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# Improving Quality Through a Better Patient Experience and Patient-Centred Care

REPORT FROM ISQUA'S 34TH  
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# INTRODUCTION

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Health systems throughout the world are now more focused on creating a more patient-centred approach to healthcare, ensuring the voice of the patient is heard through every level of the system. This focus on the patient is driven by a desire to improve quality of care as the two are inevitably linked.

However, some countries are struggling to change systems which take a traditional approach based on a patient's clinical presentation of signs and symptoms, followed with a management plan and medical treatment.

This report highlights many ways in which we can give patients more say in the decisions about their treatment and care. It draws on keynote presentations and seminars from ISQua 2017 – a world-leading conference on quality improvement.

Lessons and viewpoints from the ISQua 2017 annual conference provide a useful insight into practical ways we can improve quality by delivering patient-centred care. For example, sharing decision making about treatment and care means giving patients timely information in ways that can be easily understood. Managers and clinicians must be prepared to listen to patient stories and their experience of care while the data collected about treatment must be properly shared with those at the frontline.

The development of technology solutions which track healthcare and offer self-management through portable equipment or phone apps, are other ways to involve patients in their care.

One important insight from ISQua 2017 is that this patient-centred care requires a culture change within health systems that not all staff will engage with. As the keynote speeches and seminars showed, listening to patients has clear links to quality improvement and this requires investing time in patients as well as time in training and supporting clinicians.

# PATIENT STORIES AND THE NARRATIVE

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Enabling real change in health systems where there is a traditional approach to patient diagnosis and prescribing appropriate treatments will require a focus on patient narrative as a way of understanding how care and treatment affect them.

In 2003, in a bid to highlight how patient stories can lead to improvement, researcher and writer Dr Pip Hardy and former software engineer Tony Sumner set up a website called Patient Voices, recording the stories of patients, carers and clinicians to deliver insight from within organisations through story-telling rather than relying solely on statistics.

At ISQua 2017 Dr Hardy said: “We have been in a stats dominated culture. Stats tell us what the system wants to know. But you need to ask patients about their experience. To change the culture, you need to understand the people that make up that culture.”

“Through stories, we learn to be part of a culture. It helps us connect hearts and minds and care for people as human beings. Stories need to touch hearts as well as minds to drive change.”

By putting patient stories online, any organisation can read them to help gain an insight into how to enhance patient experience. They offer evidence of experience, contribute to research and those trusts that have used them say they have made a difference by stimulating organisational change.

Listening to the patient to find out what they want can help to build trust between the clinician and patient. The clinician may not realise what the patient actually wants from their treatment and care, other than to be well again. The patient's view of how this can be achieved may differ from that of the clinician.



Karen Deeny, from the NHS England Patient Experience team, said: “Asking patients ‘what matters to you?’ rather than ‘what’s the matter with you?’ makes a huge difference to their experience of care.”

In 2013, the Kings Fund (1) acknowledged the influence of the patient voice and recommended that NHS leaders should encourage and nurture patient leaders to help build collaborative relationships and develop genuine co-production as a way of improving services.

The disparity between what the clinician thinks a patient wants, and what the patient actually wants can have a negative effect on patient experience. According to the UK’s Coalition for Collaborative Care, 30 percent of health is determined by clinical factors, while 70 percent is affected by social determinants. However current models of health care often focus on treating and fixing the medical condition rather than looking at the what the patient wants to happen to them.

A study led by MACC (Manchester’s local voluntary and community sector support organisation) revealed a clear difference between what the patient thinks keeps them healthy and well, and the answers that clinicians thought they would give. At a community event, they asked the public what they think contributes to keeping themselves healthy and well. Answers from the public overwhelmingly included: “Having a purpose, having a role to play, seeing friends and family, spending time with the grandchildren, being connected to local people and going to different groups and activities.”

When clinicians in the study were asked how they thought people had responded, their answers included: “losing weight, smoking less, reducing alcohol intake, eating more fruit and vegetables and getting more exercises.” (2)



# THE ROLE OF TECHNOLOGY IN PATIENT EXPERIENCE AND PATIENT-CENTRED CARE

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TECHNOLOGY CAN HELP PATIENTS TO TAKE MORE CONTROL OF THEIR HEALTHCARE, GIVING THEM A BETTER EXPERIENCE AND IMPROVE OUTCOMES.

The rise in the use of smartphones and associated apps can help patients monitor their own healthcare while keeping the doctor informed about changes to their condition. Giving clinicians the opportunity to monitor patients remotely using new and easy to use technology can improve efficiency by freeing up appointments for those in most need and by making identification of possible problems much quicker.

As well as smartphones, there are many ways that patients can monitor their own care – either through internet connected devices which allow for remote monitoring by the clinician or by portable diagnostics that can be used by the patient at home such as portable X-ray machines and blood testing kits.

The use of such technology enables patients to tell clinicians exactly how they are feeling and when. Without such access, some patients feel that they don't want to take up a clinician's time and will instead catch up with them at the next appointment, which means valuable time may be lost to treat them.



In his presentation at the 2017 ISQua conference, Dr Ethan Basch, cancer specialist and professor of medicine in the division of haematology and oncology at the UNC Lineberger Comprehensive Cancer Center, highlighted his research into patient reported outcomes. It showed that if a patient had a change of symptoms at home, they may not necessarily contact the clinic to discuss this straight away. Research shows that clinicians are unaware of up to half of symptoms and so miss opportunities to intervene.

