMENT

- Be clear about why you are doing it
- Understand the community you are trying to engage
- Be clear about who the leaders are
- Have a clear plan for doing it
- Set clear, focused goals
- Be aware of cultural differences
- Try to build consensus rather than the opposite
- Have a clear communications strategy
- Monitor what you are doing
- Disseminate results



risk aversion as a barrier to commissioners engaging with communities.

Passing control and responsibility to communities takes the risk of failure out of the commissioner's full control. If efforts to involve communities in designing services fail, the reputational damage is likely to be greater than if they had chosen the safer option of doing more of the same.

Community engagement should lead to better commissioning plans, improved quality of services and a reduction in health inequalities.

Local accountability will also be

increasingly important as the NHS moves into a period of cuts and a shift in emphasis from hospitals to the community which may mean closing hospitals.

If local people don't understand the changes "they'll come out on the streets and defend the services that they know because people tend to resist service change", says Ms Coulter. Getting people on board with the need for change will pave the way for necessary reforms.

Mr Cayton and Mr Blomfield also point out that co-production with communities will improve uptake of health-promoting

behaviours because communities know best what will be persuasive to their members.

The resources are there for community engagement; what is needed is a mind set change and a shift in how those resources are used, argues Ms Saddler.

"If you work in a community or voluntary organisation your resources are fairly limited but you understand the value of where those resources should go, so engagement becomes a critical part of your business," she says.

DH policy is about supporting health systems in shifting resources out of hospital care and towards prevention. There was a time when commissioners and providers were at loggerheads, each trying to get their bite of the cherry.

"Actually it's about the community's bite of the cherry, and then everything works from there," says Ms Saddler.

Engaging people as individuals and communities will continue to be important and PCTs are starting to build a track record. Examples of what works in, say, smoking cessation need to be translated to other issues. Community engagement is risky, challenging and sometimes bruising, but when communities see a PCT go through that and come back for more that builds credibility and integrity, says Ms Saddler. It is the hard edge of transformational leadership. ●

CASE STUDY: BROMLEY BY BOW COMMUNITY-OWNED CENTRE

Bromley by Bow Centre in east London is an independent charity owned by the community. It has a turnover of more than £5m and 160 staff, many of whom live locally.

Services include a children's centre, welfare and benefits programme, health trainers programme, a range of adult learning, and employment services. Twelve years ago it formed a partnership with a local GP practice and became the first healthy living centre in the UK. It was also the first health centre in Britain to be owned by the people who use it.

All services at the centre share a common reception area and people accessing health services might be referred to the housing team

or legal services, while someone who comes to a learning event might subsequently use the smoking cessation service.

Although primary care services are funded through the NHS, the buildings are owned by the community, so the centre is welcoming and free from NHS signage, grilles at reception and CCTV cameras.

But what makes the way services are delivered different from the public sector?

Chief executive Rob Trimble says: "In principle a lot of it is about an organisation that's been trusted for the last 26 years by this community, that in essence has been built by this community."

BEST IN THE LONG TERM

Two programmes that are designed to explore and share excellence in supporting self-management for people living with long term conditions are seeing strong results

Co-creating Health and Year of Care in Diabetes are two programmes that demonstrate how to embed self management support into mainstream health services for people living with a long term condition.

Both are based on the philosophy that the primary aim of care planning and supported self management is to enable people who live with long term conditions to have the best quality of life they can and for them to achieve the clinical outcomes they want.

The result is that patients have improved clinical outcomes, according to the California Healthcare Foundation's report, *Helping Patients Manage their Chronic Conditions*.

The benefits extend to the health service – clinicians' work is more fulfilling and services more cost-effective – and to society, which increasingly views health as an individual and collective responsibility rather than the domain of experts.

Both programmes use the Wagner chronic care model as their evidence base, which can be described as productive interactions or conversations between activated and engaged patients with long term conditions and prepared and proactive clinical teams, supported by the health system.

