Patient involvement in patient safety education: 
Background, practical considerations and recommendations

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"...He who studies medicine without books sails an uncharted sea, but he who
studies medicine without patients does not go to sea at all..." 
Sir William Osler (1849-1919)
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Executive summary

Greater patient involvement in the development and delivery of health care services is widely promoted in many modern care systems. In the UK it is now a statutory obligation to actively involve service users in all aspects of health care, including: personal care; planning, development, delivery and evaluation of services; clinical and health services research; and education and training of health care professionals. Patients have always been involved in the training of health care workers, but traditionally in passive roles as ‘interesting learning material’. However, professional leaders, educators, patient interest groups and the public have called for patients to adopt a more participative and active role in all aspects of health care education and training.

Evidence of this type of active patient involvement is apparent in various national and international programmes delivering health care education. Research suggests that this can benefit patients, health care workers (students) and traditional educators. However, there are a number of significant barriers and challenges to overcome if this level of involvement is to be normalised and sustained. Available research remains limited but found that levels of patient involvement occurs on a spectrum, with multiple factors determining its effectiveness. Ethical considerations, engaging minority and vulnerable patient groups and recruiting ‘real’ or ‘simulated’ patients are particularly important issues to educators and health care organisations.

In the relatively new field of patient safety education there is currently no evidence for the most appropriate, feasible and acceptable approaches to implement patient involvement. However, given perceived benefits and desirability, a number of recommendations can be made:

- A co-ordinated and rigorous research agenda should inform future design, delivery and evaluation of patient safety education.
- Experiences from current NES programmes with patient involvement should be captured and transferred to patient safety education.
- Staff will need clear guidance, support and additional specific educational resources that raise awareness of and equip them with the necessary knowledge, skills and attitudes to appropriately involve patients in teaching.
- Senior organisational commitment and support is essential. For patients to be involved in a non-tokenistic way, authentic partnership working at an institutional level should be promoted and prioritized.
Introduction

The Scottish Government has demonstrated its commitment to place patients at the heart of all NHS activities through recent legislation. However, the degree and type of patient involvement (PI) in NHS Education for Scotland (NES) postgraduate training, continuing professional development and life-long learning is currently not known. There is also limited evidence of the most effective methods, tools, techniques and models for involving patients in education and training of the healthcare workforce and particularly around education focussed on making healthcare safer. This report was commissioned by the NES Multi-disciplinary Patient Safety Group (MDPSG) as a high-level scoping exercise to help guide future strategic planning regarding active patient involvement in patient safety education.

Aims of report

The specific aims of the report are:

- To provide a contextual background of patient involvement in general and specifically in health care education (Section 1)
- To summarize the available research and experience of active patient involvement in health care education (Section 2).
- To consider the potential implications for patient safety education with recommendations for increasing active patient involvement (Section 3).
Section 1: Contextual background

The rationale for increasing patient involvement

There is now a general consensus in most modern health care systems that patients should be actively involved in all aspects of health. This dramatic change from a health professional-centred to a patient-centred culture occurred in the relatively short period of a generation. There are numerous reasons for this change, including new trends in healthcare and demographics, government policies and changing patient expectations. These factors are briefly discussed below to provide a contextual background and rationale for the need specifically for greater patient involvement in training and patient safety education in particular.

**Health care factors**

Clinical care is increasingly being delivered in the community, with shorter hospital stays. The majority of hospitalized patients tend to be very ill, frail and vulnerable. Care pathways reduce opportunities for junior doctors to practice history taking and ‘clerking’ of patients. Continuity of care decreasing – impact on learning and also on patient-doctor relationships. The European working time directive led to implementation of shorter working hours, shift systems and increased handovers. High-profile patient safety incidents have been drivers behind increased scrutiny of health care workers. New methods such as revalidation are being developed for this purpose. The proliferation of computer technology continues to influence traditional roles, for example doctors becoming ‘interpreters’ rather than sources of information. Finally, patient-centred care is now widely accepted as the basis of good practice.

