Patient and public involvement in undergraduate medical education

This advice was originally produced to supplement our previous standards for undergraduate education contained in Tomorrow’s Doctors (2009).

While the supplementary advice continues to provide information which medical schools and students will find helpful, readers should refer to our current standards and outcomes documents:

- Promoting excellence: standards for medical education and training
- Outcomes for graduates - the outcomes we set for medical students who undertake undergraduate medical education in the UK.
Patient and public involvement in undergraduate medical education

Advice supplementary to *Tomorrow’s Doctors* (2009)

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Key points

The GMC’s requirements for patient and public involvement in undergraduate medical education are outlined in *Tomorrow’s Doctors* (2009) in Domain 2 at paragraphs 43(b), 48 and 51 and Domain 5 at paragraphs 105 and 111.

This document sets out supplementary advice. It does not contain any new regulatory requirements or standards.

The advice includes the following major components:

- **a** Medical schools should ensure that their local engagement takes place for a clear purpose and is supported by a framework for recruitment, support, training and remuneration for those to be involved (paragraphs 26–27).
- **b** Medical schools should ensure that a variety of innovative approaches to patient and public involvement and support is used, depending on the nature and purpose of involvement. This would ensure that different experiences and areas of expertise of the local population are utilised, including groups that are usually hard to reach (paragraphs 28–36).
- **c** Patients or lay people should be appropriately prepared for the role they are invited to perform. Medical schools should ensure that individuals understand and are comfortable with their role, know the expected outcomes of and consent to the encounter, and know who to contact if they find it difficult to continue. Some individuals, for example those involved in students’ formal assessment, may require more extensive training to ensure consistency of approach (paragraphs 37–40).
- **d** A comprehensive support framework should be in place to meet the needs of the participants before, during and after the involvement encounter. This should include personal support, such as confirmation of arrangements for remuneration and transport and identifying the contact person; general skills training; training specific to their role; and two-way feedback following the encounter (paragraphs 41–42).
- **e** Schools should consider whether there is scope for involving patients and the public in selection of medical students, for example by inviting them to contribute to the review of the selection process or interview questions, or to feed back on individual students’ communication and interaction skills (paragraphs 45–47).
- **f** Patients can contribute unique and invaluable expertise to teaching, feedback and assessment of medical students, which should be encouraged and facilitated. Many schools already have established mechanisms for involvement at this level (paragraphs 48–57).
- **g** Patient and public involvement in development of curricula and assessments, governance and quality management and control is not yet as common but there is great potential for development. Attention should be given to the variety of perspectives that individuals can bring. Schools should consider what expertise will best meet the purpose of engagement, and call upon a range of approaches and sources to target that expertise (paragraphs 58–67).

Introduction

Background to the GMC’s production of supplementary advice

1. The GMC sets requirements for medical schools in *Tomorrow’s Doctors*. The 2009 edition reflects lessons from the first full cycle of the GMC’s process of Quality Assurance of Basic Medical Education (QABME) and responds to issues that emerged since the 2003 edition. It aims to ensure that new graduates will be fit to practise and prepared for training in the Foundation Programme and employment in the NHS and for their further education and training beyond that. The 2009 edition followed an extensive period of development, engagement and consultation and drew on research on the preparedness of graduates commissioned by the GMC.

2. Medical schools are required to be compliant with the standards and outcomes in *Tomorrow’s Doctors* (2009) by academic year 2011/2012.
3 The GMC has supported medical schools in implementing the new requirements. This has involved a series of implementation workshops across the UK and asking schools to produce Enhanced Annual Returns (EARs) on their progress. The workshops brought together representatives from the medical schools in a region as well as students, postgraduate training bodies and employers. They served as a chance for schools to discuss their progress in becoming compliant with Tomorrow’s Doctors (2009) and to highlight any challenges they were facing.

4 It became clear that the schools felt that they needed extra advice from the GMC as to how certain requirements in Tomorrow’s Doctors (2009) should be taken forward.

5 The GMC has therefore undertaken to develop a series of advisory documents supplementary to Tomorrow’s Doctors (2009) in the following areas:
   a assessment
   b clinical placements, particularly student assistantships
   c developing teachers and trainers
   d involving patients and the public.

   The documents have been developed with drafting advice from experts in these fields. Their support is gratefully acknowledged.

6 An annex contains some examples of local arrangements, as described by the medical schools or institutions involved or as set out in previous publications. These are included as snapshots which may be of interest and use to other schools as they develop arrangements appropriate for their own needs and circumstances.

7 Schools are free to make use of this advice insofar as they find it helpful in light of local circumstances. It covers relevant issues and includes suggestions. The advice is expressed as steps that schools ‘could’ or ‘should’ take, but it does not indicate any new regulatory requirements or standards.

What does Tomorrow’s Doctors (2009) say about patient and public involvement?

8 The idea of putting patients at the heart of healthcare and learning to work in partnership with patients permeates Tomorrow’s Doctors (2009). It requires early and continuing student contact with patients (paragraphs 84 and 103–105 of Tomorrow’s Doctors (2009)), and further advice in relation to clinical placements, in which this patient contact often occurs, can be found in Clinical placements for medical students – advice supplementary to Tomorrow’s Doctors (2009). Many of the outcomes set out in Tomorrow’s Doctors (2009) aim to cultivate patient-centred skills and behaviours in all future doctors.

9 Additionally, Tomorrow’s Doctors (2009) fosters a culture which enables patients and the public to contribute actively to the educational processes. It calls for systems which give patients an opportunity to feed back on the quality of teaching, learning and assessment as well as individual students’ performance.

10 Specifically, patient input is sought in Domain 2 of the ‘Standards for the delivery of teaching, learning and assessment’. The overarching standard requires systematic monitoring, review and evaluation of the quality of medical education programmes, based on quality data including feedback from patients as well as students, teachers and employers (paragraphs 38 and 43(b)). Detailed requirements are that:
   a Patients should be involved in quality management and control processes (paragraph 48); and
   b The quality of teaching, learning and assessment must be monitored through a number of different systems including patient feedback (paragraph 51).

11 The ‘Clinical placements and experience’ section of Domain 5 on ‘Design and delivery of the curriculum, including assessment’ requires that involvement of patients in teaching is consistent.
with *Good medical practice* and other guidance from the GMC such as *Confidentiality* and *Consent* (paragraph 105). The ‘Feedback and assessment’ section states that patients and carers who come into contact with students should have an opportunity to give feedback on their performance (paragraph 111).