The Health Foundation's Co-creating Health programme is based on three strands of training and development. First, an advanced development programme for clinicians develops skills to support and motivate patients in taking an active role in their own health. Second, a self-management course for people with long term conditions helps them develop skills they need to manage their condition and work in effective

partnership with their clinicians. Third, in an organisational development programme patients and professionals work together to identify new approaches that enable patients to take a more active role in their health.

The pilots have been covering four disease areas: chronic obstructive pulmonary disease, diabetes, depression and musculoskeletal pain.

Embedding self management

"Supporting self management is a no brainer," says national clinical lead for Co-creating Health Alf Collins. "We're showing how you can embed self management support into health communities."

The North Bristol Trust Co-creating Health site has focused on chronic musculoskeletal pain. Trust chief executive Ruth Brunt says the revolutionary part of the programme is running training

programmes for both patients and health professionals.

The plan is to roll out the approach to other long term conditions.

Ms Brunt says: "As we spread this out into more and more areas I would expect us to see quite a significant impact in the cost of healthcare that is tied up in treating long term conditions."

Addenbrooke's Hospital consultant physician Jonathan Fuld has been involved in a Co-creating Health site for COPD. Clinicians have found the approach

challenging to integrate into their other responsibilities. He would like a culture change towards long term conditions "so people see it as a given that self management support is of benefit" but says

CASE STUDY: DIABETES PILOT

Diabetes has been the focus of the Co-creating Health pilot at NHS Islington, NHS Haringey and the Whittington Hospital Trust.

Patients on the self management programme have achieved reductions in HbA1C and LDL cholesterol, while 89 per cent of clinicians who attended the advanced development course said it had improved their knowledge of how to support patient self management.

Having both primary and secondary care involved means that everyone is working towards the patient's own goals.

"The level of collaboration and patient input into this programme is quite unusual and that's the hugely innovative part of it," says NHS Islington long term conditions coordinator Mary Price.

the mechanics of goal setting and follow-up could be performed by members of the workforce with fewer clinical time pressures.

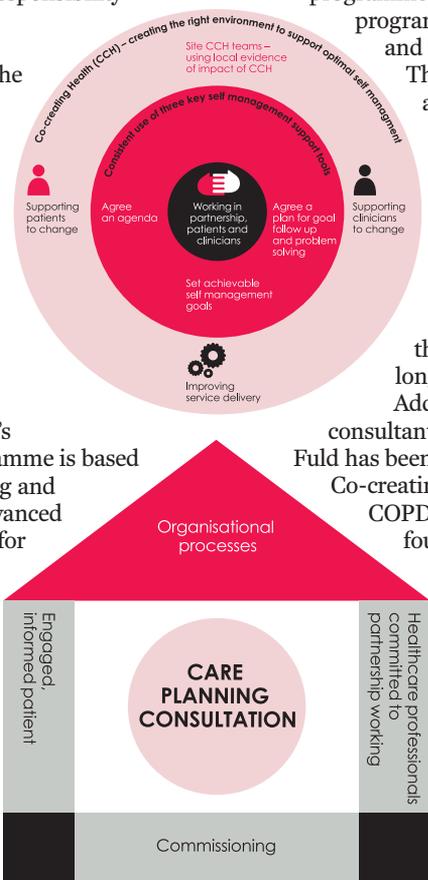
The Year of Care programme – a partnership between the Department of Health, Diabetes UK, NHS Diabetes and the Health Foundation – has tested the approach in diabetes via care planning. This is a planned consultation, based on shared decision making. Individuals receive the results of their tests in enough time to reflect before the consultation, and leave with action plans based on their own goals.

At present 95 per cent of people with diabetes have annual reviews but fewer than 50 per cent address self management.

Year of Care programme board chair Sue Roberts says: "Care planning is transforming this tick box activity into a truly collaborative event."

The House model describes key organisational and commissioning support needed to introduce and sustain this culture change (see illustration).

NHS Tower Hamlets medical director Douglas Russell says: "We were sceptical at first that this approach would be suitable for our diverse population. But it has proved to be a lever for wider change in how we engage with this population and is popular. We have adopted it across all our practices and see it as the model for commissioning in all long term conditions." ●



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A DECISIVE IMPROVEMENT

Fully informed service users make more conservative decisions and use fewer healthcare resources

Shared decision making is when patients and clinicians work together in partnership to choose the most appropriate treatments or care management options.

