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Patient empowerment in acute settings

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EPF Conference 2016

KING'S IMPROVEMENT SCIENCE

KING'S College LONDON

Guy's and St Thomas' NHS

King's College Hospital NHS

South London and Maudsley NHS

Policy background

Patients should become **active partners** in improving the safety, quality and efficiency of health service delivery

Patients are increasingly recognised as **'experts'** in their own illnesses and care, able to usefully participate in **recognising and averting** errors, near misses and adverse events

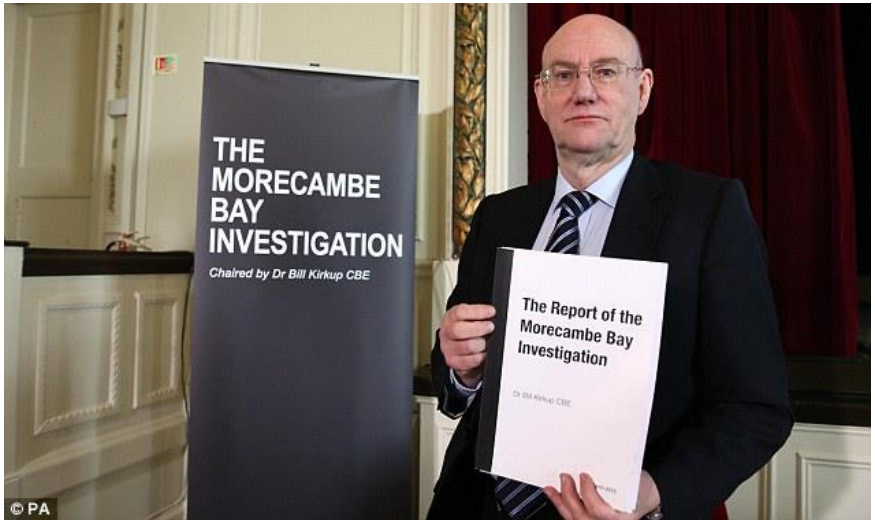
Increasing emphasis on patient choice, individual responsibility, shared decision-making, partnership and agency

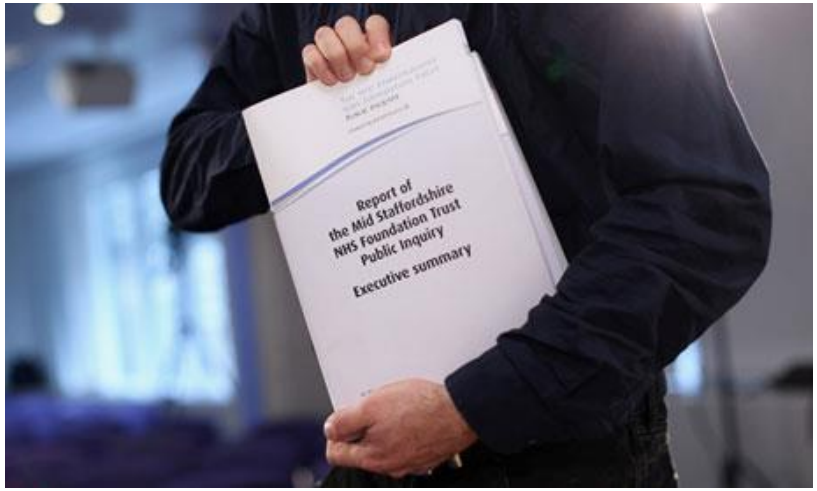
Patients' voices in management of acute illness:

Avoidable harm (and in some cases, death) results from delays in recognition, referral and management of severe illness (NPSA 2007, NCEPOD 2005, 2012)

Many patients / partners raise alerts which are not attended to (Sands 2012, Kirkup 2015, DoH 2013, MBRACE 2015)

These adverse outcomes carry potential for both short and long term harm (Lobel & DeLuca 2007; Furuta et al 2012)





King's patient safety research programme 2008 - 2012

Programme: funded by UK National Institute for Health Research

Focus on implementation of service and technological innovations in healthcare and impact on quality of care and patient safety

Research priority identified at international level – to develop and test safety solutions and actions from a theoretical base (Ovretveit 2007)

Project: Two year ethnographic study examining care of acutely ill patients in medical and maternity settings

- 2 inner city acute hospital providers
- 270 hrs observation, staff interviews (79), document review
- **patients' (30) and relatives' (11) interviews**

One aim: to identify factors that influence patients', families and staff's ability to contribute to the management of complications.