In the postgraduate context:
The 'Standards for Deaneries' in *The Trainee Doctor* state:
5.2 The deanery must ensure active and meaningful involvement and engagement of key stakeholders: trainees, trainers, patients, and the service or employer.

**Purpose of the supplementary advice**
12 This advice is developed in order to help medical schools meet the aspects of *Tomorrow’s Doctors* (2009) standards which relate to involving patients in design, delivery and evaluation of medical students’ education. It is complementary to *Tomorrow’s Doctors* (2009) and the other existing GMC guidance and frameworks. It does not cover the equally important issue of the outcomes in *Tomorrow’s Doctors* (2009) which focus on preparing doctors for enabling patient involvement in treatment decisions and self care, which are expected to have been embedded in the medical schools’ curricula.

13 First of all, the document outlines some key principles which underpin and enable effective patient and public involvement. Medical schools might wish to consider these during the review of their engagement strategy. Then it sets out examples of specific areas of medical education where patients and the public could be directly involved, such as student selection, teaching, feedback and assessment, curriculum and assessment development and, finally, quality processes and governance. For each section, examples of local practice are provided.

14 As stated earlier, none of the examples, or the terms of the advice, are in themselves standards or requirements, and medical schools will not be automatically expected to address all aspects of the advice. The GMC aims to encourage a culture where the patient and public perspective is sought and recognised across the spectrum of medical education. This can be done in a variety of ways, taking account of the great diversity in local environments, circumstances (including financial) and needs.

**Who is the advice for?**
15 This advice is largely aimed at medical schools. The advice reflects views of experts and practitioners in the field, including patient and public involvement managers, GMC QABME visitors and public members of the GMC Reference Community, researchers, deans and programme directors. Many schools have already successfully involved patients and the public for some time, and may find little new in the advice. But we anticipate that it will assist some schools as they seek to broaden and improve their patient and public involvement programmes.

16 It might also be of interest to individuals responsible for the design and delivery of teaching and training locally, such as clinicians who teach medical students, and medical students themselves.

17 We also expect that local and national patient advocacy and support groups, charities and other organisations could promote the importance and value of patient involvement in medical education.

**Who are patients and the public?**
18 When referring to ‘patients’, ‘lay individuals’ or ‘patients and the public’, the GMC means a wide variety of individuals and groups. Each could bring a somewhat different perspective and expertise. Depending on the particular context and circumstances, one perspective may be more appropriate and beneficial than another.

- Patients or current patients – those attending a clinic or calling on a particular healthcare service. The GMC recognises that the term
‘patient’ may be considered contentious in some contexts where other terms are preferred, such as ‘service users’ or ‘users’ or ‘clients’. For ease of reference this document talks about ‘patients’ but other terms could be substituted.

- **Expert patients** – patients, usually with a long-term condition, who attend clinics on a regular basis, have extensive knowledge in various aspects of their condition and have agreed to participate in teaching and/or assessment sessions. Expert patients are also able to offer insight into aspects of continuity of care and inter-agency working. The term is used here to cover a wider group than the participants in the NHS initiative, the Expert Patients Programme.¹

- **Carers, advocates and support workers** – people who provide regular care, advocacy or support to somebody using health services. Whenever possible, input should be sought from both patients and carers, as the two groups provide distinct and complementary perspectives.² ‘Carers’ could also mean parents or guardians of children.

- **Standardised or simulated patients** – actors or role-players who have been trained to portray the characteristics of a patient, in order to give students and trainees an opportunity to learn, or be evaluated on, clinical skills.³ Sometimes volunteer members of the public or participating expert patients are trained to play the role of the patient in a particular scenario.

- **Virtual patients** – characters in an interactive computer simulation which allows the learner to take the role of a health care professional and develop clinical skills such as making diagnoses and therapeutic decisions. Patients are often involved in developing the scenarios.

- **Lay people or ‘the public’** – while in this context ‘lay’ means someone who is not medically qualified, it is suggested that involvement is sought of lay individuals with relevant expertise. This ensures that lay people can bring a valuable alternative perspective to a discussion or a decision making process. This could be a (possibly recently retired) non-medical healthcare professional, a teacher, a bio-scientist, an educationalist and so on, but people from many other walks of life, unconnected with health or education may be equally appropriate.

- **Patient groups or representatives** based around a particular service or location, including those formally established to promote patient focus and involvement in the NHS.

- **Local voluntary or community sector organisations** or national patient advocacy bodies which might include organisations working with particular groups.⁴

### Enabling patient and public involvement

#### Changing role of the patient in medical education

19 Medical education has always been based on apprenticeship learning in the course of patient care. To that extent, patients have always had a role in medical education, albeit somewhat passive, to illustrate symptoms or procedures.

20 Nowadays, a number of demographic and social shifts in the wider healthcare arena are leading to changes in the patient/doctor relationship, which is becoming a partnership. In response to this, Government policy has had an increasing focus on patient and public involvement in healthcare for some time. *Equity and excellence*, the White Paper on the reform of the NHS in England, stressed the importance of shared decision-making. In relation to collective public involvement, the Department of Health (England) has announced plans to create a new consumer champion, HealthWatch England.⁵ In Wales, the patient voice is now represented by the Community Health Councils⁶ and in Northern Ireland by the Patient and Client Council.⁷ The Scottish Health Council supports the NHS in Scotland to improve how it involves patients and the public in decisions about health services, with a national office in Glasgow and a local office in each NHS Board area.⁸
21 As the recognition is growing of the valuable role patients have in their care, new educational strategies are needed to ensure that students have adequate access to real life situations where they can develop their skills and attitudes to support this relationship. At the same time, there is more recognition of patients’ right to influence, from the outset, the attributes possessed by newly qualified doctors. Asking patients to volunteer to become ‘partners in education’, empowering them to decide whether to be involved and acknowledging their role as active teachers has become essential.9

22 Although not yet used to its full potential, a more direct and active patient involvement in medical education is growing and proving to be hugely beneficial.3 There appears to be scope for patient and public input throughout the stages of healthcare education development, from commissioning, through design and delivery, to ongoing evaluation and periodic review.10

Benefits of active involvement

23 Involving patients in medical education can be beneficial to learners: not only does it facilitate acquisition of skills such as communication, but it can also change professional attitudes positively11 and develop empathy and clinical reasoning.12, 13 It provides context to the learning material and motivates learners.14, 15, 16 Patient feedback on encounters with students, if carefully designed and used formatively, is largely welcomed by students and appears to improve their performance, as measured by exam results.17 Some learners prefer the teaching they receive from trained patients to that from doctors.2 Many students comment on gaining new insights and confidence when practising examination skills on patients who give constructive feedback, and claim that such training increases their respect for patients and deepens their understanding of the experience of disease.18, 19 If patients remind students to wash their hands, put on gloves or explain their status, the message may be more powerful than when it comes from staff.

