

THE UNIVERSITY *of York*

DEPARTMENT OF HEALTH SCIENCES

Patient Involvement in Patient Safety

Dorothy McCaughan

on behalf of the PIPS Group



Social Dimensions *of* Health Institute

Bradford Teaching Hospitals



NHS Foundation Trust

PIPS Group members

Yvonne Birks¹, Vikki Entwistle², Simon Gilbody¹, Su Golder¹, Jill Hall¹, Dorothy McCaughan¹, Peter Mansell³, Maggie Peat¹, Trevor Sheldon¹, Ian Watt¹, Brian Williams² and John Wright⁴.

¹University of York, UK. ²University of Dundee, UK. ³National Patient Safety Agency, UK. ⁴Bradford Teaching Hospitals NHS Trust, UK.

- **Study participants - patients (and their representatives) and members of support and 'consumer' groups**
- **Clinical and other collaborators**
- **Ms Sandi Newby for project support**

This research is funded by the Department of Health, Patient Safety Research Programme, UK. The views and opinions expressed in this work do not necessarily reflect those of the funding body.

- 850,000 adverse events each year in the NHS (NPSA)
- Reduction strategies focused on systems and professionals
- Growing interest in involving patients in safety initiatives

Five Steps to Safer Health Care



1

Ask questions if you have doubts or concerns.

Ask questions and make sure you understand the answers. Choose a doctor you feel comfortable talking to. Take a relative or friend with you to help you ask questions and understand the answers.



2

Keep and bring a list of ALL the medicines you take.

Give your doctor and pharmacist a list of all the medicines that you take, including non-prescription medicines. Tell them about any drug allergies you have. Ask about side effects and what to avoid while taking the medicine. Read the label when you get your medicine, including all warnings. Make sure your medicine is what the doctor ordered and know how to use it. Ask the pharmacist about your medicine if it looks different than you expected.



3

Get the results of any test or procedure.

Ask when and how you will get the results of tests or procedures. Don't assume the results are fine if you do not get them when expected, be it in person, by phone, or by mail. Call your doctor and ask for your results. Ask what the results mean for your care.



4

Talk to your doctor about which hospital is best for your health needs.

Ask your doctor about which hospital has the best care and results for your condition if you have more than one hospital to choose from. Be sure you understand the instructions you get about follow-up care when you leave the hospital.



5

Make sure you understand what will happen if you need surgery.

Make sure you, your doctor, and your surgeon all agree on exactly what will be done during the operation. Ask your doctor, "Who will manage my care when I am in the hospital?" Ask your surgeon: "Exactly what will you be doing? About how long will it take? What will happen after the surgery? How can I expect to feel during recovery?" Tell the surgeon, anesthesiologist, and nurses about any allergies, bad reaction to anesthesia, and any medications you are taking.



U.S. Department of Health and Human Services in partnership with



American Hospital Association



American Medical Association

PHS 50-49902-9-001018

6 *Ways to a safer hospital stay*

- 1. Ask questions**
- 2. Involve your loved ones**
- 3. Know your medicines and supplements**
- 4. Remind visitors to wash their hands**
- 5. Understand your treatment or surgery**
- 6. Know what to do after you are discharged**

W
Washington State Hospital Association
wsa.org

LET'S WORK TOGETHER FOR SAFETY

WSMA
Washington State Medical Association
wsma.org



Agency for Healthcare Research and Quality • 2101 East Jefferson Street • Rockville, MD 20852



AHRQ is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, address patient safety and medical errors, and broaden access to essential services. AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes, quality, and cost, use, and access. The information helps health care decisionmakers—patients and clinicians, health system leaders, and policymakers—make more informed decisions and improve the quality of health care services.



U.S. Department of Health and Human Services
Public Health Service

Medical errors are one of the Nation's leading causes of death and injury. A recent report by the Institute of Medicine estimates that as many as 44,000 to 98,000 people die in U.S. hospitals each year as the result of medical errors. This means that more people die from medical errors than from motor vehicle accidents, breast cancer, or AIDS.

Government agencies, purchasers of group health care, and health care providers are working together to make the U.S. health care system safer for patients and the public. This fact sheet tells what you can do.

What are Medical Errors?

