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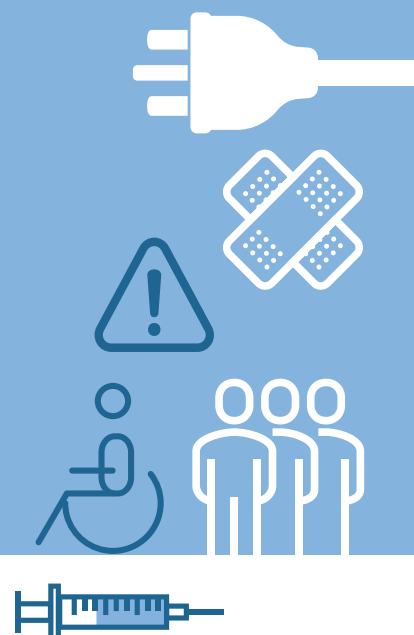
Patient Powered Safety: Reducing harm through co-production with patients

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I was pleased to be asked to write a Foreword to this summary of the Patient Powered Safety Event that was held in Bangor in May 2019. I was able to personally attend the first day and was thus able to see and hear for myself the various presentations made on what is a critically important subject: How can we avoid harm coming to patients and what role can patients and relatives play in this? The answer was that much more can and should be done and the health service has a largely untapped (but highly motivated) resource in the form of the general public to help it do so. This is an important topic and deserves more attention and I hope that the summary of the two days will be read widely. In doing so, it will encourage both clinicians and managers to ask what actions they can take to make the services they run both safer and more people friendly. The speakers over the two days provided some novel perspectives and insights for anyone who is seriously interested in patient safety to think further about.

Professor Chris Jones

Introduction

1. All too often, we are witnessing or reading about harm in healthcare: [In the Welsh NHS] '77 patients died due to an "unintended or unexpected" safety incident between June 2018 and May 2019. Over the same period, 372 patients suffered "severe" harm while a further 8,463 experienced "moderate" harm.'

2. When reviewing the recollection of staff, patients and relatives of these events it becomes clear that many were predictable, were indeed predicted, often by circumspect patients and some could clearly have been prevented. At the same time, the health service is under increasing pressure to provide care that matches the ambitions of the quadruple aim: to improve outcomes, focus on patient satisfaction, provide value for money and to look after its staff.

3. The global nature of this challenge and its echoes from around the world mean that incremental changes, or business as usual, are not likely to be credible options. Thoughtful analysis combined with disruptive innovation and real ambition are needed if all of us want to benefit from the care that modern technology and healthcare systems might be able to provide.

4. At no time have the principles of 'Prudent Healthcare' been more pertinent: Public and professionals need to work as equal partners to co-produce services, focus on those with the greatest health need first and do no harm, do only what is needed as we understand things with our current knowledge and at the same time reduce unjustifiable variation.

5. Co-production as the driving model for change has been successfully applied in many areas to improve the dimensions of quality as described by the Institute of Medicine and assure that care is delivered in a way that is effective, person-centered, timely, efficient and equitable. There is significantly less evidence on how co-production is being applied to improve safety of individuals and systems. This is where the current report tries to explore how structure, process and outcomes of health services might be affected by making greater usage of the knowledge, skills and passion of patients and their personal networks.

6. The present report summarises the inputs and discussions from a two-day conference held in Bangor, North Wales in May 2019. It is our hope, as authors and sponsors, that we can make this an annual learning event for public and professionals, that it will inspire changes in beliefs and behaviours and ultimately lead to safer healthcare.

Chris Subbe and Rob Royce

1. Executive Summary

Patients are suffering from increasingly complex conditions and healthcare systems are increasingly difficult to navigate. Against this backdrop a large number of reports have found that medical errors are common and harm is affecting between five and ten percent of patients. Half of this harm is potentially avoidable but 20 years of research into quality improvement has only brought moderate improvements in the rate of patients who suffer from adverse events.

There are two systems to understand errors: 'Safety 1' focuses on finding the root causes of why things go wrong, while 'Safety 2' describes the circumstances in which things go right.

Prudent Healthcare is the framework that underpins Welsh healthcare policy and delivery: Prudent Healthcare focuses on serving those with the greatest need first, treats the public and professionals as equal partners through co-production and emphasises to do only what is needed and to do no harm. The transparent use of evidence-based medicine is seen as an important mechanism to achieve this.

This report illustrates the value of co-production in the prevention of harm through the experience of patient advocates, safety campaigners, health service researchers and people working in healthcare, collected as part of a symposium on 'Patient Powered Safety' in Bangor in May 2019.

The 'expert witnesses' show how impactful patients' engagement in their own safety is, especially in the context of chronic disease, when the patient is often the person with the best knowledge of their condition and the person with the best perspective to detect deterioration. The testimonies highlight how the knowledge of patients and those close to them has the power to prevent serious adverse events. The report also explores the likely risks and benefits of technology to facilitate safer delivery of future healthcare.

In a system that is struggling to manage complex healthcare, co-production between public and professionals has the potential to reduce adverse events and improve safety in the NHS. This report intends to inspire those who require medical care and those who work in health or healthcare policy to explore alternative models in an attempt to reduce avoidable harm.

Acknowledgement: The authors would like to thank the speakers for giving up their time and gathering evidence on the opportunities and limitations of a more active role of patients in ensuring the safety of healthcare.

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2. Background: The problem with safety

Modern society has invested more resources and hope into medical innovation than into any other industry. Despite this investment, the incidence of patients being harmed while being cared for in hospital, or in primary care, remains high with one in 20 patients expected to suffer harm during medical care (1). During the process of care, patients and their families are more often than not perceived as passive recipients of care rather than active members of their care team.