24 Patients and members of the public involved in education have also described it as a largely positive process. Their motives range from the wish to improve services or ‘give something back’ to the satisfaction of helping,20, 21 catharsis, increased knowledge, confidence and self esteem.12, 14 Patients appreciate sharing their knowledge, using their condition to facilitate learning and contribute to doctors’ training. Some patients feel empowered by their experience.11, 15, 19, 22, 23 For some people, involvement may provide a starting point towards ongoing employment.

25 As for the rest of the faculty and the medical school, it has been noted that when patients are given adequate support, training and remuneration, they can become colleagues in medical training rather than just a teaching resource,19 and offer experiences unavailable through other methods of learning.15 Different perspectives can inject new life into the course content; teaching staff may gain new knowledge and update their skills, for example if they are no longer actively practising.2 Establishing mechanisms for meaningful and wide-ranging patient and public involvement requires investment and cultural change, but it is an important way of enhancing the patient-centred approach of the course itself and of the student as a future doctor.

Emphasis on local engagement

26 Meaningful and useful engagement strategies are best developed locally, given variations in the profile of the local population, the structure of the health services, curriculum nuances and already existing local patient involvement infrastructures which schools can draw upon. There was consensus on this during the Tomorrow’s Doctors (2009) implementation workshops. Engagement should also take place for a specific, clearly identified purpose.24 this will vary according to the local circumstances and needs.
However, there are some underlying principles of effective engagement which are explored further in this paper. Along with setting a purpose for involvement, the local engagement strategy should cover a clear framework for recruitment which facilitates diverse views and perspectives, as well as support, training and remuneration for those to be involved.

### Recognising diversity and differences in perspectives

Patients and the public are not a homogenous group. Their experiences and areas of expertise differ. These differences should be recognised and welcomed as they enrich the contribution that patients and the public can make to medical education. However, making the most of the differences is one of the biggest challenges of effective engagement.

Medical schools should strive to ensure appropriate diversity among those involved in medical education (covering age, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, social or economic status, illness and healthcare delivery setting). Issues such as dignity and cross-cultural awareness are best conveyed through direct patient contact and exposure to and experience of dealing with a variety of individuals, including those with disabilities or from vulnerable groups. Tomorrow’s Doctors (2009) requires that:

104. From the start, students must have opportunities to interact with people from a range of social, cultural, and ethnic backgrounds and with a range of disabilities, illnesses and conditions. Such contact with patients encourages students to gain confidence in communicating with a wide range of people, and can help develop their ability to take patients’ histories and examine patients.

Involvement could be challenging among some groups of patients, such as children, those who are acutely ill or frail, those with learning disabilities or some ethnic groups. Medical schools may need to use innovative methods of engaging and supporting these groups. Previously published evidence and the examples set out below demonstrate that effective engagement is achievable, provided participants are appropriately selected, trained and supported, and the involvement strategy itself is wide-ranging and mindful of participants’ wishes and sensitivities. Different groups of people may have different needs. Schools should aim to anticipate these and make, or be prepared to make, reasonable adjustments to facilitate wider participation, such as disabled access and facilities, carer or parent attendance, language support, transport, reimbursement of expenses or flexibility on the time of day involved, as well as other elements of support discussed later. It can be helpful to engage the ‘elders’ of under-represented ethnic groups. Involving senior representatives of the medical school can demonstrate the value the school places on the engagement.

When developing their engagement framework schools should take into account that:

- individual patients can describe their own experience but they may not necessarily be able to speak for others
- patient group members usually know about the experiences of others like themselves, and are likely to have extensive expertise in one rather specialised area
- patient representatives or advocates usually have broader experience, perhaps of working with several groups, and have wider knowledge about issues at strategic and policy levels. They can have an important contribution to make on patients’ interests on strategic, ethical and policy matters.
The different perspectives and areas of expertise will be suited for different purposes and usually need to be drawn upon in different ways.\textsuperscript{10, 30} The decision on who should be involved and how, and at what level their input would be most beneficial, depends on the purpose of involvement and needs to be made in each particular set of circumstances.

Diverse contribution from patients and the public should be achieved by seeking a wide range of different perspectives across various areas of medical education, utilising a wide range of different engagement approaches. For example, participation of several trained patients or lay individuals with relevant expertise in committee work should be supported by wider engagement and consultation activities. These may include focus group discussions and liaison with patients’ forums and carers’ groups\textsuperscript{2} on specific issues. It is helpful to work towards setting up or collaborating with existing networks of individuals whose expertise could be engaged when required, particularly reaching out to those whose voices may tend to be excluded.

Also, knowledge and experience of the medical education environment and curriculum comes with continuous or repeated involvement of patients or lay individuals over a period of time. But this should be balanced with the need to ensure independence of their perspective from the institution itself.

In 2000, an international group of experts in patient involvement developed ‘The Cambridge framework’ for monitoring whether there is enough variation in the involvement of patients in a course or part of a course.\textsuperscript{14} It may be used by curriculum developers and other teachers to evaluate patient involvement, with the potential to adapt and improve the learning situation. Evaluation takes place across four sets of attributes:

- Who? – aiming for the patients involved to be diverse and representative of the population wherever possible
- How? – the patients’ role(s), for example as active teachers or providing brief encounters for students on the ward where patients are recipients of care
- What? – the type of the learning experience for the patient and the student, for example whether the patient has a long established health issue or is acutely ill with significant uncertainty about diagnosis
- Where? – a hospital, community or educational setting; the patient’s place or the doctor’s place

Schools should undertake an Equality Impact Assessment (EIA) of their engagement framework to ensure that the processes for recruitment, support, training and remuneration of patients and the public are fair and equitable. They should also conduct EIAs when developing new initiatives and prior to implementing change.