Medical errors happen when something that was planned as a part of medical care doesn't work out, or when the wrong plan was used in the first place. Medical errors can occur anywhere in the health care system: in hospitals, clinics, outpatient surgery centers, doctors' offices, nursing homes, pharmacies, and patients' homes. Errors can involve medicines, surgery, diagnosis, equipment, or lab reports. They can happen during even the most routine tasks, such as when a hospital patient

on a salt-free diet is given a high-salt meal.

Most errors result from problems created by today's complex health care system. But errors also happen when doctors and their patients have problems communicating. For example, a recent study supported by the Agency for Healthcare Research and Quality found that doctors often do not do enough to help their patients make informed decisions. Uninvolved and uninformed patients are less likely to accept the doctor's choice of treatment and less likely to do what they need to do to make the treatment work.

What Can You Do? Be Involved in Your Health Care

The single most important way you can help to prevent errors is to be an active member of your health care team. That means taking part in every decision about your health care.

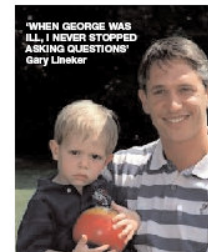
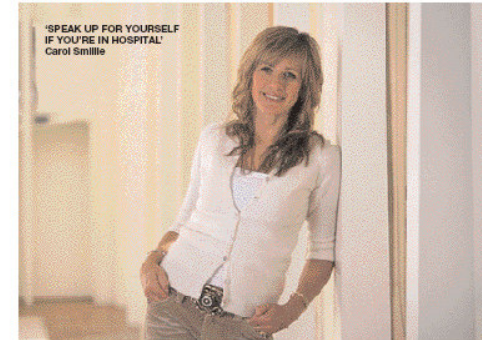
Research shows that patients who are more involved with their care tend to get better results.

Here are some specific tips, based on the latest scientific evidence about what works best:

Please ask

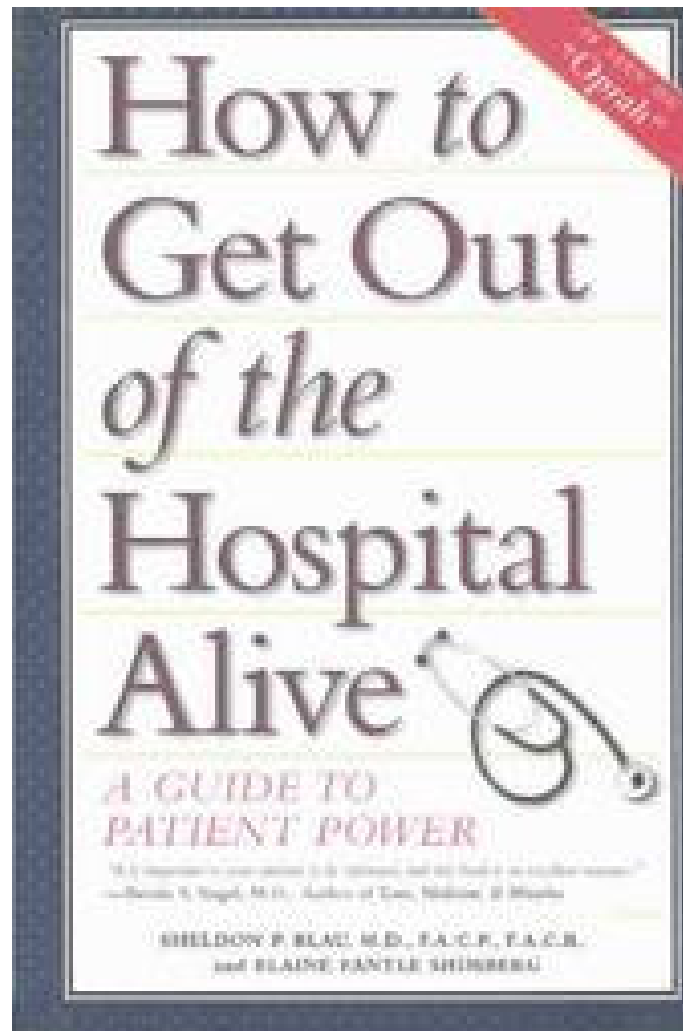
TOP TEN TIPS FOR SAFER PATIENTS

- Find out all you can about your condition or treatment. Ask questions and look for other sources of information, such as on the internet or at the library.
- Ask the doctor or nurse to explain all the treatment options that are open to you, including any potential risks.
- If you're not quite sure what a doctor or nurse is saying, ask them to repeat it. Staff are always happy to explain medical terms in everyday language.
- If you're allergic to anything – or have reacted to a medicine or anaesthetic in the past – make sure your doctors, nurses and pharmacist know about it.