**Demographic factors**

The UK has an ageing population with increasingly complex care needs, cutting across professional boundaries. The social contexts of disease are also changing, with increasing diversity of social, ethnic populations and disease patterns. Health inequalities persist stubbornly in many areas and may have widened by some measures.
**Government policies**

Various national government policies have promoted greater patient and carer involvement in all aspects of UK healthcare. In Scotland, the Scottish Executive Health Department (SEHD) defined a *patient-focused* NHS more than a decade ago. Their 2001 publication ‘Patient Focus and Public involvement’ was a proposed framework for prioritizing patient and carer involvement in designing, delivery and evaluation of all NHS services. The aim is that ‘…modern health care service must do things *with* the people it serves…’

In 2003 it became a *statutory requirement* for all NHS boards to develop a local strategy for patient and public involvement. Boards were to ‘listen to and respond’ to patients and take them on as full and equal partners. Since 2005 NHS boards have to give account of how they involve the public and patients in planning and delivery of services. The Scottish Government reinforced their commitment to place patients at the ‘very heart’ of the NHS by introducing the *Patient Rights (Scotland) Bill* in March 2010. The Bill outlines 16 Healthcare Principles, nine of which directly relate to patient focus and participation.

**Changing patient expectations**

Patients are increasingly aware of their rights, responsibilities and are assuming ‘new’ roles. This may be as a natural response to dissatisfaction with care quality, a growing consumerist mentality and increased access to information. Some exercise these rights through increased assertiveness not to be ‘teaching material’. Others would like to be actively involved in their own overall care design and delivery, starting with the planning process through to self-management.

These (and other) developing trends in healthcare provide a contextual background and rationale to understand the need for greater patient involvement in education and training. Postgraduate training and education has to be aware of and respond to all these factors. A receptive and supportive approach will be required to meet this challenge in a way that benefits all parties. Health care and health care professionals will have to adapt, change and consider the appropriate and required skills-mix, knowledge and attitudes. In this regard, education and training will be essential.
Specifically, postgraduate education and training will need to increase trainees’ understanding of growing linkages across health and social care.

This report is one of several high-level reviews that were commissioned in recognition of these requirements. Its main aims are therefore to identify the current state of patient involvement in education and training, the principles underlying patient involvement, to identify knowledge gaps and to make recommendations for potential future strategic development of patient safety specific educational resources.

Patient involvement in education and training

Patients have ‘always’ been involved in medical education. Traditionally, their role was passive, as interesting ‘teaching fodder’. In this role the sum of their teaching value was the presence of clinical signs of medical conditions and to lesser degree disease specific symptoms. Then, during the 1960s, some patients started to acquire additional roles as educators. One of the first published pilots involved patients teaching intimate physical examinations to medical undergraduate students. Over the next decades these functions were expanded to a number of other clinical areas and health care professions and some patients also acquired further responsibilities. Patients came to be viewed as experts in their own illness and it was recognized that their knowledge is often under-utilised.

In response, the British Medical Association (BMA), the Postgraduate Medical Education Training Board (PMETB) and other stakeholders have recently called for patient-centred learning and increased involvement of patients with more active roles in all aspects of education and teaching. An essential requirement for this is thought to be partnerships based on mutual trust and respect at the heart of the relationship between patients and health care providers.

‘...patients and service users should be much more involved in the teaching, delivery and assessment of postgraduate medical education and training...Patients should be involved at all stages of training to explain and portray the patient journey...every patient should be considered a teacher as well as a patient...’

PMETB, 2008
NHS Education for Scotland (NES) is a special health board concerned with the educational needs and training of all health care professionals in Scotland. This presents a strategic challenge if the assumed responsibility is to give account of ‘direct’ patient involvement. However, the vast majority of NES activities, resources and products will have an indirect effect on patient experiences and outcomes. It could be argued that patient feedback, involvement and experiences may usefully be incorporated with that of health care workers in planning, designing and delivering strategic objectives.