The Institute of Medicine's report 'To Err is Human' (2) published in 2000 estimated that preventable adverse events were a leading cause of death in the United States. Studies from the United Kingdom (3,4), Sweden (5), Denmark (6), Canada (7), Australia (8), New Zealand (9,10) and the Netherlands (11) have shown that a significant proportion of people admitted to hospital suffer harm. Many adverse events are due to failures to provide basic monitoring and administer routine treatment such as fluids and antibiotics in a timely manner (12). A substantial part of these are thought to be avoidable (13).

While patients directly suffer from the results of errors in healthcare, their families are also affected. There is additional evidence that healthcare staff who witness harm are deeply affected and often take prolonged periods of time to recover (14,15). Adverse events come at a significant financial price (16): In the NHS, safety incidents cause significant costs (17) with the cost of harm estimated at £7 – 8 billion by the NHS Litigation Authority in 2017/18 (18).

System-wide changes have improved safety of care in some areas: In the Netherlands, a national program focused on a small number of safety problems led to a reduction in preventable adverse events (19). In the USA, the implementation of interventions in 5 areas of harm during an 18 month period, including treatment of heart attacks and deterioration of patients in hospital, led to a reduction in mortality by more than 100,000 patients below the expected rate (20). In Wales the implementation of the 1000 Lives Improvement program has improved outcomes (21).

Despite this, an overarching assessment by Jeffrey Braithwaite from the Australian Institute for Healthcare Innovation summarising 20 years of improvement efforts in healthcare in 2018 concluded that at best, 60% of currently administered treatment worked, 30% of interventions do not have a reasonable evidence base and up to 10% of care is outright harmful (22).

This report presents findings of a two-day symposium on 'Patient Powered Safety' that was held in Bangor on the 23rd and 24th of May 2019. The symposium was hosted by Bangor University and supported by the Health Foundation, Accelerate Wales and the Bevan Commission. Based on principles of the Design Council (23) the symposium aimed to:

1. Discover the knowledge of patients and carers that is relevant to their safety,

2. Define challenges to safety that are amenable to patient and carer involvement,

3. Develop concepts to augment safety by and with patients,

4. Deliver examples of good practice to inspire safer clinical care and influence policy.

3. The Policy Context: Prudent Healthcare in Wales

Mistakes and oversights can harm patients and cost money. In Wales, litigation pay-outs rose from just over £64m for 643 claims in 2013 – 14 to £91.4m for 792 payments in 2017 – 18 (a 43% rise in payments). Although this is around 1.5% of the total NHS budget in Wales, the true cost of such mistakes and the resultant harm are of course much greater – to individuals and society. The numbers involved also serve as a tip of the iceberg of people who had care that was below the standard we should be expecting from our NHS. Sitting alongside this is a growing culture of 'defensive medicine' being delivered to patients who often feel themselves as powerless recipients of whatever care is provided. This erodes trust and drives up costs.

The historical approach to quality improvement and monitoring has failed to stop scandals occurring. The review of Cwm Taf Morgannwg Maternity Services (which has led to the Health Board being put in Special Measures) is the latest, but there is little reason to think that it will be the last unless Wales can change its approach to quality assurance. This requires organisations to embrace a true learning culture rather than seeing quality as a 'compliance' issue. As part of this, we need to enlist both patients and relatives as partners in the quality journey. Numerous examples were heard over the two days of the Bangor event that highlighted the wisdom of such an approach.

This very much accords with the 'prudent' approach originally developed by the Bevan Commission (an independent think tank, hosted by Swansea University) and accepted by Welsh Government in 2016. The prudent healthcare principles are:

1. Achieve health and wellbeing with the public, patients and professionals as equal partners through coproduction

2. Care for those with the greatest health need first, making the most cost-effective use of all skills and resources

3. Do only what is needed; no more, no less and do no harm

4. Reduce inappropriate variation, using evidence-based practices consistently and transparently.

Reducing harm in the manner described in these proceedings meets all four of the prudent principles through a series of tangible actions:

- The importance, use and value of coproduction with the public was a constant feature in presentations.

- Improving health and wellbeing through the practical application of coproduction (where death is the alternative, the health and wellbeing gain is stark)! Care is directed to those in greatest need – not languishing unnoticed on a ward and resources utilised to best effect.

- Do no harm.

- Increase transparency, and use what is known to work.

Prudent Healthcare Principles

01 Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production

02 Care for those with the greatest health need first, making the most effective use of all skills and resources

04 Reduce inappropriate variation using evidence-based practices consistently and transparently

03 Do only what is needed; no more, no less and do no harm

Much of the above is so simple in conception that it is somewhat puzzling why it (apparently) can be so difficult to actualise. The proceedings shine some light on how we might turn policy objectives into practicalities and thus make a meaningful and sustained positive impact on patient safety; something that would not just apply to Wales but would have a near uniform application.

4. How we think about safety

Acknowledging the nature of the problem

People do not go to work to do a bad job, to miss a diagnosis, to overlook a significant observation, or fail to take action that then harms a patient (and sometimes leads to death), any more than pilots look to deliberately crash the planes they are flying. Yet mistakes will sometimes be made. Systems that rely on humans to observe events, make decisions and take the required actions can never be foolproof. The likelihood of errors is however more common in either poorly working systems or overloaded systems. Over the course of the two day conference, examples were given of the NHS sometimes doing both.