- Always read the instructions. Medication comes with a leaflet that explains how to take it and possible side-effects to watch out for. If it's not clear, ask your pharmacist, doctor or nurse.
- If you or your child are going to have an operation, check all the details on the consent form are correct before you sign it.
- When a family member or friend is in hospital and has trouble speaking for themselves you can ask questions for them.
- It's very important to make sure that the staff have the correct information about you. There could be other patients with similar names to yours, so you may be asked to confirm your name a number of times.
- If you're pregnant, or think you might be, make sure you tell the doctor or nurse before you have any treatment or X-rays.
- It's OK for you to ask doctors and nurses if they've cleaned their hands before they treat you.

▶ The National Patient Safety Agency (NPSA) helps the NHS learn from its mistakes so that it can improve patient safety. It does this by collecting reports on errors and other things that go wrong in healthcare so that it can recognise national trends and introduce practical ways of preventing problems. The NPSA doesn't investigate individual cases or complaints, but it does listen to public concerns and use what you say to improve safety – so your story could help to prevent the same thing from happening to other people. Visit www.npsa.nhs.uk/pleaseask to find out how you can help the NPSA to make the NHS a safer place for patients. You can also find out about other organisations that can help if you want to make a complaint about your specific case.



To investigate how patients (and their family members and other representatives) might appropriately be involved in their health care to effectively promote their own safety

1. Focused set of literature reviews
2. **Primary research to generate new knowledge about patients' views and experiences of their role in safety**
3. Development and piloting of potential patient involvement strategy

Two Reviews

- a. **Systematic review** of the research evidence on the effectiveness of interventions used with the explicit intention of promoting patients' involvement in their care to enhance safety.

- b. **Scoping review** to identify the various roles/mechanisms by which patients might act to enhance their safety AND to examine the circumstances in which patients are able/willing to adopt these roles.

Systematic Review Findings:

- 14 studies, 1 review
- Evidence for the effectiveness of interventions designed to promote patient involvement in patient safety is limited and generally of poor quality.
- Existing evidence is confined to the promotion of safe self-management of medication, most notably relating to self-management of oral anticoagulants.
- Future research should focus on areas other than medication safety. In particular, interventions in most urgent need of evaluation are those that are currently widely used but unevaluated.

Scoping review findings:

- 745 reports of interventions, commentaries and explorations of patients' willingness and ability to adopt actions that might enhance their own or others' safety.
- Patients have largely not been involved in the development of interventions.
- We know very little about patients' willingness and ability to adopt recommended patient safety promoting behaviours.
- Little exploration of negative effects of patient involvement.

- What concerns do patients have about safety?
- When and how do patients act (or consider acting) to promote or ensure their safety?
- How do patients feel about taking on recommended safety roles?

Who took part in the study ?

- People from 6 different groups to ensure inclusion of a wide range of perspectives
 - adults with type 2 diabetes
 - women treated for breast cancer
 - parents of children hospitalised with asthma
 - people scheduled for joint replacement surgery
 - people who had raised a safety related issue with the Patient Advice and Liaison Service (PALs)
 - people with severe and enduring mental health problems

- Focus groups included people who belonged to 'consumer' and support groups

- Qualitative exploratory approach
 - Individual in-depth interviews (N=71)
 - Focus groups (N=12; 68 participants)
- Transcripts analysed using 'Framework'¹
- Team approach to analysis and interpretation
- Presented a summary of preliminary findings at a meeting for study participants
- 1. Ritchie, J. & Lewis, J. (2003) *Qualitative Research Practice*. London: Sage

THEMATIC FRAMEWORK USED IN ANALYSIS OF THE QUALITATIVE DATA

- G ID
- E Clinical Group
- N Age
- E Gender
- R Ethnicity
- A Occupation
- L Characterisation
- Roles
- A Barriers and Facilitators
- W Expectations/ reflections
- A General safety awareness
- R General attribution
- E Staff reaction
- N Reporting self
- E Reporting NHS
- S NHS Learning
- S Knowledge and Information

- S ID
- P Location
- E What was undesirable?
- C Why was it undesirable?
- I What action?
- F Alignment with/ against?
- I Factors affecting action?
- C Concern affirmation?
- E Response to action?
- V Response to response?
- E Factors affecting response?
- N Evaluation of?
- T Ceased or continued?