In patient safety, improvement efforts have mostly focused on increasing involvement of individuals in their own care, so that they act as ‘safety buffers’. There is virtually no research or evidence of patient involvement in this specific topic. It was therefore necessary to consider the generic principles and lessons from patient involvement in education and training in general and makes inferences about how they may best be applied to ‘patient safety’ content.

**Defining ‘patients’ and ‘patient involvement’**

The language of patient involvement can be confusing at times. There are a large number of similar or related terms that are ill-defined, are used interchangeably and inconsistent and often describe widely disparate groups of people and activities. In this report the terms ‘patients’ and ‘patient involvement’ will be used preferentially and are defined below.

**Patients**

‘Patients’ are defined as ‘...all people with health problems, their carers and families...’ Anyone described by the following, alternative terms are also included in this definition: ‘service users’, ‘health care consumers’, ‘clients’ and ‘survivors’. Other terms, such as ‘lay people’, ‘community members’ and ‘well women’, were not considered specific enough to be included routinely in the definition.

In the specific context of education and training, ‘patients’ are defined to include anyone described by the following terms: ‘educator’, ‘teacher’, ‘instructor’, ‘mentor’, ‘partner’, ‘teaching associate’, ‘patient instructor’, ‘expert patient-trainer’ (EPT), and
‘standardised patient’ (a patient that has received training and is expected to teach specific content in a specific manner). A key requirement to be included in the definition of a ‘patient as teacher’ is relevant experience and expertise in specific areas of health, illness or disability. This definition excludes simulated patients who role-play and express symptoms or conditions that they do not actually have.

**Patient involvement (participation)**

‘Patient involvement’ can be described as ‘...involving patients and their representatives in their own care and that of others in similar circumstances to them, in the planning, development, monitoring, delivery and all other aspects of health care...’ In the context of education and training, ‘active patient involvement’ means involving patients in the teaching and assessment of undergraduate and postgraduate health care professionals and also in curriculum design and development. The level and extent of patient involvement in education and training is variable and will be discussed in more detail in the relevant section.
Section 2: Active involvement of patients in education

Current practice

Examples of educational initiatives that actively involved patients as teachers can be found in many modern health care systems, including New Zealand, Canada, the USA and the UK. The majority of programmes and examples are from undergraduate programmes and the vast majority involve medical students or doctors. The first pilot studies date back to the early 1960s. The vast majority of ‘active’ involvement examples are with patients in educational or assessment roles. A selection of practical examples of patient involvement initiatives are summarized in Appendix 1.

Patients have taught a range of clinical and non-clinical skills to health care workers. Examples of taught examination skills include: general physical, musculoskeletal, pelvic and genitoresctal and childhood developmental assessment. Patients can also teach diagnostic skills (examples include cardiovascular and pulmonary pathology) and a holistic understanding of health (examples include dementia and cancer). Patients have also taught generic communication, counselling and specific communication skills such as breaking bad news and promoting healthy lifestyles.

Patients are included as part of some examinations, for example in OSCEs. In New Zealand and the USA they have more active roles as co-assessors of clinical examination and communication skills of undergraduate health care workers. Communication skills assessment by patients is a requirement for membership of the Royal New Zealand College of General Practitioners.

Specific methods to increase awareness of the patient perspective include: reflective practice, mentoring, learning in the community, training in equality and diversity. At postgraduate level competence is acquired through supervised and graduated experience, working directly with NHS patients. Patients are also involved directly or indirectly in CPD (continuing professional development) and NHS appraisal through methods such as multi-source feedback (MSF) and patient satisfaction surveys. Patient involvement is currently being integrated into remedial training support (under development).
Potential benefits

‘...The joy from medicine and helping others frequently comes from what our patients teach us...’

Herbert Y. Reynolds, 2007

Various potential benefits have been described for patients (teachers), health care workers (students) and traditional educators and their institutions.