If you overload anything, eventually it will fail

Areas within hospitals particularly likely to suffer such problems include the Emergency Department and the Medical and Surgical Assessment areas. These are often extremely busy, with a large number of patients (some very sick), with multiple diagnostic investigations and treatments being undertaken and multiple staff handing over patient care to other staff members over the course of the day. Such environments will test the safety of any system. With regard to that dynamic, it was noted by several speakers that matters will be made much worse if there is an institutional/professional aversion to acknowledging a problem of overload and lack of resources. This problem is associated with a fear of speaking up and a reluctance to escalate concerns. In some cases it can even lead to misrepresentation of the patient's condition and the care being delivered in terms of what is recorded in the medical record.

Whose risk is being minimised?

An associated problem noted was of too much emphasis being placed on managing or minimizing risk to the institution and not the patient. One symptom of this is an emphasis on 'tick box' completion of increasing amounts of paperwork (which also take staff further away from direct patient care) rather than promoting an open learning environment. The foundation of the latter is a willingness to acknowledge that errors have been made. Organisations are often reluctant to make such an acknowledgement-commonly citing concerns about an increased likelihood of legal action. This is not only counter-productive (a lack of openness increases the likelihood of legal action) but creates an environment where future errors are more likely.

Despite a series of patient care scandals such as the Bristol Heart Inquiry (24) and Mid Staffordshire Foundation Trust inquiry in England (25) and in Wales 'Trusted to Care' (26) and the recent Maternity Services report at Cwm Taf Morgannwg Health Board (27), the NHS continues to display the hallmarks of a non-learning /closed organisation. Associated with this is a problem of a significant disparity of power relationships; both between staff and the organisation they work for, and even more so between patients/relatives and the NHS. Problems with the former are translating into increasing unhappiness of the NHS workforce (morale/sickness/attitude) and of staff leaving. For patients and relatives the stakes are, of course, even higher.

Learning from what goes wrong and learning from what goes right

Two frameworks of thinking about safety exist: Learning from what goes wrong has been labelled as 'Safety 1' and learning from what goes right as 'Safety 2' (28).

The traditional approach is to think about errors, find out why they happened and then change the circumstances in which they could occur. For example, the administration of cancer medication into the brain rather than the blood due to similar injection systems could be stopped by changing the physical design of connectors so that a drug that was meant to be given into a vein could not be connected to a line that was in the spinal canal. This type of system is called 'Safety 1'.

Given that circumstances that could lead to error are common and that errors are relatively less common, it is obvious that staff are finding ways to cope with challenging circumstances to deliver safe care most of the time. Understanding which circumstances, people and facilities need to be present to assure safe functioning can therefore also be used to design safer systems. In this type of system 'Humans are therefore no longer a liability and performance variability is not a threat' (28). This type of thinking is referred to as 'Safety 2'. One of the applications of Safety 2 is FRAM, the 'Functional Resonance Analysis Model'. FRAM breaks down work into discrete steps and analyses essential system functions; the output of each part of a system depends on available resource, precondition, input, timing and available control mechanisms. The usage of checklists before and during surgery could be seen as an example of Safety 2 (29).

5. Patient Powered Safety – the expert witnesses

In May 2019, we asked experts from around the United Kingdom to share their experience of getting involved in healthcare as part of a two-day symposium hosted by Bangor University, Accelerate Wales and the Bevan Commission.

An audience questionnaire administered by Dr Jamie Barclay highlighted the dimensions of patient participation in safety – patients are important members of the 'team' but there was scepticism about the strength of their role in identifying risks and being actively involved in deciding what an acceptable level of risk is (see below).

Speakers came from very different backgrounds: the expert witnesses were working in healthcare or researching it, developing innovations for healthcare, or bringing their personal experience of healthcare. For the purpose of the symposium, we asked each of them about their analysis of patient contributions to healthcare.

The symposium was attended by citizens, active patient representatives, senior doctors from a number of clinical specialties and representatives of the National Health Service and Health Education and Improvement Wales (HEIW). It was facilitated by three health service researchers: Paul Barach from Wayne University, Detroit, Julie Johnson from Feinberg Medical School, Chicago and Chris Subbe from the School of Medical Sciences at Bangor.

The symposium provided testimony from people living in the community and interacting with primary and secondary care. For the purpose of this conference, we used the term 'patient' for the time that a citizen is interacting with healthcare services.

Starting from the experience of personal loss and suffering in relation to medical error, these experts 'by experience' brought their contributions. For this report a number of themes have been flagged up: learning from the community, hospital and the wider healthcare sector. Learning that is related to harm in the framework of Safety 1 and learning from functioning of care in the framework of Safety 2. Each case study includes suggested reading for further study and reflection.

Audience Questionnaire on Patient Participation in Safety

Fig 1: How much do you think patients are actively involved in safety management?
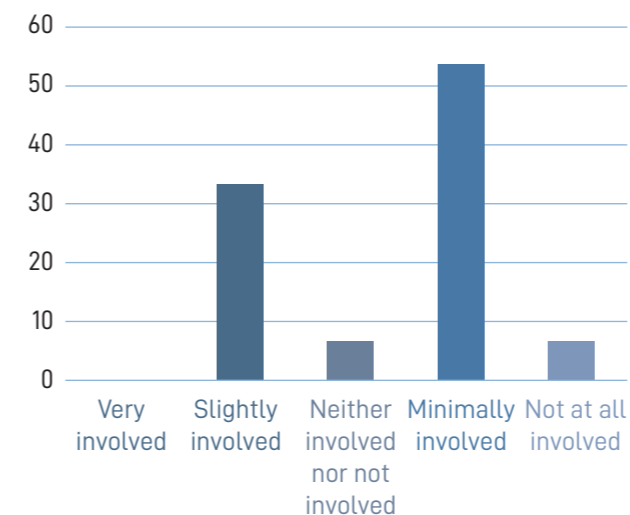