Patient expertise

‘This lady earlier on in the day shift had said to one of the nurses, ‘I don’t know what’s wrong but I just don’t feel very good, I just don’t feel quite right.’ They checked everything, but she wasn’t scoring on the early warning chart. Then [half an hour later] she started to get clammy and cold and sweaty’ (Health care assistant)

One woman] woke up at 4 o’clock in the morning and said to the midwife, ‘ I really feel unwell, I feel terrible’. The midwife fortunately took her sensibly and put her on the monitor, and there was this catastrophic terminal CTG and the woman was very ill, and she just knew’ (Obstetrician)

Complex systems and gaps in care

'You get a ward card and there's a help number on it so you ring the ward. The response is: 'Well we can't help you, there's no doctors on the ward.' ***[Daughter of Ellen]***

'*They wanted to know why they should take me seriously. I felt this in every interaction with them on the phone. I did not feel like I was being eagerly listened to, I felt like I was trying to break into a bank … almost carry off a kind of heist.* *[**husband of Pauline**]*

Key findings

- Most patients ***were informed*** and ***engaged*** in self monitoring and asked for help
- Patients' confidence and ability to contribute influenced by nature of illness, age, experience of health system, models of care
- Patients' concerns about overloading the system, upsetting staff and the potential for consequential compromise to care
- Variable response from staff

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The role of patients and their relatives in 'speaking up' about their own safety – a qualitative study of acute illness

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Abstract

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Keywords: acute illness, patient involvement, patient safety

Background Poor recognition of and response to acute illness in hospitalized patients continues to cause significant harm despite the implementation of safety strategies such as early warning scores. Patients and their relatives may be able to contribute to their own safety by speaking up about changes in condition, but little is known about the factors that
the experiences and views of
mine the potential for involvei

Methods This data set is dra
of the management of the ac
patients and seven relatives fr
NHS Trusts were interviewed.
likely to influence patients' an
to the management of deterior

Results All patients interview
within the context of a long
was influenced by the ability t
tion, self-monitoring, confiden
of health care. When patie
health-care staff had a mediat
the effectiveness of speaking u

Implications Safety strategies
take account of the complexit
more partnership may be mo
lies and staff than those that
may ultimately prove to be m

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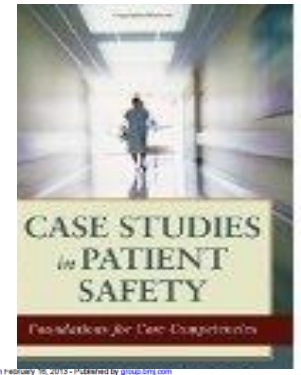


Women's safety alerts in maternity care: is speaking up enough?

Susanna Rance,[1] Christine McCourt,[2] Juliet Rayment,[2] Nicola Mackintosh,[1] Wendy Carter,[3] Kylie Watson,[4] Jane Sandall[1]

ABSTRACT

Patients' contributions to safety include speaking up about their perceptions of being at risk. Previous studies have found that dismissive responses from staff discouraged patients from speaking up. A Care Quality Commission investigation of a maternity service where serious incidents occurred found evidence that women had routinely been ignored and left alone in labour. Women using antenatal services hesitated to raise concerns that they felt staff might consider irrelevant.