Benefits to patients

The vast majority of patients actively participating in education perceived the experience as positive, empowering and as an acknowledgement of their expertise. They reported enjoying the experience, valued learning new skills, gained confidence, improved self-esteem, increased insight and understanding of their conditions and management and better understanding of health care workers. Some patients received financial remuneration, ranging from paid expenses to an hourly rate. Patients also reported benefitting from meeting other patients with similar conditions, a ‘cathartic’ feeling of sharing their experiences (especially of adverse incidents) and applying their conditions in a positive manner. A number of patients were able to expand their roles, for example HIV ‘expert patient-trainers’ who became lay counsellors in third world settings. Patients also reported feeling grateful for an opportunity to contribute to and help patients in future.

Benefits to health care professionals (learners)

The vast majority of health care workers reported enjoying participating in educational activities that actively involves patients. They recognized that their learning needs arise from human interactions and perceived patient involvement as relevant and meaningful. ‘Real’ patients help to address learning needs by providing contextual, relevant and focused learning experiences, opportunities for active engagement and greater complexity and challenges compared to standardized patients. This implies using ‘...his or her own life experiences to fill in emotional details...’ PI also provides opportunities for direct, targeted feedback given in a non-threatening environment.
Patient involvement in education is thought to have a number of important cognitive and affective benefits for health workers. Opportunities for ‘role modelling’ may contribute to development of a student’s professional identity and ‘illness scripts’ (cognitive structures with features of real or prototypical patients combined with clinical information). Active PI can directly and indirectly lead to the acquisition and improvement of valuable new skills and increased confidence in skills application. Various skills are integrated and clinical reasoning becomes more effective. Patient involvement may also help to develop patient-centred attitudes, lead to provision of care in patient partnerships and help students gain new insights and understanding of patients’ perceptions. Further benefits may include increased retention of learning, motivation and job satisfaction.

**Benefits to educators**

Active patient involvement in education is thought to have a number of important benefits for educators and their institutions. Patients can be resource-sparing, delivering parts of an agreed curriculum for a smaller financial outlay. Educators are provided with opportunities to observe and evaluate students and the course, allowing them to adjust the didactic components. Finally, increased patient expertise may be harnessed in teaching other patients.

**Barriers and challenges**

Active patient involvement as an educational tool has a number of recognized limitations and is not suitable for covering all aspects of learning. Learning can be unstructured, ‘ad hoc’ in nature and of variable quality. Selecting specific patients may also leave the impression of a ‘typical case’ and not reflect the wide variation observed in practice. While descriptions of patients’ experiences in their own words can be cathartic and are ‘more evocative and powerful’ than any reinterpretation, repeatedly using the same patient and narrative reduce the impact of their message. Repeating the same narrative may also have a negative impact on patients’ psychological and emotional well-being.
A number of important barriers must be overcome before the benefits of active PI can be realised. There has been a relative decline in the availability of appropriate patients, ‘expert patient-teachers’ are in very short supply and retention can be problematic. At present this type of learning is still often poorly supervised and often superseded by the pressure of service delivery as first priority. When patients are incorporated into organisations they take on the attitudes and values of the healthcare team, thereby losing their initial objectivity and independence (main value), a process called ‘norming’ (professionalizing).

Developing and assuring active patient involvement in ‘all’ aspects of education will require substantial resources, time and expertise. Educators have to attempt to balance these and other potential differences between patients’ agendas and patient care while still enabling students to acquire the necessary professional skills and realise the potential benefits of active patient involvement.

**Determinants of effective PI**

There are many factors that influence whether patients should or choose to be involved in safety improvement or education, and the extent of their involvement. The factors that influence recruitment and selection can be grouped into at least five categories:

- **Patient factors**: socio-economic status, ethnic and cultural background, age and gender, confidence, previous exposure and experience in education-related fields
- **Factors relating to the patient’s condition or illness**: the type, extent and prognosis of the clinical condition and the presence and severity of signs and symptoms
- **Healthcare professionals**: attitudes to, previous experience of and willingness to participate
- **The healthcare setting**: primary or secondary care, geographical distribution
- **Required educational tasks**: Frequency and duration of teaching sessions, teaching methods, degree of required knowledge, expectations, degree of latitude in relation to the curriculum.
Given the sensitive nature of patients’ clinical conditions and their specific personal and contextual conditions, it is unlikely that a ‘one size fits all’ approach is feasible for recruitment. Not all patients are suitable for involvement while some may choose not to be involved. Recruitment and selection have to be selective. Particular consideration should be given to patients’ professional and physical background and whether they are representative (ethnic, culture, condition). However, learning may be enhanced by recruiting patients who challenge stereotypes of a condition – for example, a man with breast cancer, a young athlete that had suffered a stroke.

Patients may be recruited from many sources, including: members of the general public, people with local knowledge or expertise (community interest groups, organisations representing others), people with direct experiences of services (users, carers) and through advertising (posters, newspapers). Recruitment may be purposive, for example from paramedics, degree students, nursing staff, qualified educators or existing training bodies.

For patients and students to benefit, it is important that patients are provided with support, required and adequate training and that they receive appropriate remuneration (in selected cases). Patient-teachers are more effective if they had received training, are formally integrated into the curriculum and their teaching linked to clear learning objectives. Traditionally, training provision has varied widely in duration, style, intensity and assessment (formative, summative). Training methods included individual or group instruction, practice with students, use of audio or video tapes, instruction manuals and home study. Training intensity ranges from none to one programme providing 50 hours of training with additional required home study. Content varied but few programmes providing training for teaching, assessment and effective feedback skills.

**Involvement spectrum**

The extent of patient involvement exists on a continuum from none to full user control. There is often a hierarchy and involvement can occur on different levels, which can be visualised as a ladder. The bottom rung is no involvement, then informing patients, moving to consultation through to participation and collaboration, with the final rung full partnership in planning, designing and delivering of strategic objectives and programmes.
There is great variation in the extent to which patients are involved at each of these levels, ranging from active to passive, individual to organisational and tokenistic to representative numbers. One implication for integrating patient involvement in an educational curriculum or training resource is that they do not necessarily have to participate in every aspect (although this is currently promoted). Depending on local and organisational requirements they may not contribute to design, but have important roles in active delivery. Examples include patients delivering presentations, facilitating seminars, teaching in one-to-one encounters, providing personal tuition, small group demonstrations and in giving feedback. They may also be assessors, can be included in conferences, existing educational or reference groups and involved in production of learning material.

**Ethical considerations, vulnerable and minority patient groups**

A number of patient groups require additional sensitivity and due consideration of ethical issues, recruitment, selection, support and active involvement. Examples of patient groups include the elderly, children, teenagers and patients from ethnic minorities. Potential concerns can be addressed in several ways. In one study actors simulated teenage patients as an initiative to teach communication skills. The training was well received with students valuing the authentic atmosphere, immediate feedback and opportunities to repeat the same scenario trying out different approaches.

Examples of clinical conditions include cancer, gynaecology, sexual health and certain long-term conditions such as HIV. A UK-based study found even patients with terminal cancer in a hospice-setting can be actively involved in teaching. The patients were ‘…strongly positive…’ about the experience and generally felt that health care workers ‘…got to learn…’ In developing countries HIV’s large burden of disease, relatively new interventions and management options implied that active non-specialist participation and training at postgraduate level for all members of the health care team was essential. This was achieved through ethical recruitment, adequate training, support and partnership working with patients.
Quality of the evidence base

There is insufficient or no research in many areas of patient involvement in health care education. The available literature is limited in at least three important ways. First, the majority of studies concerns medical education, and specifically *undergraduate* medical teaching. Second, the vast majority of published studies are descriptive, ‘one-off’ events and pilots with little or no formal evaluation of outcomes or sustainability. In a recent review the Patient Safety Research Programme found ‘high quality’ evidence that increased patient involvement had improved safety outcomes in only one study (self-management of anticoagulation therapy). Thirdly, there is no standardised terminology.