With the appropriate use of technology, patients can track their symptoms and send an alert to their clinician advising of any changes. Professor Basch presented research into a computer system which sends an automatic reminder to encourage patients to report symptoms. If the symptoms worsen an alert can be sent to the medical team. Such a pro-active approach brings the patient and clinician together. Evidence shows that using the new system, clinicians discuss symptoms more often with their patients. The study also showed that patients who self-report their experience had an improved quality of life and better symptom control.

During the study, some chemotherapy patients were asked to report between visits. When they reported a worsening symptom, an email was sent to a nurse in real time so that they could contact the patient. As a control, other patients were asked to call if they experienced a symptom that was bothering them.

When prompted, patients reported their symptoms 73 percent of the time and nurses took action 77 percent of the time. As a result, 31 percent more patients experience quality of life benefits (an increase of 16 percent compared to traditional care). Patients in the self-reporting cohort also had an average survival rate of 5.2 months longer than patients who were asked to call.

Overall, the study showed that integration of patient-reported symptoms into cancer care is associated with clinical benefits and that future strategies should focus on integrating self-reporting into clinical workflow and electronic health records.

In England's NHS work is ongoing to ensure patients can be involved in or take greater control of their care. Several apps are available in the NHS Digital Apps library which hosts assessed and approved leading healthcare apps, to help patients cope with and monitor mental health, weight management, physical activity and chronic conditions such as diabetes. An app called Patient Knows Best, enables patients to access their notes from any healthcare provider, send messages to their healthcare team, have online consultations, track symptoms and edit care plans with their clinician online. The service can also store information from a range of devices and apps that track and monitor health. (3)

Other initiatives in England include remote monitoring. Croydon Health Services Telehealth Care Team, which involves the local council, CCG and a social enterprise firm, issues medical devices to patients with complex, long-term conditions to take measurements such as blood pressure, temperature, blood oxygen levels and weight which are relayed back to the trust. A team monitors the results with healthcare professionals alerted by text message if readings move outside ranges they have previously set. (4)



# HOW DATA CAN HELP TO IMPROVE PATIENT EXPERIENCE

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Patient experience data, such as the Friends and Family Test in England is a valuable tool to help create change and drive improvement. The NHS in England generates large volumes of data every day, but it can only be of help if it is used in the right places and seen by the right people. The siloed nature of current working (even within the same trust) can make it difficult to see broad trends in patient feedback.

Sharing data between health and social care can create a faster and more consistent flow of information. Not only can it help health and care professionals work between different locations, it can also improve patient experience by enabling information to flow with the patient as they move between different settings, for example from GP to hospital to care home.

As IT systems develop, patients will be able to access their own care information and contribute additional information such as preferences and care plans.

Speaking at the ISQua conference 2017, Glenn Robert of Kings College London, Louise Locock of the University of Aberdeen, Laura Sheard from Bradford Teaching Hospitals NHS Foundation Trust and Caroline Sanders from the University of Manchester, considered emerging findings and lessons from a range of projects that are part of a major applied research programme into evaluating and improving the use of usefulness and patient experience data.

Friends and Family data is the most widely known and used and studies are being done to see whether it is driving improvement or whether there are better and more fine-tuned data sources that are being over-looked because of it. Emerging findings from the project show there is some inequality in terms of gaining access to the feedback. Ward staff are closest to patients and are the ones who ask them to fill out the forms, but the feedback usually goes upwards to senior management, rather than being used by frontline staff themselves.



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Providing different ways for patients to give feedback is important. Not everyone feels well enough to write down how they feel about their treatment and a face to face talk may be better for them. Others feel they may not have the time, or that it's no longer important once they are home and away from their situation. Giving different opportunities to provide feedback in ways in which the patient is comfortable may yield better results.

Data, combined with patient stories rather than being acted on alone, can be extremely useful as highlighted by Cliff Hughes, professor in patient safety and clinical quality at Macquarie University (also immediate past president of ISQua).

In his presentation, as part of a panel on the Multidisciplinary Approach of Putting the Person Back into the Health System, he pointed out the importance of using data in conjunction with patient stories to help re-engage more effectively with the patients. Using a study carried out in New South Wales into the rates of emergency and elective caesarean sections and also hysterectomy, it was found that there were clusters of areas with higher rates of C-sections and also hysterectomy across a wide age group – from 15 to 34 and 35 to 69 year-olds. In one district there was a section of the population with high incidents of hysterectomies. To see what was driving this, a panel of obstetricians and gynaecologists came together to talk to patients and doctors in those areas.

They found that, in relation to C-sections and hysterectomies, it was the preference of the patient and more particularly the obstetrician in those areas. Significantly, the second point, related to the hysterectomies. The area concerned was an area just west of the blue mountain range which was rich farming land. Over the last 150 years, the land had been carved up more and more to support different farmers, to the extent where smaller properties demanded that the whole family stay on board to make it viable.

Women who were struggling with severe stomach cramps found going into and staying in a hospital a burden. They particularly drove the charge towards hysterectomy. Such an operation is a very invasive procedure to treat a recurring symptom. When the experts explored further they found that country practitioners didn't have access to less invasive procedures, limiting the options for the patient. This information was only revealed by listening to both patient and clinician.

Online feedback through patient opinion sites can be very valuable, although if it is negative, public criticism can be hard for staff to take. However, dealt with positively, it can be a good way to create change and show that improvements are being made because of listening to patients.