128 'index' concerns identified – situations or events mentioned at the start of problem narratives

- Deteriorations in condition that were missed or not taken seriously by HCPs
- Missed diagnosis and delays in referral and treatment
- Errors in prescribing, dispensing and administering medicines
- Errors in screening and treatment procedures
- Omissions or mistakes in communication
- Shortfalls in hospital accommodation and cleanliness
- Exposure to threats from other patients
- Deficiencies in in-patient nursing

Concerns about nursing care

Deficiencies in in-patient nursing were associated with:
preventable dehydration; lack of assistance with eating
and walking; monitoring of pain; emotional distress

'I was on a drip but for over 2 hours nobody noticed that the drip wasn't running right. I kept saying, 'I am in a lot of pain'. I was going mad with pain...eventually I got a nurse, I said, 'Will you get someone to check this for me? There's something wrong here.' My own anaesthetist, as soon as he had finished in theatre, he came down and put it right. And apparently it hadn't been dripping. Everything had been blocked up and nobody had noticed. He put me a fresh cannula in, started again. He was great, just took over, started over again and said 'I am so sorry about this'

Woman in her late 70's, following joint
replacement surgery

TOP TEN TIPS FOR SAFER PATIENTS

National Patient Safety Agency

- Find out all you can about your condition or treatment.
- Ask the doctor or nurse to explain all the treatment options that are open to you.
- If you're not quite sure what a doctor or nurse is saying, ask them to repeat it.
- **If you're allergic to anything, make sure your doctors, nurses and pharmacist know about it.**
- Always read the instructions. Medication comes with a leaflet that explains how to take it and possible side effects to watch out for. If it's not clear, ask.
- If you or your child are going to have an operation, check all the details on the consent form are correct before you sign it.
- **When a family member or friend is in hospital and has trouble speaking for themselves, you can ask questions for them.**
- It's very important to make sure that the staff have the correct information about you.
- If you're pregnant, or think you might be, make sure you tell the doctor or nurse before you have any treatment or X-rays.
- **It's OK for you to ask the doctors and nurses if they've cleaned their hands before they treat you.**

Ask a family member or friend to accompany you
when you go to the doctor or hospital

'I didn't want my mum and daughter in floods of tears...I wanted to manage it myself...it was mine, my illness, my way of dealing with it...maybe some family members thought I was being a bit selfish...'

'What it boils down to, it's a very personal thing.'

'I must be dead selfish then! I just thought everybody should come! Anybody, the whole family, I'll let them deal with their own emotions!'

Focus group 2: women
treated for breast cancer

Patients' experiences of 'speaking up'

SpeakUP™

To prevent health care errors, patients are urged to...

Everyone has a role in making health care safe. That includes doctors, health care executives, nurses and many health care technicians. Health care organizations all across the country are working to make health care safe. As a patient, you can make your care safer by being an active, involved and informed member of your health care team.

An Institute of Medicine report says that medical mistakes are a serious problem in the health care system. The IOM says that public awareness of the problem is an important step in making things better.

The "Speak Up™" program is sponsored by The Joint Commission. They agree that patients should be involved in their own health care. These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services.

This program gives simple advice on how you can help make health care a good experience. Research shows that patients who take part in decisions about their own health care are more likely to get better faster. To help prevent health care mistakes, patients are urged to "Speak Up."

Help Prevent Errors in Your Care

SpeakUP™

The Joint Commission is the largest health care accrediting body in the United States that promotes quality and safety.