Fig 2: How important would you rate the following as decision makers in safety management?
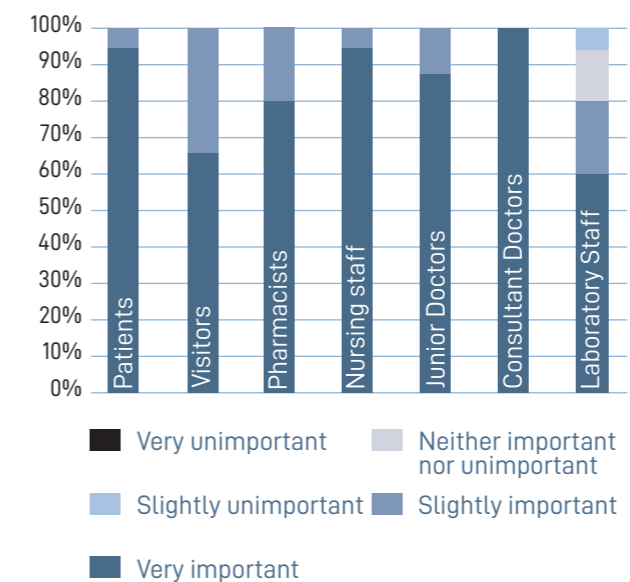

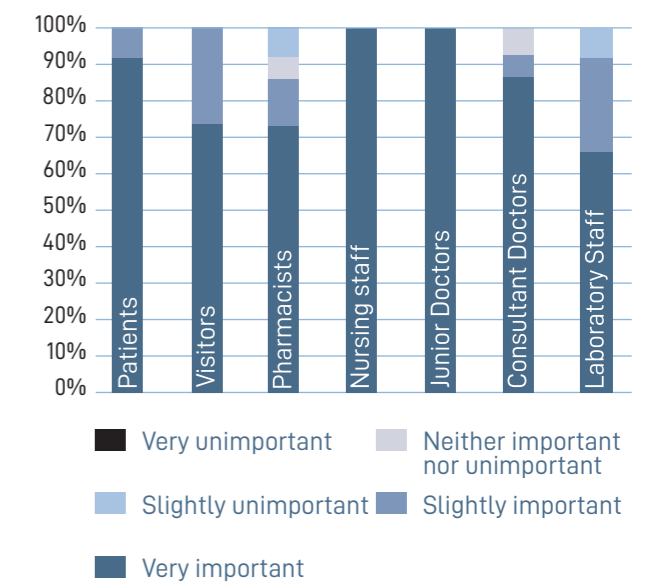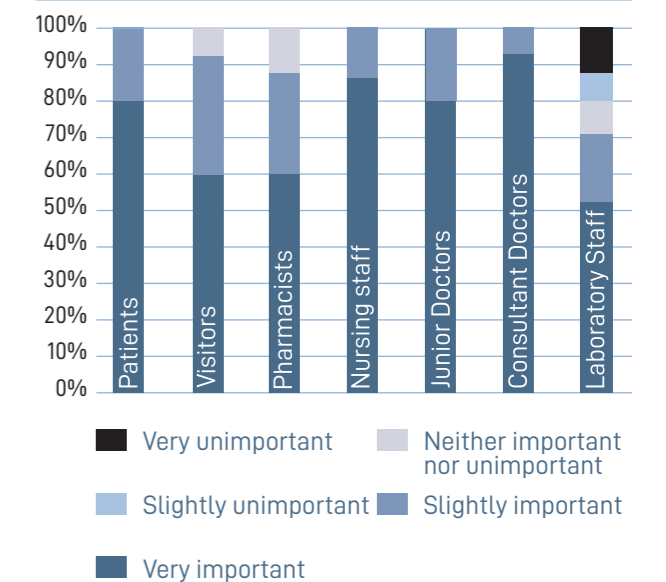**Fig 3: How important would you rate the following as hazard/risk identifiers in safety management?**

Fig 4: How important would you rate the following as deciding the acceptable level of risk to the patient in safety management?

5.1. 'Listening to those who know': Gemma Bailey & Linda Schermer

Evidence provided	Gemma is the daughter of Mrs B and Linda is a medical doctor and lawyer. Gemma's mother (Mrs B) was admitted to hospital. Mrs B was a member of staff at the hospital but had chronic kidney problems. When Gemma arrived at the hospital to visit her mum, she realized how ill her mother was but found it difficult to get her mother the care she needed. It took more than 40 hours to escalate care. She ended up writing an email to one of the consultants who normally looked after her mother. Gemma's mother was finally admitted to Intensive Care.
What can patients/ relatives do?	Gemma knew her mother well. Because of this it was easy for her to realise the fact that her mother was not her normal self and to recognise the severity of her condition. Gemma acted as an advocate for her mother when her mum was seriously ill and unable to fully articulate her needs.
The biggest opportunity?	For the patient/family to be provided with a dedicated, direct point of contact who they can contact at any time when they have concerns that are not alleviated by the team in charge of their care. Even for patients admitted to hospital this should be the consultant.
The biggest challenge?	To move from 'Lessons need to be learnt' to actual implementation!
Other learning	Patients, families and friends can act as sensors of deterioration. Where the normal process fails informal networks can at times bridge gaps. The hospital where Gemma's mother was admitted did not provide a patient or family activated Rapid Response System or an automated system to escalate deterioration.
Framework & Reading	Safety 1; hospital medicine Reading: Case studies in Patient Safety (30)