The sustainability of active PI, its long-term impact on health care workers’ behaviour and patient outcomes, how or when reinforcement of training may be necessary and potential transferability to other professions and settings remain unclear. Some researchers have expressed concern over increasing direct patient roles in teaching further. They suggest that efforts would be best concentrated on encouraging appropriate attitudes and communication skills in professionals, rather than on direct involvement of patients. The intention being that these skills would allow the establishment of open patient-professional relationships from which patient involvement will naturally flow.
Section 3: Implications and recommendations for patient safety education

A number of recommendations, potential future strategic options and implications of previous experiences and research (section 2) of active patient involvement in education are described below, with special reference to patient safety.

Ethical considerations

Educators and other relevant staff groups will require additional training and clear guidance on the ethical issues involved in increasing patient involvement in education. Examples of specific considerations include consent, recruitment, selection and patient choice, confidentiality and appropriately addressing concerns of patients. The practical aspects of these considerations should be explored. For example, as consent is time-limited, who will be responsible for reviewing educational materials periodically? What are the ethical issues to consider with different teaching methods? Any audiovisual resources will have to be stored securely, should only be used for stated purposes and only certain individuals would have overall rights to the material.

‘Real’ and ‘simulated’ patients

Manikins have been used successfully to teach technical skills, especially at undergraduate level. However, the method is limited by a lack of realism, feedback and exclusion of interpersonal and communication skills. ‘Real patients’ address these limitations but are not as readily available, training quality can be variable and a number of previously described barriers have to be overcome. Simulated patients are usually actors trained to act out or portray characteristics of real patients and may be a suitable alternative. More recently, the concept of ‘virtual patients’ have been piloted. Virtual patients are electronic renditions of real or simulated patients and are a cost-effective way to deliver training and to facilitate and assess development of clinical reasoning.

Simulated patients have a number of potential benefits, including reducing students’ feelings of inhibition, are readily available, there is no infringement on patient rights and fewer ethical considerations. Simulated patients are highly adaptable, for example
learning objectives, degree of complexity and scenarios can be changed. Training variability is minimized, they can provide real time feedback to students and some studies have reported equivalent short term benefits compared with actual patients. In blinded studies they were found to have a high rate of authenticity, with only 1-15% of simulated patients detected by practicing doctors.

In practice the different options are complimentary. Real Patient Learning (RPL) has been described as the ‘…bridge between simulated learning and independent [unsupervised] practice…’ An undergraduate curriculum could be constructed using the following methods: didactic lectures and manikins, virtual and simulated patients, patient teachers and finally supervised patient care. At a postgraduate level feasibility concerns would guide the choice between real, simulated and virtual patients.

Prioritize and agree a research agenda

Given the potential benefits of, multiple drivers for and initial research findings that active patient involvement is feasible and acceptable, it becomes self-evident that the area is worthy of and should be the focus of a large, co-ordinated and rigorous research agenda. Such an agenda would ideally include more representative studies in postgraduate medical and especially non-medical health care professions. Potential research can be grouped into four main categories: antecedent variables, structure, process and outcomes. Examples of research topics include:

- Understanding the different factors that determine patient involvement, their relative impact, importance and interaction.
- Developing a standardized taxonomy for active patient involvement in education.
- Assessing the importance of and ways to minimize ‘norming’.
- Producing guidelines to ensure appropriate recruitment and inclusion of all patient groups
- Assessing the feasibility, cost-effectiveness and sustainability of active patient involvement
- Evaluating the impact (positive and negative) for students and patients.
- Consideration of the transferability of patient involvement: 1. from under to postgraduate level; 2. from medical to non-medical professional groups and 3. from general education to patient safety specific education
API and educational resources

“...It is apparent that continuing medical education must be developed from two ends: needs assessment and outcome evaluation...”

P METB, 2008

There are a many different ways in which patients could potentially be actively involved in or help design, deliver and evaluate (assess) the education and training currently provided by NES. A large number of programmes and projects already have a degree of patient involvement. Joining together these various strands and transferring and spreading their principles to other and new areas of work may be a particularly resource-effective option.