Helping health care organizations help patients

Speaking up considered difficult BUT people were prepared to, depending on their judgements about:

- the seriousness of the situation
- their own ability to assess the problem
- roles and responsibilities
- possible consequences of speaking up

'they came to give me an insulin injection, which was a complete mistaken identify. And had I been feeble or semi-conscious, I don't know what would have happened. So I was compos mentis to say, 'On your bike! You're not going to give me an insulin injection!' I don't know whether it was a doctor or a nurse and he said, 'Oh, I've come to give you an insulin injection' and I said, 'No, I don't think you have.' And so he just went and a nurse later on apologised and said she'd got mixed up and there was another [person with the same name] in one of the other wards' [patient bays]

Individual interview, patient
undergoing joint surgery

NHS
National Patient
Safety Agency

**CLEAN
HANDS?
IT'S
OK TO ASK**

AS OUR PATIENT YOU SHOULD EXPECT TO
SEE US CLEAN OUR HANDS BEFORE AND
AFTER WE TOUCH YOU, BUT IF YOU THINK
WE'VE FORGOTTEN, **IT'S OK TO ASK.**

onepartnership
for more hygiene

NHS
NHS Supply Chain

B. BRAUN
ADVANCED SCIENTIFIC

NICOLAS

gojo

cleanyourhands[®]
campaign

'I made such a hash of it'

'I tried to [challenge the HCP] when somebody didn't use the hand gel when they came to change my drip, but I made such a hash of trying to say 'It says on that notice that I can challenge you', and he misunderstood and brought me some hand gel, he still went ahead and did me, and I thought I'm not going to ask again. I tried and got it all wrong. I obviously didn't express it in a way he understood... and saying what it says on the poster... it's OK to challenge if you think they haven't used it...no, I'm telling you, you should be using it'.

I could see he hadn't used any...he was rushing here, there and everywhere...but I blurted it out in a way he didn't understand, and I felt too embarrassed to say, 'No, that's not what I meant'

Individual interview, patient having treatment for breast cancer. This woman was particularly concerned about the risk of infection.

'if you complain, you are a difficult patient'

'My husband's in hospital...I noticed that the nurses are not washing their hands...and his drip is empty and it was drawing blood out of his arm. But I thought, well if you make a complaint, it is worse for the patient. So I just went politely along, I didn't say anything about they weren't washing their hands, but I did say they could do something about his drip.'

'It's not easy. I think if you complain, your number's marked and you are a difficult patient'

Focus group: People with severe and enduring mental health problems, discussing how easy or difficult it would be to challenge staff if something seems wrong

- Sometimes staff listened and acted promptly to correct problems or provide reassurance.
- Sometimes staff did not listen, were dismissive, did not address concerns or reassure.
- Patients often tried to raise concerns again, frequently in a more confrontational manner.
- Or, they gave up trying...

'I had an incident where they were doing some chemo treatment, I had so many sessions, I think 12 and there was something they were doing, flushing something through and I couldn't remember them doing this bag at all, and I sat there thinking, 'I can't remember this, is this right?', so I queried it, and to be fair, the chemo nurse, she was really good in this instance, she went off, she looked at the paper work, she got another nurse to come as well, they went through it and I wasn't made to feel as if I was challenging them as such. I was reasonably reassured about it. That was a good, more positive experience. But there's other incidences depending on the person where it has turned into like a confrontation and I've not intended it to be. It's just simply that they're not used to people speaking up and asking a simple question even.'

Individual interview, woman having treatment for breast cancer

'the look I got from her'

'I said, 'That cream you are going to put on, she reacts to.' And she [health care professional] said to me, 'How do you know?' [daughter] couldn't breathe, she was laid on the bed not able to breathe, she had oxygen on, and this young girl said to me 'How do you know?' I said to her. 'She's been coming here for 6 years and the cream irritates her and she's also allergic to plasters.'

But she was going to put a plaster on, and the look I got from her...I didn't say anything because [daughter] was really ill, so I didn't say anything but you want to scream at some of them and say, 'Why can't you understand what I am telling you?'

If I did speak up sometimes I'd probably get thrown out...but then you've got to speak up because if they've made a mistake and you can prevent it, you know...'