5.2 Call-4-Concern in hospital: Mandy Odell

Evidence provided	Mandy Odell is a Nurse Consultant in Critical Care. 'Call-4-Concern' is a system where patients, families and friends can activate a Rapid Response Team. Rapid Response Teams consist of nurses and doctors with a background in Intensive Care Medicine; these are specialists in looking after very sick patients. They can examine a patient, order some tests, start emergency treatments and transfer patients to the Intensive Care Unit, if that is needed. If patients and those close to them feel that their worries are not being taken seriously enough they can call a dedicated number in Mandy's hospital and someone from this team will see the patient almost immediately. Prior to starting 'Call-4-Concern' there were considerable anxieties from hospital staff that patients and relatives would abuse the service, call with trivial concerns, or that the service would undermine trust into the patients' own team. A formal evaluation showed that most concerns raised by patients and those close to them are justified (31). Mandy's experience is now being recommended by the International Society for Rapid Response Systems as something that all hospitals should provide (32). As Alison Philips, one of the patients involved in writing the document, put it: "Everybody should be allowed to save their own life, even in hospital."
What can patients do?	In Mandy's hospital, patients and families can directly alert the Rapid Response Team to attend to a deteriorating patient.
The biggest opportunity?	Patient empowerment and partnership in care, as well as the opportunity to help detect deterioration.
The biggest challenge?	Concern by healthcare professionals of being overwhelmed by patient/ relative demand.
Other comments	Allowing patients to bypass traditional pathways of escalation is a big step. It serves as a back-up mechanism when clinical teams are missing important deterioration or are too junior, overwhelmed or dysfunctional.
Framework & Reading	Safety 1; hospital medicine Reading: Odell M et al. Call 4 Concern (33))

5.3 Harmed patient: Josephine Ocloo

Evidence provided	Josephine Ocloo is a researcher and patient safety activist. Josephine's 17-year-old daughter died as a result of a failure to manage her heart condition. Josephine has subsequently been unable to get open and transparent answers from both the healthcare organisation that was meant to look after her daughter and the investigating authorities on why these failures occurred.

Reports into catastrophic failures in healthcare (Bristol, Mid-staffs, Morecombe Bay, Southern Health, Gosport) commonly describe the absence of a 'culture of listening' and transparency in NHS organisations. On the surface, organisations seem to promote patient and public involvement to improve services and foster transparency and safety culture. In practice, more often than not, patients and their representatives find it difficult to be heard. This is particularly the case for representatives who are from a less privileged or minority ethnic background or with those who have disabilities. Their experience ranges from a lack of compassion to the feeling of 'not fitting in' to outright hostility. |
What can patients do?	Patients and their families who speak up are crucial for improvement in patient safety. Getting involved in patient and public engagement processes or joining the local hospital or a patient charity can provide a pathway to make the patient voice better heard.
The biggest opportunity?	To develop a learning culture after harm occurs.
The biggest challenge?	To do this based upon a just culture for harmed patients and staff that delivers openness, justice and transparency as well as improvement.
Other comments	Patients who suffer harm as a result of failures of organisations and individuals require transparency and justice. Healthcare improvement tries to learn from errors without attributing blame. These are two goals that NHS organisations need to reconcile as part of their approach to providing a 'Just Culture' for patients and staff.
Framework & Reading	Safety 1; community & hospital
Reading: Ocloo et al. From Tokenism to Empowerment, BMJ Quality & Safety (34)

5.4 Healthcare Safety Investigation Branch: Cara Taylor & Louise Pye

Evidence provided	Cara Taylor is a team leader for maternity investigations and Louise Pye is Head of Family Engagement for the Healthcare Safety Investigation Branch (HSIB). HSIB was established by an expert advisory group following recommendations from a government inquiry into clinical incident investigations. HSIB has been operational since April 2017 for National Investigations and since April 2018 for Maternity Investigations. It conducts independent investigations across the NHS in England with the aim of identifying improvements to influence systemic change. It draws on methodology and experience from aviation and other industries that have significant knowledge within the safety arena. HSIB has focused on family engagement from the very start of an investigation. HSIB provide information to and facilitate the required care for the family and ensure any signposting to other agencies if needed.
What can patients do?	All families are invited to work with investigators.
The biggest opportunity?	Developing meaningful and influential recommendations which aim to drive positive change at a wider level.
The biggest challenge?	Creating a national standard of investigating serious adverse events to restore patients' confidence into the processes of investigation.
Other comments	The Healthcare Safety Investigation Branch (HSIB) has developed a methodology for engaging patients and families using an approach adapted from that used by the police when investigating serious crime. Unlike healthcare investigations, where good practice has been to simply keep families informed, police investigations seek to gather family narratives as evidence which is integral to the investigation. Gathering additional evidence helps inform the investigation and ensuring that patients and families are more likely to feel respected and engaged.
Framework & Reading	Safety 1; community & hospital
Reading: Setting up an investigator that facilitates learning (35)

5.5 Self-management programme - Patients as experts: Jules Horton & Christine Roach

Evidence provided	Jules Horton and Christine Roach are part of the 'Education Programmes for Patients (EPP) Cymru' team, which provides a range of self-management, health and well-being courses. Jules was struggling with back problems and depression after suffering with cancer in 2012 when she joined an education programme for patients in chronic disease self-management. She took part in problem solving exercises that helped her to start to work out problems for herself and gave her the opportunity to share her ideas with other patients. From being wheelchair-bound she has made big improvements and has since won international horse-riding competitions. Jules is now one of the instructors on the EPP Programme. The programme is trying to reach patients with a broad range of chronic health programmes throughout Wales.
What can patients do?	Self-management programmes increase self-confidence, self-efficacy, self-care behaviours, quality of life, clinical outcomes and patterns of healthcare use. This includes management of complications of chronic illnesses.
The biggest opportunity?	Ability to focus on 'what matters' to patients and controlling care in areas with good evidence base.
The biggest challenge?	Lay people delivering education and support means that lay people also carry the risk of adverse events.
Other learning	Specialist knowledge and peer support can enable patients to improve aspects of their own health including management of complex medications. A review of almost 600 studies found that when people are supported to look after themselves, they feel better, enjoy life more and have less need to visit GPs or hospitals.
Framework & Reading	Safety 2; community Reading: Patient driven solutions to common problems (36)