The Birthplace in England programme, which investigated the quality and safety of different places of birth for 'low-risk' women, included a qualitative organisational case study in four NHS Trusts. The authors collected documentary, observational and interview data from March to December 2010 including interviews with 58 postnatal women. A framework approach was combined with inductive analysis using NVivo8 software.

Speaking up, defined as insistent and vehement communication when faced with failure by staff to listen and respond, was an unexpected finding mentioned in half the women's interviews. Fourteen women reported raising alerts about safety issues they felt to be urgent. The presence of a partner or relative was a facilitating factor for speaking up. Several women described distress and harm that ensued from staff failing to listen.

Women are speaking up, but this is not enough: organisation-focused efforts are required to improve staff response. Further research is needed in maternity services and in acute and general healthcare on the effectiveness of safety-promoting interventions, including real-time patient feedback, patient toolkits and patient-activated rapid response calls.

INTRODUCTION

There has been increasing interest internationally in the ability of patients and their families to contribute to their own safety.[1–3] There is some evidence that patients can detect suspected adverse events earlier than professionals.[4] However, most interventions have focused on educating patients and encouraging them to question staff on pre-established issues such as hand washing and medication.[5] Patients' readiness to speak up was substantially affected by the quality of their relationships with staff.[6] Many were reluctant to challenge professionals because of previous experiences of not being heard or having their input belittled, or fear of victimisation.[7–11]

Less is known about the role of women speaking up in maternity services. A study of interaction in antenatal clinics found that women used indirect ways to broach issues that worried them, feeling that they might not be considered valid by staff.[12] Women's narratives about birth trauma referred to professionals' neglect of communication and their own feelings of powerlessness.[13] In an investigation of a maternity service where serious incidents had occurred, the Care Quality Commission documented cases of women routinely being ignored and their description of their labour being dismissed by staff; being left alone for long periods of time while in labour; being spoken to rudely by staff; and not receiving adequate pain relief.[14] UK media have reported on incidents when staff failed to attend to labouring women's safety alerts.[15–18] A report on stillbirths and neonatal deaths found that many bereaved parents had suspected something was wrong and had raised alerts which staff did not consider to be valid.[19]

The Birthplace in England research programme was designed to provide a solid evidence base regarding the quality and safety of different places of birth for 'low-risk' women. Its component studies aimed to map the configuration of maternity services; compare perinatal and

Vulnerabilities

Some perceived attributes make it even harder to be taken seriously

Ethnic minority backgrounds

Level of education

Stigma, ‘difficult patient status’ such as mental health or substance abuse use,

Ability to speak English

Being alone

Evidence base of interventions to aid patient / family involvement?

Involvement in escalation of care is defined as

- **recognising** signs and symptoms of acute deterioration and **seeking professional help**
- **speaking up about concerns** about timeliness or appropriateness of care received for acute deterioration (diagnosis, treatment and management)