It relies on two sources of expertise: the health professional, an expert on the effectiveness, probable benefits and potential harms of treatment options; and the patient, an expert on his or her own social circumstances, attitudes to illness and risk, and values and preferences.

National patient surveys reveal that about half of inpatients wanted to be more involved in decisions about their care and about one third of primary care patients say the same. Most health professionals agree in theory, but in practice genuine shared decision making is rare.

"Most health professionals think it's their role to make the decisions and the patient is a passive recipient of care," says independent consultant Angela Coulter. In her report for the Health Foundation, *Implementing Shared Decision-Making in the UK*, she outlines examples and challenges.

There is plenty of evidence showing the benefits of shared decision making and why it should be done. Ethically it is the right thing to do. People feel empowered, more satisfied with their choices, and may have better outcomes. It is a better way of getting informed consent and may reduce litigation.

CASE STUDY: CANCER TESTS

Glyn Elwyn, departmental director of research and chair of the clinical epidemiology interdisciplinary research group in the Department of Primary Care and Public Health at Cardiff University, develops decision support tools, found at www.decisionlaboratory.com.

ProsDex is for men considering the PSA prostate cancer test, which is a non-specific, non-sensitive test, www.prosdex.com.

BresDex is being developed for women who have been diagnosed with breast cancer to help them choose between lumpectomy or mastectomy, www.bresdex.com. Women are asked to consider their priorities – cosmetic, avoiding recurrence, and so on.

Professor Elwyn says: "It's involving patients in actually making treatment decisions where there are uncertainties."

'We can manage demand by empowering patients to become effective consumers. That's much more ethical and sustainable'

It is also cost effective because when people are fully informed about the risks and benefits of treatment they tend to take more cost effective decisions, usually with no detriment to their healthcare.

"We [can] manage the demand for healthcare not by commissioners setting arbitrary thresholds for treatment but empowering patients to become effective consumers of healthcare," says GP Steve Laitner, who is associate medical director for NHS East of England. "That's a much more ethical, sustainable way of managing demand for healthcare."

Decision aids

Moves are afoot to integrate shared decision making into mainstream health services. One way is to increase the availability of evidence based decision aids for patients, and NHS Choices and NHS Direct plan to introduce some on the web.

Decision aids include videos, DVDs and web-based tools. They set out the treatment options and possible outcomes, clarify what is most important to the patient, and help patients make a decision that matches their informed preferences.

As clinical lead for informed decision

making in OA knee at the NHS Institute for Innovation and Improvement and NHS Direct, Dr Laitner is developing a decision aid for people with osteoarthritis of the knee. He is modifying work from the Foundation for Informed Medical Decision Making and Health Dialog to create a web-based tool hosted on NHS Direct. Specialists will send patients a link before their appointment.

For these people, treatment options might include knee replacement surgery. Decision aids are beneficial whenever there is a treatment choice between reasonable alternatives and discretionary surgery is one such area.

Dr Laitner hopes that in future decision aids will use patient reported outcome measures to provide a better prediction of individual risk and benefit from treatment options, which will make decisions even more informed.

He is also working for the quality, innovation, productivity and prevention team to find ways of rolling out decision aids across the health service for multiple conditions.

Implementing shared decision making has proven difficult, with some clinicians believing it will be too consuming.

There is also a skills deficit in communicating risks and benefits, and engaging patients in decisions.

"Some of that means clinicians themselves being comfortable with uncertainty," says Richard Thomson, professor of epidemiology and public health at Newcastle University.

Professor Thomson is working with Cardiff University to help the Health Foundation demonstrate how shared decision making can be put into practice across primary and secondary care. ●



Magic is the new shared decision making programme, supported by the Health Foundation, run by a team led by the Cardiff University, Cardiff and Vale University Health Board, University of Newcastle, and Newcastle upon Tyne Hospitals Foundation Trust. An overview of their work can be found at www.health.org.uk



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