Preparing patients for their role

Where current patients are involved, due attention should be given to their sensitivities and the possibility of distress caused by sharing painful experiences or undergoing repeated examinations. Patients can no longer be automatically expected to take part in medical education. The dignity and confidentiality of the patient must always be respected.\textsuperscript{31} Patients should be informed about the possibility of medical students being present or undertaking a procedure as early as possible. The principles of seeking consent from patients are explored in more detail in the GMC guidance \textit{Consent: patients and doctors making decisions together}\textsuperscript{32} and \textit{Clinical placements for medical students – advice supplementary to Tomorrow’s Doctors} (2009), as well as other literature.\textsuperscript{30, 33, 34, 35} Patients should be reminded that they can refuse being involved in teaching, assessments and other aspects of medical education, or withdraw their consent at any time, without detriment to their care.
Whatever role the patient or the lay person is invited to perform, it is important that this role is clearly set out to them, they understand and are comfortable with it, know the expected outcomes of the encounter, give their consent and know who to contact if they find it difficult to continue. The expectations of the parties around the purpose and outcome of the engagement encounter should be carefully managed.

The extent of the briefing should be proportionate to the extent of interaction and the level of patients’ active involvement. Other than setting out the role and expected outcomes and seeking informed consent, there may be limited opportunity or need to provide further briefing to patients who are involved in teaching medical students in clinic or on the wards. For other patients and members of the public, such as expert patients delivering recurring teaching sessions, simulated patients taking part in examinations or lay visitors undertaking a quality management visit, more extensive briefing/training and ongoing support structures will be required. The participants will need to develop confidence in their expertise, and to learn how they may use this expertise to contribute to students’ learning. Some training in working with diverse groups would also be an advantage.

Patients’ training can vary in style, duration and intensity, and entail individual or group instruction, practice with students, use of audio or video tapes and home study. Again, this will depend on the nature and intensity of the involvement. Structured training is particularly important where consistency and impartiality are needed, such as patient feedback as part of formal assessments.

Sustaining lay participation

A comprehensive support framework should aim to meet the needs of the participants before, during and after the teaching or other encounter. It will require planning, resources and expertise. Involvement should take place within an ethical framework with formal evaluation of impact, and with clear faculty commitment to change as a result of lay input and feedback to the individuals on how their contribution has been taken forward and the impact they have made. As teaching may be emotionally and physically demanding, there should be mechanisms for monitoring and evaluating its effect on the patients and lay participants as well as on students and the rest of the faculty. This should enable identification of any necessary adjustments to the engagement strategy or training for students, patients or faculty. A support framework should include.

- personal support, encouragement and help to develop confidence and enable participation, including:
  - a contact person/link to liaise with before, during and after participation
  - supportive infrastructure, with arrangements confirmed beforehand including payment provisions and any adjustments that could be made, such as disabled parking and facilities, transportation or carer attendance
- clear guidance on generic issues such as remuneration, reasonable adjustments and the support available
- skills training – from basic assertiveness to delivering a presentation or lecture
- specific knowledge relevant to the educational process and the level of involvement, including
  - briefing on the content and boundaries of the learning encounter, group size and teaching environments and so on
  - clear, simple information with explanations of the terminology
- opportunities for two-way de-briefing and feedback on engagement, especially for those involved in direct delivery and supporting learning practice. This should cover feedback on both the particular involvement encounter and on the engagement strategy overall.
Selection of medical students

An emerging area for patient and public involvement is the selection of medical students. If they have not already done so, medical schools may wish to consider the value of a patient or public perspective in their selection processes.

Direct involvement of patients and lay members in student selection would need to take place within clear parameters and a robust framework which adds value and is fair and consistent. For example, it may be appropriate to enable patients or lay individuals with relevant expertise to feed back their views to the admissions team about the applicants’ communication and interaction skills. Those directly contributing to selection should themselves be carefully selected, trained and supported in their role.

Patients and the public could also be involved in regular reviews of the selection process itself or contribute to the formulation of the interview questions and other wider aspects of the selection process.

Teaching

Many patients have a wealth of knowledge about their illness and can share insights into their experience that cannot be gained through any other means. Enabling them to be actively involved in teaching medical students and postgraduate trainees is an increasing and international trend. Their roles include giving presentations, facilitating seminars, demonstrating to small groups, providing personal tuition and mentoring students. Active involvement in teaching requires some preparation and training, and therefore is usually delivered by someone on an ongoing and recurrent basis, such as an ‘expert patient’. Medical schools should be aware that some groups of patients will have distinct presentation styles, and embrace these differences.
Examples of areas where patients are often involved in teaching are:

- the ‘patient journey’, or community-based teaching over an extended period
- communication skills
- mental health
- physical examination skills (for example, a general physical examination, musculoskeletal examination, genitorectal examination or pelvic examination)
- diagnostic skills (for example, relating to cardiovascular and pulmonary conditions)
- developmental disabilities of children
- dementia
- ambulatory care of patients with HIV
- developing a holistic understanding of health (including inter-agency working)
- cardiac care
- cancer
- long term conditions, such as diabetes mellitus
- aspects related to patient safety.

Medical students generally encounter simulated patients more frequently during the earlier stages of their course and real patient contact tends to increase as undergraduate education progresses. Current patients bring credibility and relevance to the learning experience. They have a varying complexity of illness or often multiple illnesses, which makes the encounters realistic but possibly also inconsistent and excessively difficult. Furthermore, at times patients may be unable or unwilling to undergo examinations, or unable to give consent.

Where consistency is required or there is particular sensitivity, simulated patients are used. The simulated patient is trained to mimic the signs and symptoms of a current patient, and can consistently reproduce specific clinical histories, behaviours and symptoms over and over again. Simulated patients can provide constructive feedback and they may be less reluctant than current patients to express concerns or difficulties experienced with a student. They will not, however, have the credibility of a current patient in the learner’s eyes, and cannot replace the value and validity that interaction with a current patient provides.

The advantages and limitations of these approaches need to be carefully weighed by the programme designers to involve the right individual for the purpose, ideally coordinating and integrating the use of both types of patient throughout the programme. Sometimes the current or expert patients are involved in designing and delivering simulated scenarios, or developing the roles of simulated patients, making the learning experience more realistic.

There are additional ways of bringing the patient’s perspective to teaching that do not involve face to face contact. Patients and carers may work with students in web based discussion groups or act as e-based consultants for problem- or enquiry-based learning. They also may be commissioned to develop a video or a written piece about a particular issue or experience, and/or devise questions for discussion. Healthtalkonline is an internet resource, run by the DIPEx Charity, which provides access to video interviews with a broad range of patients accounting for their experiences. The Patient Voices project has been successfully used in nurses’ education on clinical governance, presenting personal stories in a unique way. There are a number of other websites providing access to patient stories and experiences. Many schools have also developed interactive e-learning materials using virtual patients. While e-learning can never substitute for interaction with and learning from a patient, it is a safe, innovative and accessible way of putting theory in the context of a clinical encounter. Patients should be actively involved in developing these resources.