At ISQua 2017, Michael Greco, chief executive of Patient Opinion, Australia, discussed building relationships with patients through public online engagement. He highlighted a case where a patient had commented negatively about their care on a patient opinion website. The case study revealed staff as too busy to fully talk to and prepare family members for the death of a loved one. One member of staff was quoted as saying "One of the nurses on the ward said to me later; 'It's harder for family because while we see this a few times a week, it's all new to you.'"

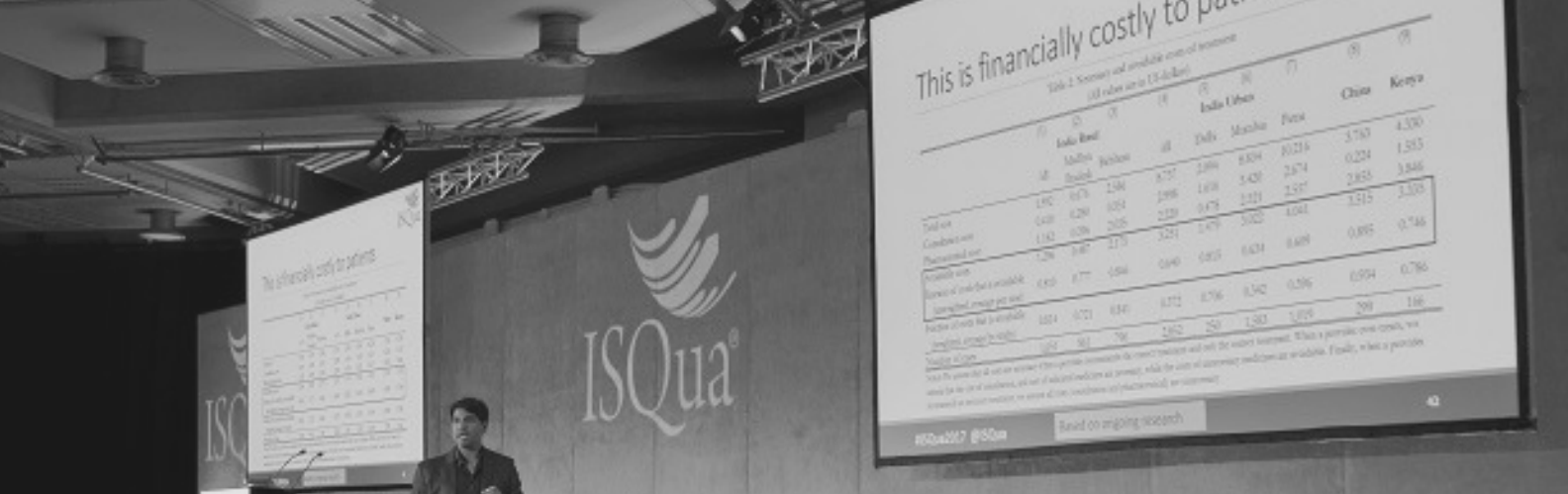
However, from the patient point of view, communication here was vital. If staff are used to seeing it, they should use their experience to support the family. The online complaint was not ignored and the chief executive of the hospital replied personally on the same forum. The family now works closely with the trust to help create change.

At NHS Lanarkshire, online qualitative data is used to help to give staff positive feedback on their performance. In 2014 when it started using such data, there were 222 stories posted online.

By 2016/17 this had risen to 658 stories with between 65 and 70 per cent positive feedback. One service manager said: "This kind of feedback is a gift. I'm able to acknowledge the author and congratulate staff on their performance. Staff have been encouraged, energised and motivated by positive feedback." Another added: "Receiving critical feedback publicly was challenging at first but staff quickly recognised the opportunities it presented for learning and improvement."

By responding and reacting to online feedback, this can result in increased transparency, better communication, increased levels of accountability and leadership improvement.

Putting patients at the forefront of healthcare, effective organisation of care is needed as well as professional skills. New types of measures enabling patients to report treatment outcomes are a valuable source of quality improvement and reporting that can bring a greater focus to ensuring care is more patient centred.



Highlighted in the paper, ‘Using patient-reported outcome measurement to improve patient care’ in the International Journal for Quality in Healthcare, PROMS are seen as a valuable way of creating improvement. As well as drawing on reviews and guidance documents, it also included the authors’ experiences using PROMS for quality research and their workshop at the 2016 ISQua conference. (5)

Getting the right data can help to drive quality improvement, but in some areas, particularly low to middle-income countries (LMICS) this can prove challenging and may even require starting from scratch.

Jishnu Das, lead economist in the development research group (Human Development and Public Services Team) at the World Bank, revealed at ISQua 2017 that in some LMICs clinical records often don’t work and there is almost no data on how patients are treated. Many private sector companies do not keep patient records and neither do care providers.

Some data is kept by public sector providers but this can often be unreliable. The researchers spent a lot of time thinking about which measures of quality could be used. One of the most promising ways forward was to look at what knowledge doctors have. This was measured by using medical vignettes which showed quite a wide variation between countries. It was also found that while providers know to give the patients what they need, they don’t know how to give them what they don’t need, for example, unnecessary antibiotics.

Das said: “The problem turned out to be whether these measurements of knowledge actually measure clinical practice. Is it really the case that a doctor would say to me ‘If a patient comes in with chest pain, here are the questions I would ask, here are the examinations I would do and depending on those, this is what I would recommend.