Includes help seeking in community and hospital settings

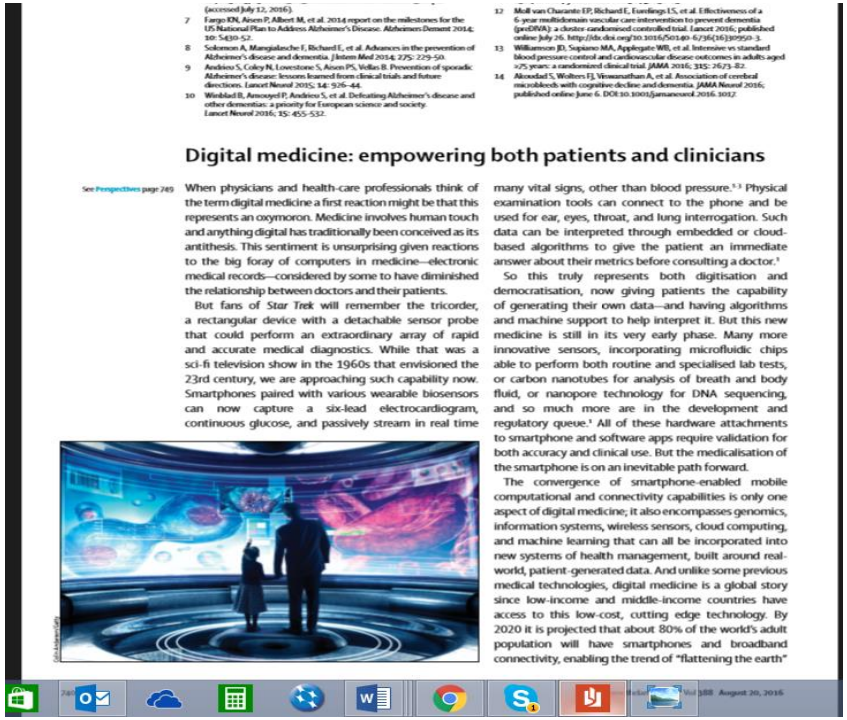
Low and high resource countries

Potential solutions – digital interventions for changing power relations?

Will they increase access and reduce power differences?

Reduce inequalities?

Digital divides?



(accessed July 12, 2016).

7 Fargo KN, Alzen P, Albert M, et al. 2014 report on the milestones for the US National Plan to Address Alzheimer's Disease. *Alzheimers Dement* 2014; 10: S430–52.

8 Solomon A, Mangialasche F, Richard E, et al. Advances in the prevention of Alzheimer's disease and dementia. *J Intern Med* 2014; 275: 229–50.

9 Andrieu S, Coley N, Lovestone S, Aisen PS, Vellas B. Prevention of sporadic Alzheimer's disease: lessons learned from clinical trials and future directions. *Lancet Neurol* 2015; 14: 926–44.

10 Winblad B, Amouyel P, Andrieu S, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. *Lancet Neurol* 2016; 15: 455–532.

12 Moll van Charante EP, Richard E, Eurelings LS, et al. Effectiveness of a 6-year multidomain vascular care intervention to prevent dementia (preDIVA): a cluster-randomised controlled trial. *Lancet* 2016; published online July 26. http://dx.doi.org/10.1016/S0140-6736(16)30950-3.

13 Williamson JD, Supiano MA, Applegate WB, et al. Intensive vs standard blood pressure control and cardiovascular disease outcomes in adults aged ≥75 years: a randomized clinical trial. *JAMA* 2016; 315: 2673–82.

14 Akoudad S, Wolters FJ, Viswanathan A, et al. Association of cerebral microbleeds with cognitive decline and dementia. *JAMA Neurol* 2016; published online June 6. DOI:10.1001/jamaneurol.2016.1017.

Digital medicine: empowering both patients and clinicians

See Perspectives page 749

When physicians and health-care professionals think of the term digital medicine a first reaction might be that this represents an oxymoron. Medicine involves human touch and anything digital has traditionally been conceived as its antithesis. This sentiment is unsurprising given reactions to the big foray of computers in medicine—electronic medical records—considered by some to have diminished the relationship between doctors and their patients.

But fans of *Star Trek* will remember the tricorder, a rectangular device with a detachable sensor probe that could perform an extraordinary array of rapid and accurate medical diagnostics. While that was a sci-fi television show in the 1960s that envisioned the 23rd century, we are approaching such capability now. Smartphones paired with various wearable biosensors can now capture a six-lead electrocardiogram, continuous glucose, and passively stream in real time many vital signs, other than blood pressure.[1–3] Physical examination tools can connect to the phone and be used for ear, eyes, throat, and lung interrogation. Such data can be interpreted through embedded or cloud-based algorithms to give the patient an immediate answer about their metrics before consulting a doctor.[1]