(Individual interview, parent of child hospitalised with asthma)

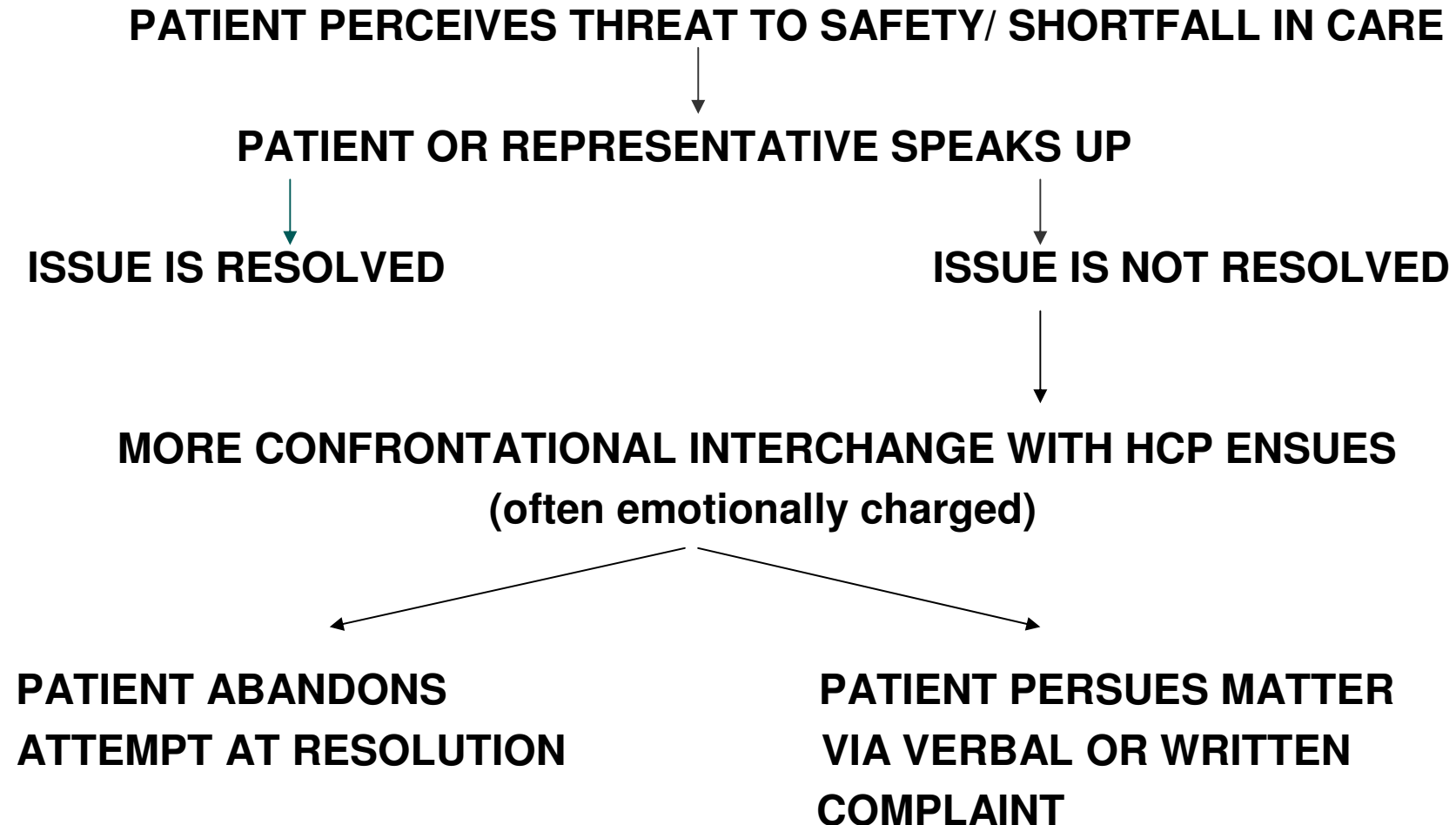
'it was a nuisance to them'

'My psychiatrist said I had particularly to have some medication at 8am, but it was given at 10am, because the take over [handover] was between 8am and 9am...so I knocked on the door...they told me to go away, and I was really quite distraught...I was very upset and afterwards they were a bit grumpy...'

And the next day, as soon as I knocked, it was different staff, obviously, I could hear them saying something about me. And they went and got the medication, but it was a nuisance to them. So eventually I did make a complaint to the psychiatrist because I was so angry. And she did take it very seriously and this particular nurse was reprimanded...when I came in [to the ward] in the future she would sort of blank me and I sort of felt alienated by the others...so you feel awkward, so you think, 'I am just going to stick to the 10 o'clock because they can't be bothered and I can't take the rejection.' So I just left it. I didn't bother any more, despite what the psychiatrist said.'