Assessment and feedback

Receiving direct patient feedback on performance brings undisputed value to students’ learning. The educational processes should enable this in a constructive and
proportionate way. Where practicable, those providing feedback should receive some training, as feedback could worsen rather than improve performance if not carefully sought and evaluated.\textsuperscript{46} There is also a discussion of feedback in the GMC’s separate advice on Assessment in Undergraduate Medical Education. Tomorrow’s Doctors (2009) states that:

111. All…patients and carers who come into contact with the student should have an opportunity to provide constructive feedback about their performance.

In the postgraduate context:

The ‘Standards for postgraduate training’ in The Trainee Doctor state:

5.16 A range of methods of assessment should contribute to the overall judgement about the performance of a foundation doctor…Other sources of evidence providing insight to competence should be recorded and may include feedback from patients who have been in contact with the foundation doctor and the outcome of audits.

Informal feedback from patients on the ward or in clinic immediately after a student-patient interaction is very valuable and powerful. As it would not be feasible to train these patients in feedback methodologies, the feedback should be facilitated by the trainer and should be aimed at supporting learning. There is also plenty of potential for informal feedback when a student works with an expert/trained patient for an extended period of time.

Patients could be, and often already are, also widely involved in the formal assessment of medical students. Due to the need for benchmarked and standardised marking, especially in the case of summative assessments, trained expert or simulated patients contribute more often. While reduced realism and other disadvantages of using simulated patients would still apply, they are often considered to be outweighed by the advantages of achieving a fair marking process and minimising the risk of adverse events during examinations.

There is limited research into the role of untrained patients in formal assessment of medical students in the clinical setting. While extensively used and recognised in postgraduate training,\textsuperscript{47} there are reservations about, and lack of specific tools for, gathering formal patient feedback as part of students’ workplace based assessment (WPBA),\textsuperscript{17} as the nature and often the duration of students’ interaction with patients differs significantly at this stage. Should patients contribute to the assessment score, a stable and reliable result may call for feedback from a significant number of participants or careful management by the medical school.\textsuperscript{14, 17, 48} Also, should current patients be recruited to participate in assessments, especially away from the clinical setting where urgent care is not readily available, this participation should be along guidelines set by medical schools. These should cover arrangements before the day, on the day and after examinations, including access to equipment and staff in an emergency and communication with patients’ regular healthcare team.\textsuperscript{26, 39}

Development of curricula and assessments

While it is widely agreed in principle that patients should contribute to deciding what outcomes medical students need to meet in order to graduate, there is a recognised difficulty in achieving effective patient and public involvement in curriculum and assessment development in practice. The content of learning is often technical and the range of issues covered wide. It is challenging to engage individuals who can make a sufficiently heterogeneous contribution across the breadth of the curriculum to reflect the needs of the community,\textsuperscript{49} and even more so in relation to technical aspects of assessment development.

However, there are ways of effectively getting lay/public/patient feedback on the attributes of those graduating from a programme and methods of their assessment. These focus on gathering input from a wide variety of
individuals, advocacy and support groups utilising a range of involvement approaches. Each individual or group should be engaged with a clearly identified, tangible purpose which targets their areas of expertise, and be appropriately briefed and supported in their task. For example, medical schools may seek feedback through patient groups or discussion fora on the curriculum content for particular areas, such as mental health or diabetes. Patients and lay people can effectively comment on the overall emphasis of assessment and the weight attached to its various components, perhaps through focus group discussions.

60 One study, focusing on lay involvement in undergraduate curriculum development, identified three distinct groups of lay people that should be consulted: interested and motivated members of the general community, users of health care services, and community health advocacy and special interest group representatives. They could be recruited through press advertisements, health care services, community health advocacy and special interest groups, databases of volunteer lay participants and local community notice boards and forums. Their views could be gathered by means of focus group discussions around specific topics, lay advisory panels for medical school committees and electronic discussion groups where lay people could share their personal health care experiences with medical students.

61 Patients, carers and lay people involved in teaching and assessing students should also be involved in the development and planning of the involvement where possible. Feedback can and should be sought from them when major changes are proposed to the aspect of the curriculum they teach or assess.

Quality processes and governance

62 Tomorrow’s Doctors (2009) states that:
43(b). Quality data will include… feedback from patients.
48. [Parties to the education process including] patients should be involved in quality management and control processes. Their roles must be defined and information made available to them about this.
51. There must be procedures in place to check the quality of teaching, learning and assessment, including that in clinical/vocational placements… monitored through a number of different systems including… patient feedback.

63 Patient and public involvement in quality and governance arrangements is a broad and challenging area, with the greatest potential for effective, constructive input which could influence strategic and long-term decisions, and at the same time the greatest threat of tokenism. It is therefore not surprising that involvement at this level is not as widespread as it is in teaching and assessment.

64 Careful planning is required to ensure that a range of contributions is sought via a variety of means to achieve meaningful and balanced patient and lay input, both within the schools and within other education providers.

In the postgraduate context:

Standards for Curricula and Assessment Systems state:
Standard 14: Plans for curriculum review, including curriculum evaluation and monitoring, must be set out.
The varying perspectives and expertise of contributors are likely to meet different objectives. It is therefore key that individuals are involved for a specific, pre-defined purpose, have the required expertise and confidence and are appropriately prepared for and supported in their roles.

65 The existing quality control systems at clinical placements may have patient and lay input already. These include the mechanisms established as part of the deaneries’ quality management of postgraduate medical education and training, which could be drawn upon or adapted to include information relevant to undergraduate education. The local systems for ensuring the quality of patient care, such as patient experience surveys carried out by the Care Quality Commission, the Picker Institute or the local NHS Trusts or Boards, might also provide an insight into areas relevant to the quality of education provision. Some aspects of patient feedback on their experiences may serve as indicators, for example information on whether, how and by whom consent was obtained prior to an educational encounter. Patients may also be able, and should be given an opportunity, to feed back on the performance of students, and possibly their educators, after taking part in an educational session.

66 There are many opportunities for patient and public involvement at the school’s quality management and wider governance levels, for example through participation in visits, committees, consultations, focus group discussions and so on. Schools may find it useful to hold periodic strategic meetings, separate from the day-to-day running of the course, and to prioritise patient and public involvement in those. It will be important to ensure that the outcomes are fed across between the two sets of meetings.