5.6 Social prescribing: the power of networks: David Evans

Evidence provided	David Evans is an embedded researcher. David is working with an Artisan Collective and a 'Men's Shed'. Men's sheds are 'community spaces for men to connect, converse and create. They help reduce loneliness and isolation, but most importantly, they're fun.' As an example, David tells the experience of an individual with an early diagnosis of Parkinon's Disease. At the Men's Shed group he is able to share and teach a particular artisanal skill and share experience with other members. He is defined by and known for his skills and expertise not his diagnosis. An Occupational Therapist will drop in and provide a brief but valuable consultation to that person – this exchange happening not on the terms of health, but on the terms of the individual. The healthcare professional serves to broker and translate healthcare into something that is relevant to individuals. The setting of the encounter stays outside healthcare.
What can patients do?	Peer support in a social network such as 'Men's Sheds' increases self-confidence, self-efficacy, self-care behaviours, quality of life, clinical outcomes and patterns of healthcare use. This includes management of complications of chronic illnesses.
The biggest opportunity?	Ownership of health by patients. Removal of stigma of disease.
The biggest challenge?	Lack of professional safety netting.
Other learning	Specialist knowledge and peer support can enable patients to improve aspects of their own health including management of complex medications.
Framework & Reading	Safety 2; community Reading: Men's Sheds (37)

5.7 Co-design of services – expertise through experience: Gareth Presch

Evidence provided	Gareth Presch is an expert leader at the United Nations Global Sustainability Index Institute. He is working on the World Health Organisation's Sustainable Development Goals programme. The WHO has realized that we are running out of healthcare staff: a projected shortfall of 18 million healthcare workers globally by 2030. In this context, one of the strategic options is to 'flip' healthcare – if patients and their families can do some of the things that currently are done by healthcare professionals then those with highly specialised training are able to focus on things that only they can do. In his previous job as Chief Officer of the National Haemophilia Council of the Irish Health Service, Gareth witnessed another example of 'Patient Powered Safety': patients with serious conditions affecting their blood are always at risk. Patients are often young and active. Poorly designed services can stop patients getting on with their lives and increase the risk to suffer serious complications. By working with patient groups to setup services, audit their quality, pick products and facilitate usage of mobile technology, Gareth witnessed how patients were able to support their own safety.
What can patients do?	Patient expertise can help to shape services to make them responsive to sudden deterioration or unexpected changes in well-being.
The biggest opportunity?	Involvement in design and leadership of health services – but knowledge and expertise of patient advocates to improve care should be recognised for the value it brings (38).
The biggest challenge?	Special Interest groups might control the agenda at the expense of the 'common good'.
Other learning	Design of services sounds complicated but there is an increasing number of examples where involvement of service users has led to better services (usually at lower cost).
Framework & Reading	Safety 2; community Reading: Coproduction studies from Wales (39); WHO Sustainability Goals (40); Paying for Advocates (38)

5.8 Activism – the power of painful experiences: Terence Canning

Evidence provided	Terence Canning is Chair of the UK Sepsis Trust in Wales. Terence's brother died in 2012 unexpectedly at the age of 41 from sepsis. Sepsis is the term that is used for severe overwhelming infections. Despite the severity of the illness, the warning signs of sepsis can look harmless, like a cold – achy joints, shivering. This makes sepsis an easy condition to miss. Everybody can get sepsis, but patients who are taking medication for chronic conditions such as diabetes or rheumatoid arthritis are more at risk. Educating the public and lobbying to set free resources for better care is, therefore, an important part of healthcare. Terence became involved in the work of the Sepsis Trust after the death of his brother. He has supported Public Health Wales in their campaign for better sepsis care and is secretary of the cross-party group on sepsis at the National Assembly for Wales.
What can patients do?	Getting involved in healthcare charities to raise awareness about conditions that are not receiving the necessary resources or attention is an important motor for change of healthcare. Activism is often undertaken by patients or their relatives who have been affected by the condition. Activists can become an essential conduit between the community, healthcare professionals and government through support groups, online forums, peer to peer and social media pages. When this happens, it can help to reshape negative experiences into (hopefully) positive outcomes.
The biggest opportunity?	The patients' experience is a powerful tool for lobbying public opinion and healthcare funders.
The biggest challenge?	Conditions with no organised patient groups might miss out.
Other learning	'Patients are the experts of their own lives' – the importance of the role of personal experience of the patient/family member/advocate in the relationship with the health professional is hard to overstate.
Framework & Reading	Safety 2; community Reading: www.sepsistrust.org (41)

5.9 Co-design – translating complex information into action: Hawys Tomos

Evidence provided	Hawys Tomos specialises in user-centred design. She worked as a designer with the Helen Hamlyn Centre at the Royal College of Art, developing methods to engage with patients and staff and discover insights about what could go wrong in hospital, in order to guide better design. As part of a research programme funded by the Health Foundation she observed the confusing documentation used on hospital wards and the complex interactions between specialists. Her work showed that the information that was needed to save a patient's life was often buried between large piles of notes that had little or no value for patient safety. One of the problems identified was the worsening function of some patients' kidneys during an acute illness. Patients (and staff) often did not know about this – despite the fact that one in four patients with poor kidney function die and that treatment is comparatively simple – plenty of fluids and stopping of certain medications during the acute illness. Giving patients bracelets that had drops in different shades of yellow printed on them helped nurses to monitor urine, and therefore kidney function, three times better than without the bracelets.
What can patients do?	The most important parts of treatment often require all members of the healthcare team to hold information. Patients (and families) can be empowered to understand and hold information themselves and to speak up; to remind staff, ask questions and query decisions.
The biggest opportunity?	Using good design to make complex information visible and understandable, and to empower patients (and families) to be active participants and experts in their own health and care.
The biggest challenge?	Getting decision makers to fully understand and engage with the health and economic value of good design.
Other learning	Subtle hints and reminders are sometimes called 'nudges'. In order to improve care they need to be easy to use, attractive to do or look at, sociable in connecting people, and timely with no need for patience.
Framework & Reading	Safety 2; hospital & community Reading: Nudge Unit's report on how to change behavior (42), Safety=Design, report from a design led patient safety program (43)