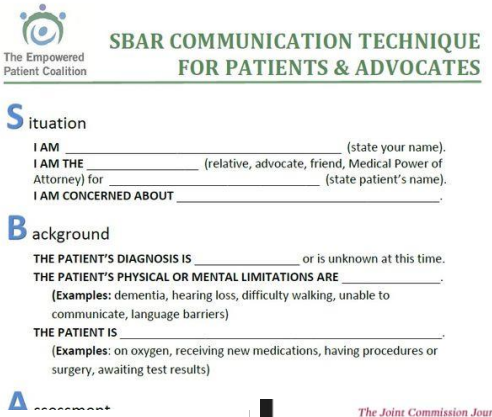
So this truly represents both digitisation and democratisation, now giving patients the capability of generating their own data—and having algorithms and machine support to help interpret it. But this new medicine is still in its very early phase. Many more innovative sensors, incorporating microfluidic chips able to perform both routine and specialised lab tests, or carbon nanotubes for analysis of breath and body fluid, or nanopore technology for DNA sequencing, and so much more are in the development and regulatory queue.[1] All of these hardware attachments to smartphone and software apps require validation for both accuracy and clinical use. But the medicalisation of the smartphone is on an inevitable path forward.

The convergence of smartphone-enabled mobile computational and connectivity capabilities is only one aspect of digital medicine; it also encompasses genomics, information systems, wireless sensors, cloud computing, and machine learning that can all be incorporated into new systems of health management, built around real-world, patient-generated data. And unlike some previous medical technologies, digital medicine is a global story since low-income and middle-income countries have access to this low-cost, cutting edge technology. By 2020 it is projected that about 80% of the world's adult population will have smartphones and broadband connectivity, enabling the trend of "flattening the earth"

Solutions - joint patient and family interventions?

Early testing of team training shows feasibility

Shared decision making interventions targeting **patients and healthcare professionals together** show more promise than those targeting only one or the other



The Empowered Patient Coalition

SBAR COMMUNICATION TECHNIQUE FOR PATIENTS & ADVOCATES

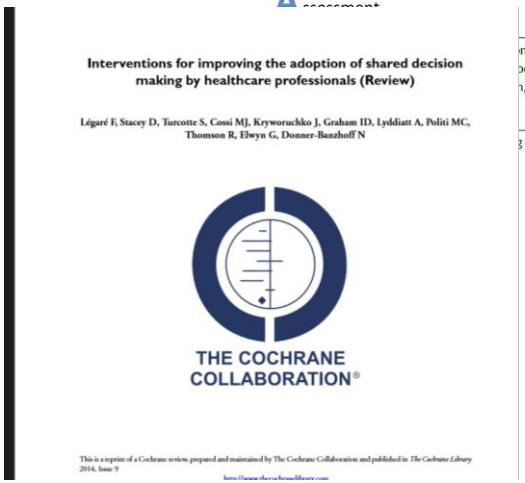
S ituation

I AM _____ (state your name).
I AM THE _____ (relative, advocate, friend, Medical Power of Attorney) for _____ (state patient's name).
I AM CONCERNED ABOUT _____.

B ackground

THE PATIENT'S DIAGNOSIS IS _____ or is unknown at this time.
THE PATIENT'S PHYSICAL OR MENTAL LIMITATIONS ARE _____.
(**Examples:** dementia, hearing loss, difficulty walking, unable to communicate, language barriers)
THE PATIENT IS _____.
(**Examples:** on oxygen, receiving new medications, having procedures or surgery, awaiting test results)

A ssessment



Interventions for improving the adoption of shared decision making by healthcare professionals (Review)

Légaré F, Stacey D, Turcotte S, Cossi MJ, Kryworuchko J, Graham ID, Lyddiatt A, Politi MC, Thomson R, Elwyn G, Donner-Banzhoff N

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Patient and Family Involvement

The You CAN Campaign: Teamwork Training for Patients and Families in Ambulatory Oncology