67 It is worth considering the use of informed ‘patient champions’. These individuals would be trained in participation issues and experienced in committee work, and have sufficient background knowledge to bring value to the discussion and decide which issues to take to other patients and how. Wider input could then be gained, for a specific purpose and when required, through the involvement networks of patients and lay people with required expertise established by the school, or by collaborating with existing local and national organisations representing patients.

Annexes

Extracts on patient and public involvement from Tomorrow’s Doctors (2009)

Domain 2 – Quality assurance, review and evaluation

Standard

38 The quality of medical education programmes will be monitored, reviewed and evaluated in a systematic way.

Criteria

43(b) Quality data will include… feedback from patients.

Detailed requirements and context

48 [Parties to the education process including] patients should be involved in quality management and control processes. Their roles must be defined and information made available to them about this.

51 There must be procedures in place to check the quality of teaching, learning and assessment, including that in clinical/ vocational placements… monitored through a number of different systems including… patient feedback.
Domain 5 – Design and delivery of the curriculum, including assessment

Detailed requirements and context

The involvement of patients in teaching must be consistent with Good medical practice and other guidance on consent published by the GMC.

All doctors, other health and social care workers, patients and carers who come into contact with the student should have an opportunity to provide constructive feedback about their performance. Feedback about performance in assessments helps to identify strengths and weaknesses, both in students and in the curriculum, and this allows changes to be made.

Related documents

British Medical Association. Role of the patient in medical education, 2008:
www.bma.org.uk/images/roleofthepatient_tcm41-175953.pdf

Department of Health (England). Equity and excellence: liberating the NHS, 2010:

General Medical Council, Standards for Curricula and Assessment Systems, 2010:

General Medical Council, Tomorrow’s Doctors, 2009:
www.gmc-uk.org/education/undergraduate/tomorrows_doctors_2009.asp

General Medical Council, The Trainee Doctor, 2011:

Hasman, A., Coulter, A., Askham, J. Education for partnership. Developments in medical education, Picker Institute, 2006:
www.pickereurope.org/Filestore/PIE_reports/project_reports/E4P_report_19-5-06_with_cover.pdf.pdf

Hogg, C., Patient-centred care – tomorrow’s doctors. GMC Education Committee Discussion Document, GMC, 2004:

Acronyms

CPD Continuing Professional Development

GMC General Medical Council

EAR Enhanced Annual Return, the information supplied by medical schools to the GMC about the implementation of Tomorrow’s Doctors (2009)

QABME Quality Assurance of Basic Medical Education, the GMC’s quality assurance process for undergraduate medical education up to 2011 when it was superseded by the Quality Improvement Framework

QAFP Quality Assurance of the Foundation Programme, the GMC’s quality assurance process for the Foundation Programme up to 2011 when it was superseded by the Quality Improvement Framework

RCP Royal College of Physicians, London

UNTRAP Universities/User Teaching and Research Action Partnership which involves users of health and social care services and carers, the University of Warwick and the NHS

VTS Vocational Training Scheme for trainee doctors wishing to become GPs
Patient and public involvement in undergraduate medical education

Postgraduate Medical Education and Training Board, Patients’ Role in Healthcare – the future relationship between patient and doctor, 2008: www.gmc-uk.org/Patients_Role_in_Healthcare_working_group_report20080620_v1.pdf

Quality Assurance Agency, Code of Practice for the assurance of academic quality and standards in higher education, updated in sections: www.qaa.ac.uk/academicinfrastructure/codeofpractice/


Wykurz, G., Developing the role of patients as teachers: literature review. British Medical Journal, 325, 818-821, 2002: www.bmj.com/content/325/7368/818.full

Local examples

Emphasis on local engagement

The Universities of Leeds, York and Newcastle and partners – recruitment of patient champions

Bradford Institute for Health Research, the Universities of Leeds, York and Newcastle, and West Yorkshire and North Yorkshire and East Coast Foundation Schools (NYECFS) are conducting a randomised controlled trial to ascertain whether involving patients in Foundation doctors’ tutorials on safe prescribing, communication and team working improves learning experience.

Patient Champions for this research – all with direct or indirect negative experience of healthcare – have been recruited in a variety of ways. Five patients were recruited through Action Against Medical Accidents (AVMA) and the National Patient Safety Agency (NPSA); others via the patient and public involvement groups at the trust and a couple of recruitments followed a press release in the local paper. Ten patients have now completed the Patient Learning Journey preparatory course run by the Patient Voice group in Leeds. Participating patient champions are liaising with the Director of the West Yorkshire Foundation School and the Trust Foundation Programme Directors regarding the delivery and the content of their tutorials.

Belfast medical school – recruitment of simulated patients

‘Patients as Partners’ is a programme launched in 2006 at Queen’s University within the School of Medicine and Dentistry. Simulated patients are recruited through public advertisement, interviewed and trained to enable them to take part in examination and teaching sessions throughout the five-year curriculum. Their simulated patient pool, now in excess of 60, offers students opportunities to practise their skills in history taking and examination. Simulated patients are recruited from all walks of life and they bring a variety of experiences with them. The value of using simulated patients in developing good training practice has been noted by students, staff and the simulated patients alike.

Newcastle medical school – roleplaynorth: powerful experiential learning

Roleplaynorth (rpn) is an agency of professional roleplayers and trainers established in 1998 and based in the School of Medical Sciences Education Development in Newcastle medical school. It provides simulated patients for teaching and assessments in the undergraduate medical and dental curricula, and regional postgraduate deanery. However, whilst originally specialising in the field of health communication, rpn has expanded to provide professional communication training to a national
clientele including higher education, the NHS, schools, private industry, government initiatives and charities. The director is also communication lead in the undergraduate medical programme and is intimately involved in developing teaching and assessment materials. Several of the more experienced and senior roleplayers act as facilitators in teaching sessions, as well as providing induction and on-going training and support for the other roleplayers.

Further information is available at www.roleplaynorth.ncl.ac.uk/about.html

Royal College of Physicians, London – recruitment to the Patient and Carer Network

The Patient and Carer Involvement Steering Group (PCSG) and the Patient and Carer Network (PCN) at the College are managed by the Patient Involvement Unit (PIU). The main aim of the PIU is to encourage and promote patient, carer and public involvement in College activities to make sure that the patient voice is heard in every area of the College’s work and that patient involvement becomes part of our everyday practice. The Patient and Carer Involvement Steering Group operates at a strategic level and assists with the development of College policy to improve clinical standards for the benefit of patients. Its role is also to ensure that the views of patients and carers are fully taken into account within the work of the College. The Steering Group has a membership of 12 and reports to College Council through the Clinical Standards Board. Lay members of the Steering Group are appointed for a term of two-three years. The lay Chair is one of the two lay members of Council.