Participation in delivery of training implies that patients’ contributions are integrated into existing curricula and their teaching linked to overall course objectives. This option assumes that patients and students have similar priorities and perceptions of learning needs. For example, ‘expert patients’ can contribute to small group teaching during the half day release programme for general practitioner trainees (see Appendix 1).

Where students, educators and patients do not have similar perceptions or agreement on learning needs and suitable educational strategies, patient involvement in designing a patient safety curriculum may be required and beneficial. For example, in patient safety education there may be a mismatch between perceptions of the definition and nature of harm and error. Patient involvement provides a ‘patient lens’ in addition to the ‘professional lens’ which may enrich the final educational product.

Collating patient experiences of safety incidents (adverse events) in an audiovisual and digital format may be a viable option. Patients’ narratives and insights may be catalogued and used in the many and various educational events run by NES. This would avoid duplication of work and provide easier access to a patient with experience of a specific issue. This would provide health care workers with new insights and learning opportunities over time without undue demand on patients.
Awareness of PI

Health care workers in general and NES staff may not be aware of the patient involvement agenda. They may also require further knowledge and skills training. This implies the need for specific educational solutions. It may be necessary to develop formal educational and training resources for staff involved in work force training to raise awareness of patient involvement and to equip them with the necessary knowledge, skills and attitudes to appropriately involve patients in teaching.

One way to achieve this aim would be through commissioning of an e-learning module that considers the ethical and practical considerations of patient involvement, outlines educational strategies, approaches and methods that can be used in wide range of settings and explores appropriate options and uses of alternatives to ‘real’ patients. It may also be useful to develop a guideline for patients, learners and individuals regarding involvement in education, with specific reference to expectations, consent, and confidentiality.

Training and support of patients

Effective involvement of patients often requires adequate training, resources and support. Ideally, this would be contractually provided. NES may be better placed to ‘train the trainers’ and focusing on clinical placement leads (champions) rather than to directly provide this service to patient teachers. This option would help to build capacity and ensure continuity. This is especially important as expert teachers tend to contribute for shorter periods than traditional educators for a variety of reasons. For example, through ‘norming’, their illness, personal circumstances and the emotional drain of repeating and sharing experiences and the need for different learning experiences for health care professionals.

Patient involvement and organisational leadership

While there is some evidence of the benefit of greater and active patient involvement in education at individual and group level, there is virtually none for it at management and
senior organisational level. Active patient involvement has often been used as a rhetorical device, but there are few examples where it has been clearly and systematically operationalized in an organisation and especially in management. Further research using a mixed-methods approach and longitudinal evaluation seems essential if involvement is to change from a ‘...fashionable trend to an established managerial technique...’

However, without senior organisational commitment and support, implementation of active involvement in education will not happen. The way in which an organisation’s leadership articulates involvement in their policy can position patients on a spectrum as consumers, partners or co-educators. For patients to be involved in a non-tokenistic way, authentic partnership working at an institutional level should be promoted and prioritized. An organisation or institution should move from isolated pilots and initiatives to coordinated and sustained programmes. If patient involvement is to be truly adopted and implemented at all levels, staff will need to overcome stereotyping and attenuate intrinsic power differentials between patients and health care professionals. Staff will also need clear guidance, support, patient involvement curricula and additional resources.
Conclusion

Patients are increasingly adopting active roles in the education and training of health care professionals at under and postgraduate levels. However, there is still very little research or experience of their roles, specifically in patient safety education. This report summarizes some of the important experiences and lessons from patient involvement in general education, considers their potential application to the relatively new field of patient safety in particular and makes a number of recommendations for stakeholders to consider.

Active patient involvement has been found to be feasible, acceptable and beneficial for health care workers (students), patients and educators. However, increasing involvement requires additional resources, recognizing and resolving a number of challenges and considering a number of ethical issues. There are several options and different ways to increase active patient involvement. At present, increased patient involvement may be most valuable in bridging the gap between theory and practice and when implemented at the individual health care worker and team levels.