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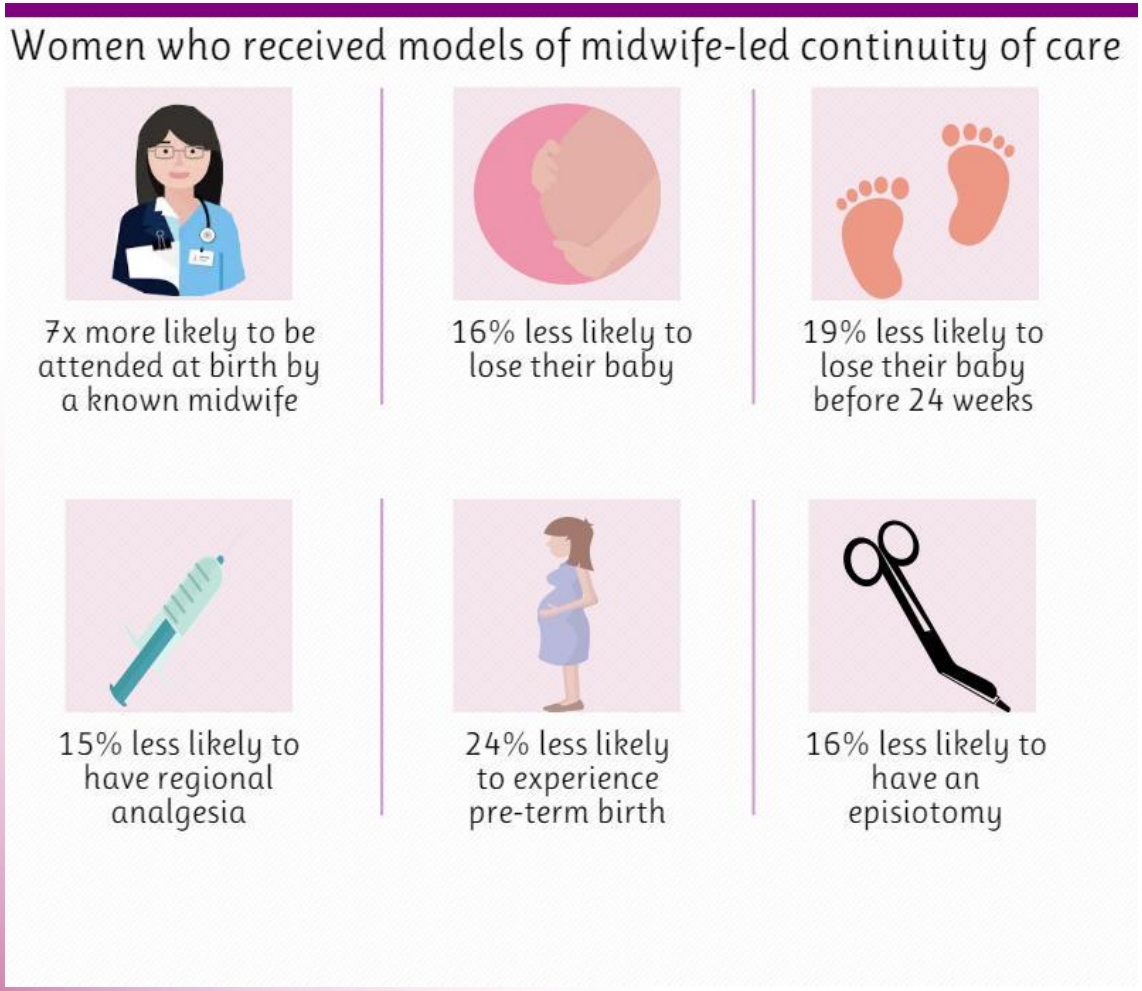
Article-at-a-Glance

Background: Health care organizations have begun to adapt high-performance teamwork training techniques from aviation to clinical environments. Oncology care is often delivered in multispecialty teams and with the patient's and family's active involvement. To examine the potential value of a patient-oriented teamwork intervention, a teamwork training initiative for oncology patients and their families was developed at the Dana-Farber Cancer Institute.