The Patient and Carer Network currently has 75 members who are patients, carers and members of the general public from a range of backgrounds and across a wide geographic spread. These individuals wish to help the College develop and enhance its relationship with patients in the interests of improving healthcare. The College can draw on this wide pool of skills and knowledge, derived from professional and personal experience, which provides a valuable insight into the needs of the communities in which Network members live, thus better informing our work.

The RCP recruit to the Patient and Carer Network by the following methods:

- advertisements are placed in the national press, including the Big Issue
- patient organisations are notified of the advertisement
- RCP representatives throughout the UK – such as hospital consultants – are asked to bring the advert to the attention of interested parties
- RCP website.

An application form is sent to interested individuals together with a role description and background information about the College. A key part of the selection process is an informal interview lasting 30 minutes. This meeting outlines the purpose of the Patient and Carer Network and finds out more about the applicant’s experience and background. The College wishes to recruit people who are able to give a balanced viewpoint, who are able to carry out the activities for which they have been recruited and to ensure that the Network is made up of a variety of individuals from different walks of life. Following interview, successful applicants are telephoned to ask if they are willing to accept a place on the Network. Upon agreement, referees are contacted.

Once satisfactory references are received, successful applicants are sent a Patient and Carer Agreement which confirms their place on the Network and invited to an induction day. The members join the Network for three years and once appointed undertake a number of activities including membership on College working parties and committees, providing comment on consultation documents and taking part in Invited Service Reviews.

Recognising diversity and differences in perspectives

Bristol medical school – enhancing awareness of Disability, Diversity and Disadvantage

For years, tutors with impairments have facilitated small group sessions in 3D (Disability, Diversity and Disadvantage) Vertical theme week so
We also plan to engage the Somali Development Group and the Migrant Support Steering Group in Bristol (a multiprofessional group where each panel member works closely with migrant communities) to help us develop the multi-cultural awareness aspects of the Diversity curriculum.

In addition to this, we are using two specific groups (people who are gay, and a Faith group) to deliver teaching around working in partnership with patients and their families.

Newcastle medical school – Challenging Communication

As part of a block of teaching and learning called ‘Challenging Communication’ in 4th year of Newcastle’s undergraduate medical programme, groups of students, each with a tutor, meet a person with learning difficulties, often accompanied by a friend or carer. They are all volunteers from Skills for People, a local cross-sector organisation supporting people with learning difficulties. The outcomes of the session are focused on communication and understanding the challenges that people with learning difficulties face in the community, not least in their encounters with the health services. Feedback from volunteers (who are generally keen to contribute from year to year), students and tutors alike is very positive. The Challenging Communication sessions, which also cover working with interpreters and communicating with people with profound deafness, won the BUPA Communication Award in 2000.

St George’s medical school – Intellectual Disability teaching

The Intellectual Disability (ID) teaching at St George’s is, on the whole, integrated into the curriculum. The focus is on addressing the well documented health care inequalities through raising awareness, teaching specific communication skills and promoting reflexivity. In the communication skills teaching, the students work with trained actors who have intellectual disabilities, who pretend to be a patient for the purpose of the medical students’ learning. Additionally, the students learn about the key components in addressing health care...
In addition to lectures and workshops, the students work with a patient with ID while on their GP attachment. Here they conduct a health screen that informs the patient’s Health Action Plan and they complete a Hospital Passport with their patient and, if necessary, their carers. To stimulate creativity and reflexivity, the students produce a reflective account of their patient encounter and are also given the opportunity to produce a project around a topic of interest. They present this topic to their peers in an accessible format, which is also a key skill. In the past, students conducted small research projects, examined how people with ID are represented in the media, investigated the validity of specific syndromes and even produced their own short films. The curriculum is delivered primarily by a highly specialist clinical psychologist in mental health and ID and by two trainers who both have an intellectual disability and are active in promoting the voice of people with ID.

Rethink – mental health awareness programme

The mental health charity Rethink developed a targeted awareness programme for medical students and work with four medical schools in England, with an anticipated beneficiary group of 3,112 medical students over four years. The short programme is delivered by people with mental health problems and carers. It focuses on challenging established myths about mental health issues and on building positive working relationships with service users and carers as part of the expert team.

Preparing patients for their role

Cardiff medical school – training for simulated patients prior to OSCE

Simulated patients (actors) are used to assess communication skills in year 3, 4 and 5 OSCEs. A briefing paper and training sessions from clinicians are provided for the actors prior to the OSCE. This enables actors to discuss each case and its interpretation, helping to clarify the clinical role of each actor and standardise the student assessment.

Leeds medical school – Patient Learning Journey programme

The Patient Voice Group (PVG) at Leeds Medical School consists of approximately 120 patients and carers. Some of the group prefer to be involved via e-mail (writing or commenting on documents such as student guidelines for the patient/carer home visit, writing guidelines/information for new patients and carers getting involved in the home visits and the classroom visit) but the majority help to educate students in their own homes or at the medical school. The key to the PVG work is the preparation prior to involvement – the Patient Learning Journey programme.

The programme started in 2002 and has been delivered in a number of contexts since then. The Patient and Public Involvement Manager for the Medical Education Unit at the University of Leeds regularly leads a series of three facilitated sessions with trainee co-facilitators who are from a background of significant patient or caring experience. The workshops are usually attended by approximately 10 patients/carers from the local community. They are designed to offer a confidential and supportive learning environment in which participants can comfortably share and reflect on their healthcare experiences, identifying common themes and differences within their own and each others’ ‘journeys’. The informal and supportive approach used in facilitating this work allows participants to bond socially, reflect and develop new insights and confidence together.

Focusing on the ‘learning journeys’ often prompts participants to reassess their experiences and their relationships with practice in a way which positively assists them to move forward in their own lives, and think about how their insights might be used constructively to help healthcare professionals/
students develop more patient-centred practice. Feedback from the Patient Learning Journey programme indicates that the sessions are successful as a transformative process for participants, the institution and the workforce.

Barts and the London medical school – training for simulated patients

Actors are trained for their part in the learning and assessment of clinical and communication skills. Their preparative training is essential to assure understanding of the clinical, social and behavioural brief and for a standardised performance:

- To simulate a patient with specific disorders, a set of symptoms, cultural beliefs, ideas, concerns and behaviours, in learning and OSCEs.
- To register the effects of learner behaviours and provide highly specific feedback on skills, such as clarity of explanation, empathy, rapport, listening and negotiation.
- To give feedback ‘in role’ to encourage learner reflection on the encounter and enable students to repeat and modify their behaviour.
- To vary the level of affect (anxiety, distress, anger) and provide a safe environment without harm to patients to practise and receive feedback on challenging communication encounters (for example, on sexuality, learning disability, aggressive behaviour, handling complaints, breaking bad news).