“We didn’t have a lot of data to say whether these measurements if knowledge were indicative of a clinical practice that doctors were engaging in.”

However, two papers highlighted by Das showed different results. One study which used vignettes then followed up with standardised patients (highly trained to answer any in-depth questions about the condition they were presenting with) showed comparable measures of quality. However, a further study by Rethans et al (1991) was designed to study the difference and relation between what a doctor actually does in daily practice (performance) and what they are capable of (competence). This study saw standardised patients who were known to the doctor, followed up with unknown standardised patients presenting with the same condition. The results showed that providers did much better when the patients were known, therefore the conclusion was that performance and competence should be considered as distinct constructs.

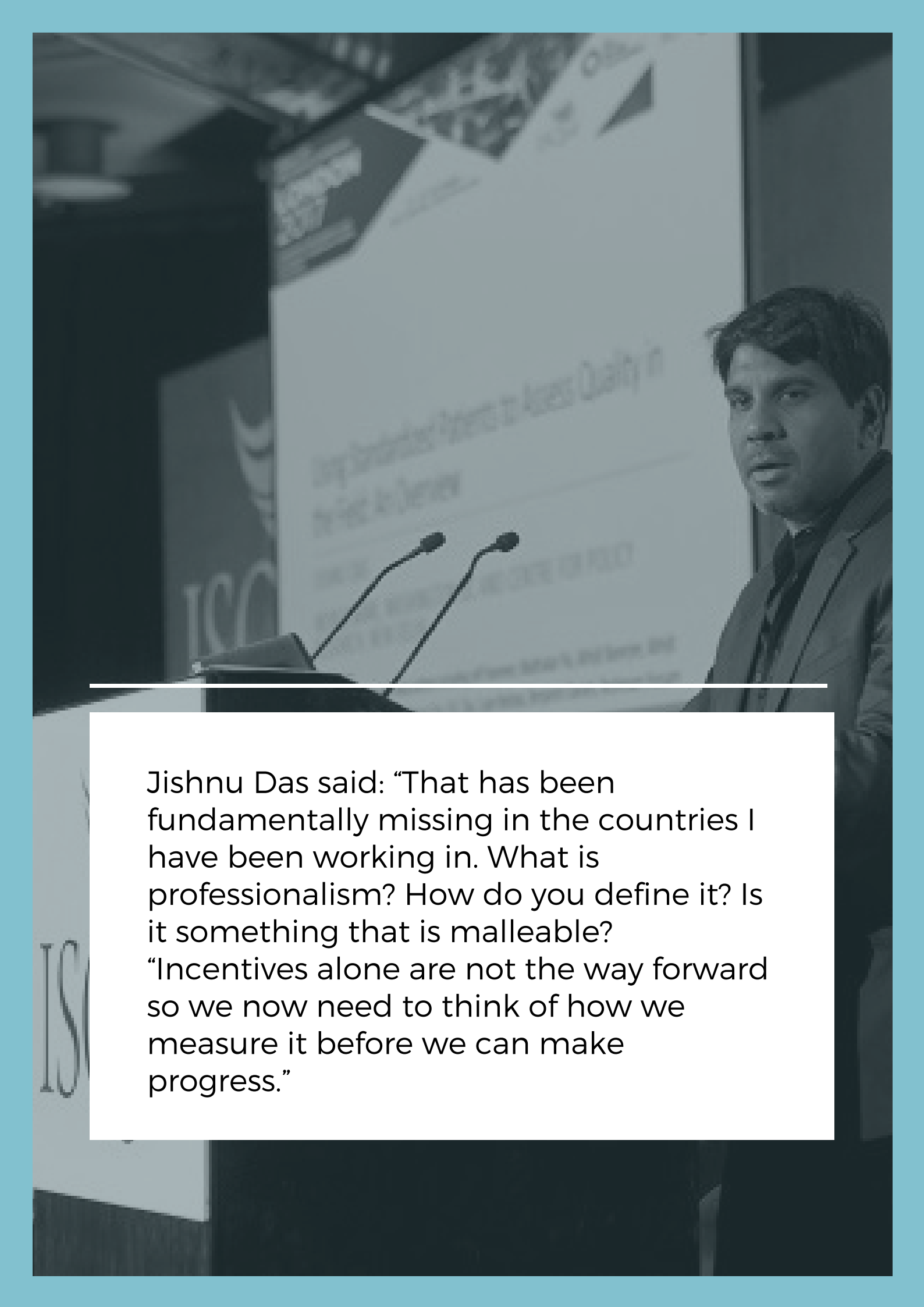
To bring about improvement, it's not just about increasing competence with extra training, there is a need to think about what is driving the wedge between performance and competence and how should it be dealt with.

The use of standardised patients is now considered to be the most acceptable way forward and has been extensively used in US and Canada in medical schools.

They are also now part of the examination system in the US.

However, Das said that while there are many studies looking at the various aspects of validation, they tend to be small in-clinic samples. He said: "There are very limited studies of viability in the field with large sample sizes. Really what we are providing is expanding this technique to population wide representative surveys of quality and starting to understand naturally occurring variation in the population on quality."

The learning from the studies showed standardising patients can be a viable tool for understanding a broad system of care in population-based samples. The researchers are confident that it is a valid measure for improvement and distinguishes care that is needed from that which isn't necessary. However, there are limitations, for example evaluating care across systems if the patient is referred or sent for lab tests. For the future, to really create improvement, Das said the focus also needs to be in how institutions instil a degree of professionalism in the training of their students, to help lessen that gap between performance and competence.