5.10 Access to safety critical data: David Hunnisett

Evidence provided	David Hunnisett is a software programmer and IT expert who has led the development of a knowledge-sharing platform called CHAI® (Connected Healthcare Administration Interface). CHAI® makes it easier for nurses to document and share the things that really matter. By providing strong graphic interfaces, CHAI® makes it intuitive to do the right thing and it enables nurses to spend 20% more time with patients compared to a paper system. Adverse events in hospital often happen after changes in vital signs. Vital signs – like speed of breathing, oxygen level, blood pressure, heart rate and temperature change dramatically if a patient becomes unwell. In order to make it easier to detect catastrophic deterioration, hospitals in the United Kingdom use a simple scoring system called an 'Early Warning Score'. The more abnormalities that are detected in a person's vital signs, the higher the score. Introduction of scores was first researched at Wrexham Maelor Hospital in Wales. David's group has now built an interface that makes this really important information available to patients in their hospital bed in real-time. This might help to support timely escalation of care in deteriorating patients (32).
What can patients do?	For patients with chronic conditions, vital signs can be different from those of a healthy person, for example in patients with serious heart conditions the blood pressure is often low. Knowing your own vital signs when you are well can help to detect when things are going wrong.
The biggest opportunity?	Empowering patients to become involved in their own care by providing access and control of their own record.
The biggest challenge?	Risk management might be based on protecting organisations rather than individual patients. Innovation introduces new risks that are often perceived to be greater than non-quantified existing risks. The result is a poor record of innovating at pace and scale in healthcare IT systems.
Other learning	The NHS Wales patient safety initiative '1000 lives' is promoting to 'Know your score' for all patients with chronic conditions.
Framework & Reading	Safety 2; hospital Reading: Measuring whether a hospital can provide safe care for deteriorating patients (32)

5.11 The power of checklists in healthcare: Derick Murdoch

Evidence provided	Derick Murdoch is an expert in user experience and user interface design. When things go wrong it is often the most common things that have gone wrong. This has led to the development of checklists in aviation, nuclear industry and in operating theatres. Cancer treatment has many side effects but most of them are well known. Derick and colleagues are currently testing a checklist for common side effects of cancer treatments that is based on the checklists that cancer specialists use but that can be jointly used by the patient, a friend and a healthcare professional. The checklist can be downloaded onto a smart phone and if the patient or their friend report a potentially serious side effect, the application will encourage a call to the right helpline for this problem.
What can patients do?	Checking something with a trusted friend is a good method to making sure nothing important is missed. Often speaking to someone is a simple first step to make sure that dangerous complications are not missed or to get simple reassurance.
The biggest opportunity?	Using the social network of patients to improve safety. The ability of a friend or family member to have an active role in patient care is empowering and provides additional reassurance during treatments.
The biggest challenge?	Funding models of care that enable involvement of patients.
Other learning	Checklists can be used in many situations. Research suggests that sharing a checklist with someone makes it a much more powerful tool.
Framework & Reading	Safety 1; community care Reading: Literature review on Health in Oncology (44)

5.12 Patients spend 99.9% their time outside of hospital or clinic: Elin Haf Davies

Evidence provided	Elin Haf Davies is a researcher & entrepreneur. Helping children with complicated diseases is a particularly tough challenge. While working as a paediatric nurse at Great Ormond Street's Children Hospital, Elin was struck by the physical discomfort to children that many studies into rare metabolic diseases cause. With her company Aparito, she developed systems that use wearable sensors that measure vital signs such as heart rate, temperature or intensity of movement and connect them to a smart phone application that also collects the answers to simple questions about the young patients' wellbeing. With this method, children and adult patients alike can collect detailed information about their health in real time and in real life without the need for many painful, invasive hospital based blood tests in sterile environments. This type of technology is being explored in many areas now but is currently limited to research (e.g. studies to understand the effects of medication) as the introduction to routine clinical care pathways is more challenging.
What can patients do?	Discuss ideas with your doctor or nurse: patient owned blood pressure machines and wearable sensors like 'Fitbits' or the Apple 'iWatch' (the first smart-watch that was registered as a medical device) can help patients to monitor their own health. Knowing what normal looks like makes it much easier to detect changes early and highlight those to your doctor or nurse.
The biggest opportunity?	Using patient reported outcomes and symptom reporting in real time via your own phone.
The biggest challenge?	Translation from successful usage in research to successful usage in clinical practice, and the safe protection of patient data.
Other learning	Technology is advancing rapidly but integration with traditional healthcare models (especially electronic health records) is likely to stay challenging for years to come.
Framework & Reading	Safety 2; community care Reading: Detection of heart rhythm problems with smart watches (45)