The report concludes that patient involvement in patient safety education and training is clearly desirable and should complement and integrate with existing resources rather than replace them. Achieving this aim in a sustainable manner will require organisational commitment, planning, additional educational resources and further research.
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Appendix 1: Selected practical examples of patient involvement initiatives

NHS Education for Scotland

Better Together
The Scottish Government’s ‘Patient Experience Programme’ is supported by NES. It aims to capture and utilize the experiences of the public and patients to improve health services in NHS Scotland. At present, the programme is gathering data from various sources, including patients with chronic conditions, experiences of in-patient care and from patients who attended general medical practices. The results are to be analyzed and used to help shape the education and training resources delivered by NES.

Little Things Make a Big Difference
This online resource was developed by NES to provide all frontline NHS staff with access to key documents and resources relating to patient experiences. The website makes use of patient stories as a learning tool. It was commissioned and developed in response to the publication of ‘Better health, better care’ in 2007 and aims to encourage staff to value patients’ experience and input.

GPST Teaching
The West of Scotland GPST Teaching programme regularly involves patients in a teaching capacity as part of the GP trainee training programme. Recent examples included a workshop on ‘communicating with hearing impaired patients’ which was organized and presented by deaf patients and a workshop ‘The Good Death’ which made use of a video and ‘Patient Journey’ article by a patient with advanced cancer (metastatic mesothelioma).

Midwifery Resource for communicating with deaf women
This resource was developed after a focus group with deaf mothers. It aims to enable midwives to communicate with deaf women during pregnancy and labour.

Dental - Cultural Competence
The Dental department in the East of Scotland have been using patient stories and role play on the theme of cultural differences and equality and diversity to improve dental trainees’ cultural competences.

Pharmacy
The NES Pharmacy department regularly use live patients in their Pharmacist CPD teaching. This usually takes the form of a presentation from an expert speaker, a patient describing their personal experience and a question and answer session. These sessions are highly rated by the vast majority of pharmacists. The department have also recruited from patient representative groups such as Diabetes UK, and have a number of videos of patients talking about their experiences on their CPD website.

**National and international examples**

**Northern Ireland GP Training Deanery**
The Northern Ireland GP Training Deanery piloted the use of expert patients as part of a teaching session for GP trainees. The expert patients described their personal perspectives on their treatment. The pilot found that initial trainee scepticism were negated, that trainees were generally positive and described learning and changing their practice as a result of the session.

**The ‘Patient Voices’ Programme**
This programme has recently been recognised in the BMJ Group Award for Excellence in Healthcare Education. It is an internet-based, digital storytelling scheme that provides access to patients recounting their personal experiences of health care. The aim is to influence the attitudes of health care professionals through listening and reflecting on their stories.

**The Expert Patient Programme**
The Picker Institute recently reviewed the extent to which doctors are being trained to work in partnership with patients. While their review identified a number of promising developments it described a large skills gaps and a general lack of awareness. They identified the need to develop and test new, creative educational initiatives to teach the competencies for patient engagement and recommended greater use of patients as teachers. In response, they developed the ‘Expert patient programme’, which has been piloted in England.

**‘Patients-as-teachers initiative’**
The initiative was launched in the Princess Alexandra Hospital NHS Trust in 2004. It aimed to discover issues important to patients, initially focusing on the clinical areas Cardiology and Cancer. While the initiative was successful and managed to capture
learning from lower socio-economic groups and ethnic minorities, there were concerns over long term sustainability.

**Practice-based small group learning (PBSGL)**
PBSGL is increasing in use and popularity in primary care in Scotland. Evidence based modules are developed and validated for specific clinical topics and conditions. The modules include case studies of virtual patients and learners apply their experience and learning. Model answers are provided and learners reflect on a group on their management. Development of a module to introduce active patient involvement and patient-partnerships by the PBSGL Project Team may help highlight the issue to practicing GPs.