A man, Jishnu Das, is speaking at a podium. Behind him is a large presentation screen displaying text. The text on the screen includes "Improving Access to Access Quality in" and "Incentives".

Jishnu Das said: "That has been fundamentally missing in the countries I have been working in. What is professionalism? How do you define it? Is it something that is malleable? "Incentives alone are not the way forward so we now need to think of how we measure it before we can make progress."



# PUTTING THE PATIENT AT THE CENTRE OF HEALTHCARE

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Making sure that patients are placed at the centre of their care is a common focus for health systems throughout the world. In England, the NHS wants person-centred care for people with long-term conditions to become the norm, helping people to self-manage their conditions where possible and giving them the support to make their own decisions. Projects are underway to help the NHS England understand areas such as how self-management can help people to improve their health as well as what needs to go into helping people to make their own decisions.

There is still a long way to go to make it work, educating both clinicians and patients who are not yet used to being placed on an equal footing with one another. Listening to what the patient wants and making them and their family one half of the medical team can make a real difference in their care and how they are treated.

Building trust and letting the patient know that the decision making is shared, is vital for a good patient experience as well as giving hope.



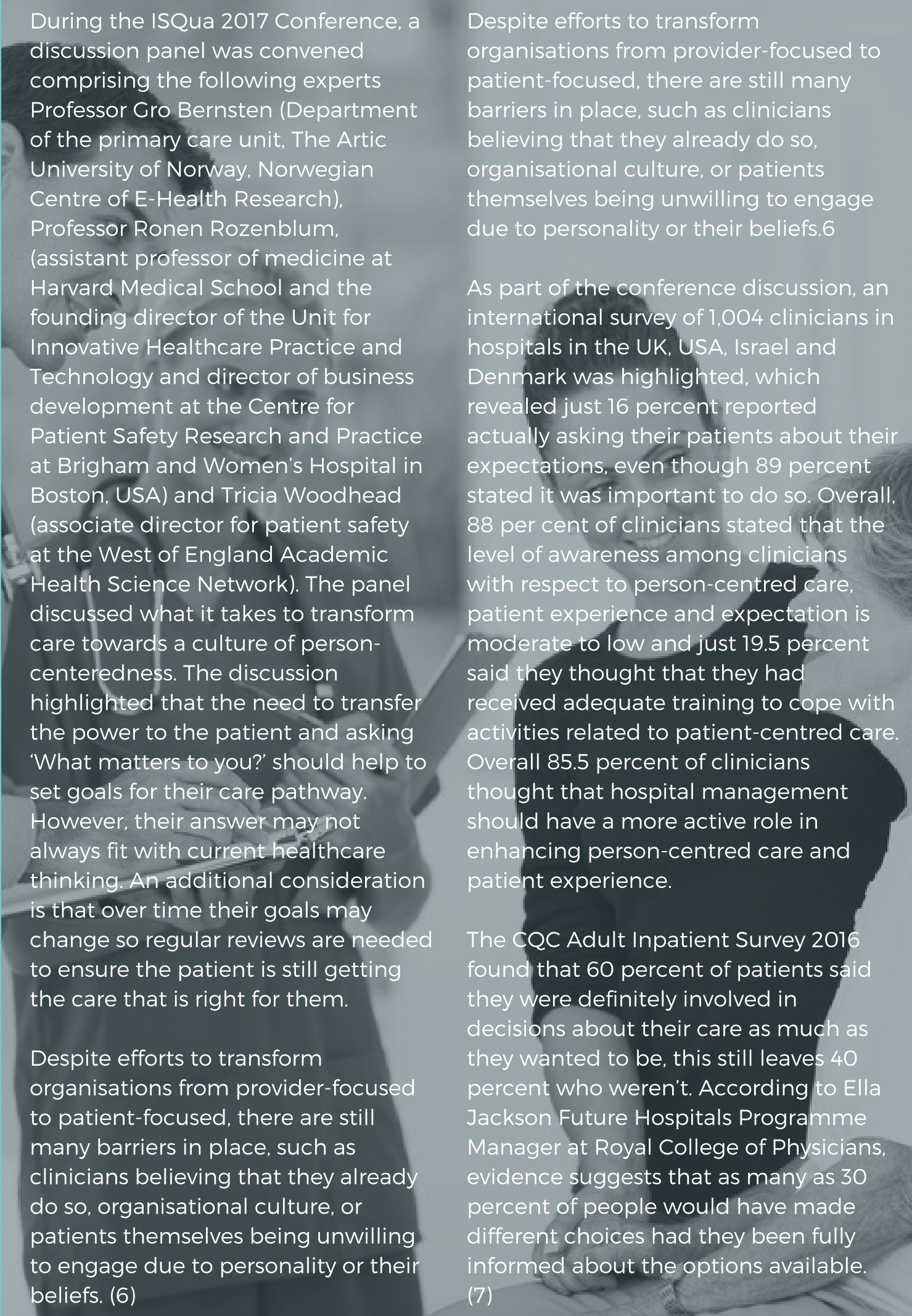
Professor Cliff Hughes shared examples of time working in a small hospital in Bangladesh. A woman was brought in to see him with a bowel obstruction. He provisionally diagnosed cancer but said they should not operate due to scarce resources. After talking to the family, he agreed to carry out a small exploratory operation and found a massive tumour. He told the family that the patient was in a terminal phase of life and suggested that they could take her home the next day. She died two days later. When the team were due to leave the hospital the head of the village threw a party for them and in a speech thanked the team for helping his family. Unaware that the cancer patient was the chief's mother, Professor Hughes spoke to him after and said "I'm so sorry about your mother. You said we looked after her, but we were unable to do anything for her."