Developing the Campaign: The content and format of the initiative evolved iteratively on the basis of several core team-training concepts derived from the research literature in health care and aviation. Initially a targeted intervention, the program evolved into a multifaceted campaign that included internal marketing, staff training, and one-on-one patient outreach by a group of volunteers. The You CAN campaign sought to convey a positive and empowering message that encouraged patients to (1) check for hazards in the environment, (2) ask questions of clinicians, and (3) notify staff of safety concerns.

Implementing the Campaign: The You CAN campaign was conducted from July through September 2007. To assess its progress, patients were surveyed at baseline and during the campaign. On the basis of the survey results, 32% (95% confidence interval [CI]: 25%–38%) of the ambulatory clinic population, or 1,145 patients, were exposed to the

Potential solutions - continuity of care



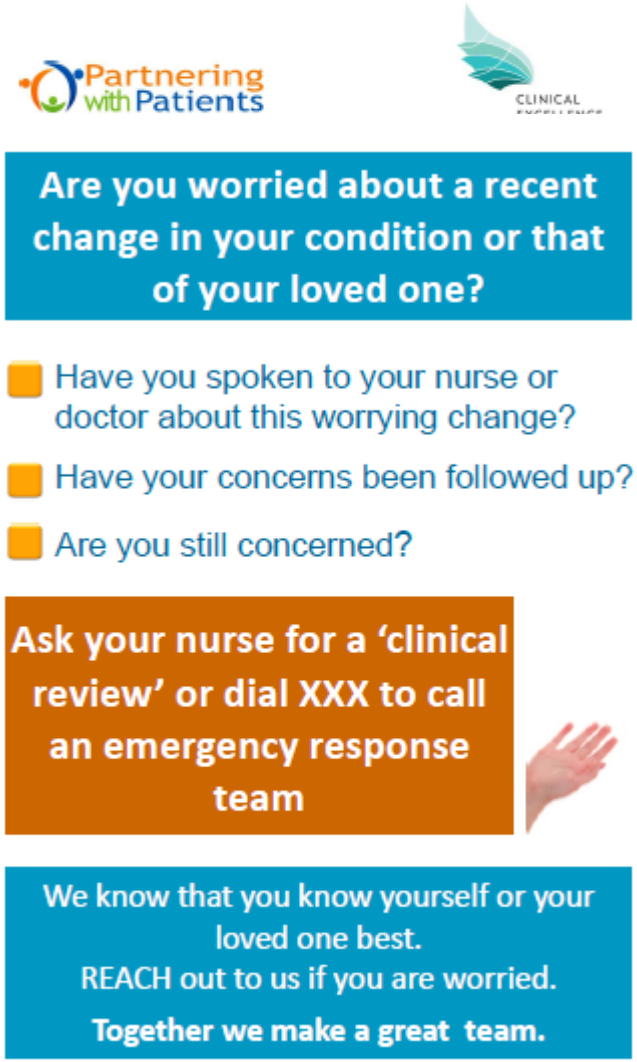
Midwife-led continuity models versus other models of care for childbearing women (Review) **Sandall et al 2016**

- Mechanisms of action – easier for women to raise serious safety concerns when they know midwives and how to contact them?
- Women and families feel safer?
- Coordination and care navigation role acts as safety net in complex system?

Potential solutions - Patient and family initiated rapid response

Albutt et al 2016 Systematic review

- Few studies designed to establish clinical effectiveness
- Few studies defined what were the important components of the interventions
- Communication failure most common reason used for activation
- Activating a RRT appropriate or cost-effective method of resolving concerns that are non- life-threatening?



Conclusions and questions

Patients and their partners *do* speak up in acute emergency situations.

Attention needs to be paid to *how* services are organised, in order to facilitate listening and response by staff in safety-promoting ways.

Questions:

- What elements at system level are needed to enable staff responsiveness to patient concerns? What are the barriers?
- Is patient involvement in acute settings a right or a burden?
- What potential digital interventions can aid self-surveillance and self-diagnosis? How might they address power differences?

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