(Individual interview, woman with severe and enduring mental health problems)

Model of 'cascade' of events



Patients were more likely to speak up if staff were:

- Approachable
- Invited them to ask questions
- Gave them 'permission' to raise concerns
- Responded in a consistently positive manner

Patients' perceptions of a positive response/ relationship with HCPs

'I mean, we have quite a good relationship so I feel comfortable to say something, if something is wrong, I would say it and they know I would, because they always say to me, especially the doctors... 'Do you feel this?' or 'Do want to say anything?' and they know I would feel comfortable speaking to them'

Parent of child with asthma talking about her relationship with staff on a paediatric ward

'I found here that speaking up is actually quite easy, because the staff were so approachable and positive and it wasn't a case of complaining - more a question of bringing things to their attention that I thought they should know. But again, where we lived before I couldn't have done it because attitudes were so different.'

Focus group participant, people with severe and enduring mental health problems

- Patients' willingness and ability to contribute to their own safety is closely linked to the attitudes and behaviour of HCPs
- For patients to 'speak up', staff need to 'listen up'
- HCPs need to be supported by health care systems to enable them to develop responsive relationships with patients



- Ethnographic studies focussing on patient-HCP behaviour and contextual factors
- Views of health care professionals about patient involvement in patient safety
- Further research about how patients might be involved in safety initiatives in general practice

Final report:

http://www.haps.bham.ac.uk/publichealth/psrp/PS034_Project_Summary.shtml

Systematic review:

Qual Saf Health Care. 2010 Apr 27. [Epub ahead of print]. Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review. Hall J, Peat M, Birks Y, Golder S; on behalf of the PIPS Group.

<http://qshc.bmj.com/content/early/2010/04/27/qshc.2009.032748.long>

Scoping review:

J Health Serv Res Policy. 2010 Jan;15 Suppl 1:17-25. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. Peat M, Entwistle V, Hall J, Birks Y, Golder S; PIPS Group.

Manuscript submitted to Quality and Safety in Health Care:

Entwistle VA, McCaughan D, Watt IS, Birks, Y, Hall J, Peat M, Williams B, Wright J and the PIPS group.

‘Speaking up about safety concerns: a qualitative study of patients’ views and experiences.’

Phase 3: Using patient stories to enhance safety

BACKGROUND

- Health care professional response and attitude to patient involvement
- Personal experience is recognised as a powerful educational tool
- Few studies of patient involvement in health professional learning
- Students displayed an improved ability to communicate and empathise with patients (Klein 1999, Wood 1999)

OBJECTIVE

To assess the feasibility, acceptability and perceived usefulness of an educational intervention to involve patients in their own safety promotion by feeding back, to a staff group, their own safety experiences.

DESIGN

Exploratory study.

INTERVENTION

- Face-to-face feedback
- DVD
- Combination of face-to-face and DVD

SETTING

- Primary and secondary care, 3 participating centres

PARTICIPANTS

- Patients – purposively selected from phase 2 and were willing to be involved.
- Staff – primarily members of relevant clinical governance groups (CGG).

Story themes

3 patients and 2 patient representatives fed back their stories, 4 face-to-face and 1 DVD

- Healthcare staff response after things go wrong
- How healthcare staff send mixed messages to patients through their words and behaviour
- How failure of staff on an acute mental health ward to take a patient's concern seriously led to loss of trust and violence
- The experience of a poorly executed discharge for the daughter of a sometimes muddled elderly patient
- The importance of planning healthcare interventions for patients with challenging behaviour

- The experience was, for the majority, a positive one.
- Failure of staff to engage often appeared to be related to other work pressures.
- Most themes familiar to staff.
- Stories stimulated discussion and reflection for both staff and patients.
- Provided neutral forum for open discussion (as opposed to complaints procedure).

However,

- Resource intensive and time consuming.
- Difficulty in finding appropriate staff group in primary care.
- Worthy of future research and formal evaluation.

- Patient involvement in safety is potentially acceptable and beneficial
- The potential is likely to be mediated by a number of factors including patient, health professional, and system characteristics
- The attitudes and behaviour of health care professionals are pivotal in facilitating patients to adopt safety roles
- Health care professionals need to be supported by wider health care systems