The chief replied "Doctor, I am 64 and my mother is in her late 70s. Neither of us has ever been cared for without someone asking for something in return."

PROFESSOR HUGHES ASKED HIM HOW HE GOT HOPE. THE CHIEF REPLIED: "I LIVE IN HOPE THAT WE WILL HAVE MORE PEOPLE COME AND LOOK AFTER US JUST LIKE YOU DID."

Professor Hughes used the example to highlight the importance of the way we engage with patients. He said: "So often we just write people off. We must not say 'you're inoperable.' We must say 'there is a better way of looking after you'. This is a more positive way of engaging with patients.

"The patient and their family are the very reason we exist. We need to build a two-way relational process of helping people to reflect on and express their preferences based on their unique circumstances, expectations, beliefs and values. Service users should be viewed as what they are capable of, rather than incapable of."



During the ISQua 2017 Conference, a discussion panel was convened comprising the following experts Professor Gro Bernsten (Department of the primary care unit, The Arctic University of Norway, Norwegian Centre of E-Health Research), Professor Ronen Rozenblum, (assistant professor of medicine at Harvard Medical School and the founding director of the Unit for Innovative Healthcare Practice and Technology and director of business development at the Centre for Patient Safety Research and Practice at Brigham and Women's Hospital in Boston, USA) and Tricia Woodhead (associate director for patient safety at the West of England Academic Health Science Network). The panel discussed what it takes to transform care towards a culture of person-centeredness. The discussion highlighted that the need to transfer the power to the patient and asking 'What matters to you?' should help to set goals for their care pathway. However, their answer may not always fit with current healthcare thinking. An additional consideration is that over time their goals may change so regular reviews are needed to ensure the patient is still getting the care that is right for them.

Despite efforts to transform organisations from provider-focused to patient-focused, there are still many barriers in place, such as clinicians believing that they already do so, organisational culture, or patients themselves being unwilling to engage due to personality or their beliefs. (6)

Despite efforts to transform organisations from provider-focused to patient-focused, there are still many barriers in place, such as clinicians believing that they already do so, organisational culture, or patients themselves being unwilling to engage due to personality or their beliefs.<sup>6</sup>

As part of the conference discussion, an international survey of 1,004 clinicians in hospitals in the UK, USA, Israel and Denmark was highlighted, which revealed just 16 percent reported actually asking their patients about their expectations, even though 89 percent stated it was important to do so. Overall, 88 per cent of clinicians stated that the level of awareness among clinicians with respect to person-centred care, patient experience and expectation is moderate to low and just 19.5 percent said they thought that they had received adequate training to cope with activities related to patient-centred care. Overall 85.5 percent of clinicians thought that hospital management should have a more active role in enhancing person-centred care and patient experience.

The CQC Adult Inpatient Survey 2016 found that 60 percent of patients said they were definitely involved in decisions about their care as much as they wanted to be, this still leaves 40 percent who weren't. According to Ella Jackson Future Hospitals Programme Manager at Royal College of Physicians, evidence suggests that as many as 30 percent of people would have made different choices had they been fully informed about the options available. (7)



# MAKING CULTURE CHANGE A REALITY

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While there is much work going on to help create change and improvement and remodel current ways of providing care, it will always be a challenge to change culture change in organisations which have been working in the same way for decades.

The current model of care relies on the clinician being the authoritative voice which finds a way to treat the medical condition, rather than having the patient on an equal footing deciding on how they want to be treated.

Trying to change this can be difficult both for the physician and the patient.

Dr Brian Robson is a GP who highlighted shared decision making at the ISQua conference 2017. He spoke about an 86-year-old patient, Mr Jamieson who had a number of health conditions and was already taking ten regular medications. Following an appointment with the practice nurse, it was found that the patient had atrial fibrillation, which can cause blood clots and lead to a stroke.

Dr Robson said: "I spent time with Mr Jamieson looking at his cardiograph and explaining the problem and the risk of stroke. I was trying to explain the importance of what we could do to thin the blood and reduce his chances of stroke."

Mr Jamieson said he would like to go home and think about it and went away with some leaflets to read. He came back the next week with some questions, was advised that the medication (Warfarin) did come with risks but would reduce his chance of stroke by 70-80 percent. Again, he went away to think about it.

He came back the next week and had decided against any more medication. He felt fine and asked if they could revisit it in the summer. Dr Robson said: "Mr Jamieson decided, with all the information, that this wasn't for him. I felt very uneasy but it was Mr Jamieson's decision."

However, a year later, Mr Jamieson was still fine. Dr Robson said: “I was grateful for the conversations that we had. Shared decision making offers us something to change the relationship.”

In order to embed shared decision making, the Royal College of Physicians has developed a range of practical support and resources to help create change. The Patients as Partners workshop, for example, supports clinicians and teams to reflect on their own practice and identify local systems and practices that may inhibit or enable person-centred care. The college is also working in collaboration with the MRCP (UK) PACES team to design practical exams to test trainee doctors' communication skills and ethical understanding. All doctors seeking to go on the speciality training will be tested on their knowledge and ability to do shared decision making.