5.13 Access to patient notes with safety-critical information: Sarah Wright

Evidence provided	Sarah Wright leads the implementation of 'Patients Know Best' in Wales and the use of the software for academic partners. 'Patients Know Best' is a patient-controlled health record. Patients who are affected by a chronic health condition often see many different healthcare professionals: their general practitioner, the practice nurse, the specialists in a hospital outpatient department, pharmacists etc. Often these do not work for the same organisation and patients find themselves frustrated by having to recount the same details repeatedly. 'Patients Know Best' has built software into which patients and healthcare organisations can load letters, reports, lists of medications, blood results and other data from all those that interact with their health. Patients can control this information and negotiate with whom they would like to share which information.
What can patients do?	'Patients Know Best' is available through a number of health boards in the NHS in Wales. Understanding information about your own health is often an important first step to improving health and contributing to co-produced health outcomes.
The biggest opportunity?	Patient ownership and control assures continuity of care and acts as an enabler for patient empowerment.
The biggest challenge?	Adoption and customisation without losing a 'common language' of patient held records. Usage while in hospital.
Other learning	Patients who have access to personal health records do better in studies ranging from inflammatory bowel disease to rheumatoid arthritis.
Framework & Reading	Safety 2; community care Reading: Landscape review of Personal Health Records (46)

6. The learning from the experts

Tackling the problem

The foundation of patient safety has to be putting safety as the paramount concern of the organisation – a first amongst equals – rather than something that jostles with competing priorities and moves up and down the agenda in response to 'events'. At the same time, we have to recognise that every organisation exists to deliver a service, not just to be safe. Operationally in the NHS, this means that systems that are meant to increase/ensure safety but that also impose significant time penalties and/or administrative duties on staff will have a tendency to being bypassed, or not completed properly (the conference heard that in the USA 49% of junior doctor time is spent interacting with technology). This is a particular risk as operational pressures mount. This is a well-observed phenomenon across multiple industries. Far from being immune (on the basis that clinicians are professionals), health services display these phenomena on a daily basis.

Promoting a learning culture and investigating adverse events

A concern for patient safety has to be embedded into learnt and taught behaviours. If it is not, then behaviours we do not want will be difficult to break. Fundamental to a patient safety culture is a willingness to acknowledge, explore and learn from mistakes. The more the investigation and response to mistakes and safety concerns is bureaucratised into a specific department the less chance there is of genuine learning. It is vital that patients and relatives are fully involved in investigations and not seen as 'the enemy'. At the conference, the process operated by the newly formed Healthcare Safety Investigation Branch (England) with regard to Maternity cases was highlighted. This sees the patient/relatives involved from the outset. Part of the investigation will specifically look to address their concerns, they are provided with regular updates and patients/relatives see both the draft and final reports. The emphasis is on learning from adverse events.

System design

Systems are supposed to be designed around 'the client'. There is a need for more 'human centred design' and not what a third-party thinks people want; or even worse a system designed to satisfy the needs of the system and/or professional interests with little thought to how 'the patient' experiences it. Given the complexity of modern healthcare, Hawys Tomos, David Hunnisett, Derick Murdoch and Elin Haf Davies all emphasised the importance of understanding the system and users and working on iterative improvements, something that is challenging within the processes of technology procurement in the NHS.

Technology can help but is not a 'magic bullet'

Technology has great potential to enable the public to interact with health services on a real time basis which will help shape a more patient centric design. For example, phone appliances and wearable technologies will facilitate biometric feedback of patient conditions in day-to-day situations and not just when they attend 'clinics'. Indeed, the requirement to physically attend health care facilities should be greatly reduced. Technology promises much but the conference also heard a warning that it has a potential to further drive the medicalisation of society and an unthinking acceptance that 'what the computer system says must be right' and ergo that if things go wrong someone must be at fault.

The human factor

Technology can help to flag up impending adverse events but the conference also heard of the importance of 'the human factor'. Central to this is the right (and the necessity) of patients and relatives being able to get staff to take notice when they 'feel something is not right'. Nobody knows the patient better than the patient himself or herself. Second to that would be close relatives and friends. Gemma, Linda, Terence Canning and Jules Horton all gave powerful examples over the two days. At the conference the Call-4-Concern (C4C) system established at the Royal Berkshire Foundation Trust was of particular interest in this regard, as it enables patients/relatives to directly the Response Team if they have concerns that a significant change in a condition/concern needs addressing. As was heard 'Everyone has the right to save their own life'.

The Rapid Response Team service is widely advertised within the hospital and it was emphasized that any patient, relative or indeed member of staff could call 24/7, 365 days a year. The Royal Berkshire is fortunate enough to have a well-established critical care outreach team. Nevertheless, there was a concern when the service was initially proposed that the team would be inundated with calls. This fear has not materialised. A recent seven-year study has been published which highlighted that whilst the critical care outreach team received over 70,000 calls over that period, only 534 (0.8%) of them were C4C referrals.

The C4C service points to the way the NHS needs to look at patient safety and to enlist patients and relatives into creating and maintaining safe services… as equal partners in a shared enterprise.

Audible voices

The fact that the patient voice is at present often not clearly audible requires greater involvement at institutional level and vocal advocacy – something that was highlighted by the contributions from Gemma, Josephine Ocloo and Terence Canning. The personal experience of loss in a system that is not delivering safe care can be used to power learning, representation and activism with or without formal organisation. Louise Pye and Cara Taylor illustrated patient input within an institution through their work at the Healthcare Safety Investigation Branch. The meeting offered two structural solutions for a more audible voice: by moving the healthcare encounter out of the clinical environment onto a terrain that is owned by patients, as described by David Evans's experience with the 'Men's sheds' or by building the patients' expression into the infrastructure of clinical record systems as demonstrated by 'Patients Know Best'.

Measuring the impact of a more patient-centred or patient-powered system on clinical outcomes, satisfaction of patients/their networks/their healthcare professionals and the resulting cost and value will require further work.

7. Further reading

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