However, despite all the research, guidance and planning that is being put in place, there is a fear that the patient is still being left out of the process.

Ceinwin Giles is Founding Director of the Shine Cancer Support and eight years ago spent many months in hospital after being diagnosed with Stage 4 non-Hodgkin Lymphoma. After her treatment she wanted to give back to the NHS that helped her so signed up to various patient committees and groups.

She said: “Eight years on, like many other patients, I am now tired and cynical of patient involvement. I go to meetings where views of patients may be trumpeted as valuable and insightful but have gone nowhere.

“I’ve been a member of a committee established to improve services only to find the service/committee are to be changed due to re-organisation, meaning everything needs to start again from scratch.” (8)





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## DESPITE THE GOOD INTENTIONS, CREATING A CULTURE CHANGE IS A BIG CHALLENGE.

Some clinicians may feel that they are already providing that level of service and not see the need for change. Others may be concerned about the medical risk and who takes responsibility for the patient's decision should something go wrong. Healthcare professionals' knowledge of support services may also act as a barrier as they may not be aware of resources in the community that could help their patients. But the skills, knowledge and confidence of patients in engaging with clinicians and having responsibility for their own care may also differ from patient to patient.

However, change is not impossible and giving support, training and the right tools to clinicians to help them work through what is a huge change to their sense of identity and recognised ways of working can help them to support their patients to make the change too. (9)

# QUALITY IMPROVEMENT IN CRISIS SITUATIONS

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DATA MONITORING, PROCESS AND MEASUREMENT MAY NOT BE THE WORDS THAT STAFF IN CRISIS SITUATIONS WANT TO HEAR, BUT TO BE ABLE TO IMPROVE PATIENT CARE, IT'S NECESSARY TO BE ABLE TO LEARN LESSONS AND LEARN HOW NOT TO DO THINGS, WHILE THE SITUATION IS ONGOING.

Rashad Massoud is chief medical and quality director at University Research Company (URC). His presentation at the ISQua London 2017 conference highlighted how the notion of improvement in emergency situations is not just about the acute response but involves looking at the whole system and creating resilience.

He said: "The key point is that we don't just look at the input part, we look at how we're going to do things and how we're going to monitor and measure what we're going to do and how we can learn from this on an ongoing basis."

A crisis or public health emergency will highlight weaknesses in the system, so it's not enough to act on input (i.e.: getting the right things in the right places) and being pleased if the eventual outcome is a good one. It's important to ensure the whole system is strengthened and resilient to help prevent something like that happening again.

Jorge Hermida is Quality Improvement Advisor, MNCH and Latin America Regional Director at the USAID ASSIST Project. He used the Zika outbreak as an example. He said: "Family planning was thought to be at a high level of development but the Zika outbreak showed up the many difficulties. Equipment and supplies and training are necessary but are not enough. Quality improvement is key."

And while one argument is that staff are so busy, they can't stop to think about improvement, Massoud argues that this is exactly the right time. He said: "Some key things spring to mind in emergency situations. Improvement is beginning with the end in mind, something that we're always thinking about - what is the outcome of interest? Where do we want it to happen and at what scale? All these things are more important when we're dealing with an emergency situation. "If we start with that, then designing a response to meet that is much more likely to happen.



“In an emergency crisis, we’re much less informed about the context and development and what things might arise in regular improvement so it actually becomes more relevant to think through how we’re going to respond and use the very methods and the mindset that we have in improvement when responding to an emergency situation.”

Real-time change and data collection are vital in what can be an ever-changing situation, as well as good communication between multi-disciplinary teams and stakeholders.

Massoud added: “I can’t underestimate the importance of real-time learning as we go along, seeing if it works or not, collecting data to see if there are any results on that, seeing what responses there are and changing in real time. The notion of rapid cycle PDSAs is critical in a situation like this as the situation itself is likely to be changing as we’re doing the work. Having that mindset and that capability of learning during an ongoing crisis is critical.”

Another crucial point is to make sure that you are working with the country’s ministry of health to ensure the improvements continue and that any improvement strategies can be developed along that country’s guidelines.

When working with large numbers of health workers or across different countries (for example in the Zika outbreak) developing a common set of indicators, step-by-step guidelines and a collaborative model for quality improvement are essential to make change happen and continue.

Sid Wong is medical director for Medicines Sans Frontieres. He said many of their projects are supported directly through Ministry of Health Services. Although this poses challenges - such as having to work by quality standards which may not be your own - the reality is that trying to impose too many systems without their support is only likely to lead to the collapse of the system once the MSF leaves the area.



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Despite those challenges the organisation continues to focus on quality improvement, enabling them to provide safe, effective and patient centred care whatever the circumstances.

To do this MSF has introduced systematic monitoring, collecting data from sites, introducing quality metrics and routine audits as well as developing assessment tools such as checklists for healthcare facilities and training managers on PDSA and root cause analysis.

Save the Children International also uses similar measures to ensure quality improvement. Clinical assurance scorecards have been introduced, along with clinical incident reporting.

Medical director, Dr John Gaffney said: “Historically we’ve been very good at answering the questions ‘How much do we do?’, ‘How many children have we vaccinated?’. We’ve never been very good at answering the questions ‘How well do we do it?’, ‘How safe are our programmes?’”

The assessment tools help the organisation to see where there are gaps and aid quality improvement, allowing progress to be monitored and providing a checklist for quality. The scorecard helps to provide more assurance, as there is scope for more information to be learned rather than just a ‘yes/no’ answer.

Work in South Sudan, Rwanda and Somalia revealed great improvement, particularly analysing the programmes using the clinical assurance scorecards. Areas included: a simple process for administration change, improving the quality assurance of clinical care, patient engagement and infrastructure improvement.





CARE OF STAFF SHOWED PARTICULAR IMPROVEMENT, FOR EXAMPLE, BETTER CLINICAL SUPERVISION, HAND WASHING BETWEEN PATIENTS AND MANAGING WAITING TIME.

### THERE ARE MANY CHALLENGES WHEN TRYING TO INTRODUCE QUALITY IMPROVEMENT IN STRESSED ENVIRONMENTS:

- People may think they're being given more work to do
- There is a feeling of being 'checked up on'
- Cultural challenges such as a blame culture or safety of staff
- People generally dislike new things and change.
- A common belief, particularly in very low-income countries that nothing can be done because there's no money.

Dr Gaffney said: "For most people, the concept of quality improvement is new ideas. The way we work is to try to ensure that field workers contribute to the process development. The fact that we can develop clinical assurance scorecards which are a good fit with what they're doing, with their help, gives them a sense of ownership which is very important for following through."

Other tips for addressing quality improvement in these situations include:

- Focus on celebrating success;
- Create context - ensure people understand why patient safety is important and also that people make mistakes;
- Keep it simple, get the basics right and avoid technology that can't be supported in crisis-hit areas.

Dr Gaffney said: "When in survival mode, clinical governance is more, not less important as the potential for error or system failure is greater."



# USING EXTERNAL EVALUATION & PROCESS TO PROMOTE IMPROVEMENT

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Improvement and change can be driven by accreditation and external evaluation. However, this is not always so easy as it sounds. The type of evaluation and inspection can drive change in different ways and have different outcomes depending on how staff perceive it.

For example, inspections that are statute driven and merely to check that providers are doing what they are legally bound to do can be perceived as a box-ticking exercise.

Looking at processes, learning lessons and learning how to do things differently in the future are all valuable tools to create improvement.

Dr Christine Dennis is chief executive officer of the Australian Council on Healthcare Standards and Australian Council on Healthcare Standards International. She said that a culture of safety needs to be built and become the norm, rather than doing it just because someone is watching you.

At ISQua 2017 she said: “We know that when we’re doing audits and inspections things look better than they might do on any other day of the year. Why do we need someone watching us to make us do what we know is right. Standards are developed in consultation with clinicians, so why is it so hard to accept that standards are a good thing?”

Accreditation is looked upon favourably by most organisations and in 2011 the Australian Institute for Health and Welfare noted that 98 per cent of public hospitals were inviting the organisation in and looking for accreditation, prior to anything being mandated around standards.

A paper written in 2003, looking at Australian accreditation services noted that the long history of work by the Australian Council on Healthcare Standards had progressively built a level of engagement of health professionals and encouraged a high level of participation in accreditation.

However, some trusts are not so keen and say they spend months getting ready for a survey inspection, putting in place extra staff, making sure all the policies are in place, making it too much of an event. The hospitals wanted to be seen in the way they present themselves throughout the rest of the year rather than during the five days the survey team is around.

The outcome of this is that the ACHS is now trialling short notice surveys. Dennis said: "It will be challenging and it might not be that every action is met but it will provide honest feedback about the way they work."

Kieran Walshe is Professor of Health Policy and Management at the University of Manchester. At the ISQua 2017, he highlighted the importance of planned visits, combined with very well-communicated and clear expectations which provide guidance to help trusts improve, rather than just catching them out at what they might be doing wrong. He said: "That doesn't mean writing standards, it means providing guidance, such as offering examples of good practice, running learning events and actively engaging with the sector to communicate what it is that you as the regulator expect them to be doing."

He suggests using routine data as feedback which can be incorporated into inspections to try to understand whether the sector has done what you want them to do.

"We must also recognise that all organisations are going to start from different points. We need to be interested in their relative progress over time rather than their absolute position."





# CONCLUSION

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INVOLVING PATIENTS IN THEIR OWN CARE PLANS HAS BEEN HIGH ON THE AGENDA FOR HEALTH SYSTEMS THROUGHOUT THE WORLD FOR MANY YEARS. IT IS INEVITABLY A SLOW PROCESS CREATING SUCH A PROFOUND CHANGE IN A SECTOR WHICH HAS WORKED IN THE SAME WAY FOR SO LONG.

To be successful, the strategy for change needs to be similar to the goal - involving the people who are at carrying out or who are part of the care.

It's not enough just to listen to the patient. The needs and concerns of clinicians need to be taken into account too, otherwise, the strategy will not work. Not all people view things in the same way and not all patients will be confident enough to make decisions about their own care.

Rapid changes are happening in healthcare with the onset of technology which can give patients the opportunity and confidence to self-manage their care and take more of an interest in their treatment should they wish to.

New ways of collecting data, such as online forums and surveys are providing more opportunity to gauge patient opinion about care as well as creating ways for trusts to make improvements.

What is clear though, is that there must be some sign of a culture change or strategy for improvement soon and patients must be properly involved in it. Patients' trust and enthusiasm to get involved will be lost if they do not see any outcome or change in the way the system is run. Paying lip-service will only drive patients further away.



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