St George’s medical school – preparing simulated patients for OSCEs

Simulated patients receive a general briefing on the level of the students and the structure of the day. They then role-play their own examination station to standardise their performance, including their response to the first question. They meet their examiners to discuss questions about the stations and discuss any ambiguities, to achieve maximum consistency of performance across circuits. At the end of the examination simulated patients are given an opportunity to feedback on examiner behaviour. New or complex stations are piloted and rehearsed in advance of the OSCE.
Royal College of Physicians, London – Induction and training for the Patient and Carer Network

All new members of the Patient and Carer Network are invited to an induction day which gives information about the College, the Patient Involvement Unit (PIU) which manages the Network, their role expectations and so on. All the new recruits are also provided with a very comprehensive handbook, which explains in detail all the processes associated with being a member of the Patient and Carer Network.

When a Network member is assigned to an activity or committee, the PIU arrange for them to meet with the Chair/organiser prior to their first meeting. This allows both parties to share expectations.

In addition to the above, the PIU carry out three workshops per year. On these occasions, Patient and Carer Network members come together and take part in various lectures, presentations and breakout sessions on a wide range of topics relevant to current issues affecting the College. These workshop days not only act as a really fruitful way of gaining patient and lay feedback on a particular area of the work of the College but we are also able to inform our members about new policies, initiatives and healthcare issues, that will frequently be addressed in many of the committees/boards/working parties they are on.

Imperial medical school – developing simulated patient roles

Traditionally, simulated patient scenarios for portrayal by actors are written according to the required topic, character, level of difficulty and so on. The School invited patients to work closely with the actors to develop the roles of the simulated patients. A first draft of the role is developed after an in-depth interview with the patient covering their medical history, their personality and attitudes towards healthcare and medical education. To further refine the role, the patient and actor observed each other being interviewed by medical students and discussed the finer detail of the roles. The patients found the process of watching the actors playing them fascinating and also became aware of how different interviewing styles of medical students could change the way information was exchanged during the interview.

Sustaining lay participation

Royal College of Physicians, London – ‘buddy’ system for lay representatives

Following successful experience in Haematology, this system is being introduced across all Committees at the college in the autumn of 2010. All Chairs of the Specialty Advisory Committees (SACs) have been asked to identify a Committee Member who will be the specific ‘buddy’ for the lay representative. The buddy should ensure that if the lay representative has any concerns or questions, they can be addressed, and that their opinion is always sought. This support is particularly important when a new lay member is recruited to an SAC.

Warwick medical school and partners – (UNTRAP) Universities/User Teaching and Research Action Partnership

UNTRAP is a partnership between users of health and social care services and carers, the University of Warwick and the NHS, based in the Institute of Health at the School of Health and Social Studies. UNTRAP uses a membership model – users and carers become members of UNTRAP. The objective of this diverse group of over 80 members with various experiences and expertise is to support the involvement of service users and carers in teaching and research so that they would have a direct influence on the skills and knowledge of professionals in training. Groups (such as the medical school) wishing to work with users and carers approach UNTRAP rather than individuals. In turn UNTRAP ensures that organisations working with UNTRAP members:

- value them
- provide training for their role
- provide practical support (for example, IT access)
- pay them for their time.

Having a group of service users like UNTRAP creates an important ‘resource’ for the medical school. It also brings together a group of patients/carers who can work together, build up networks and discuss issues. Through these relationships, they can cultivate a more proactive and developmental role in teaching and research and begin to suggest new ways of getting involved, such as in student assessment and entry interviews.
Selection of medical students

Keele medical school – involvement of lay interviewers

Before the commencement of the 2008 admissions cycle, the School consulted a sample of the lay interviewers to determine their views on how they could most usefully contribute to the interviews, given that they should be representing the patient’s viewpoint. It was decided to have the lay interviewers leading the discussion section of the interview, in which a topical issue with a social/ethical dimension is presented, on which the candidate is asked to offer an opinion and debate it with the panel. Panellists are provided with cues to prompt discussion in order to test the candidate’s awareness of the range of people affected by each issue, possible approaches to understanding/dealing with the issue and possible outcomes of proposed solutions.

Lay interviewers have been recruited via the Keele alumni office and local volunteer bureaux, as well as by word-of-mouth recruitment in the local community. Members of the lay group include local councillors, retired people and other local people seeking to engage in voluntary activity. While some lay interviewers have a connection with education, having been teachers or non-medical academics before retirement, others have backgrounds in local business and industry. Non-academic members of university staff may also be called upon. No specific expertise or experience in interviewing is required.

All lay interviewers have the lay interviewer role explained and attend a training session before their first set of interviews; they are required to attend another session at least every two years. Training covers the principles underlying Keele’s selection process, equality and diversity issues and the structure of the interview, as well as the details of the discussion scenarios. Interviewers attending for refresher training offer advice to new and existing interviewers based on their experience in the role. No formal evaluation has taken place to date, but interviewers reflect and comment on their own experience and exchange views on how to fulfil their role most effectively.

Imperial medical school – lay participation in interviews

The lay people who join our panels on occasion are usually interested parties, such as head teachers, sixth form tutors, biology teachers and so on from schools. They do not actually participate in the selection procedure but their opinions are always sought within the discussion, so they most certainly are useful in monitoring performance and consistency and can raise any issues of concern to the College. They complete questionnaires which the College Registry organise and retain.

Nottingham medical school – selection and training of interviewers

At Nottingham, approximately 800 applicants are interviewed for the A100 undergraduate course each year. Interviews take place over a four month period. Two interviewers volunteer to participate in each interview session which takes place during an afternoon. They will interview 10 applicants during the afternoon session.

Interviewers are recruited from two sources. One member of the Admissions Committee, of which there are twenty, will take part in every interview. The second interviewer is then recruited using a database that consists of experienced and new people. The majority of interviewers are either clinicians, academic or administrative staff members. The exceptions are two head teachers who are members of the Admissions Committee.

Prior to participating in the interviews, the interviewers undergo online training, to ensure consistency throughout the interview process. This is monitored by administrative staff to ensure training is carried out and reminders are sent to those who haven’t completed it. The clinicians update their diversity and equality training each year through the on-line facility on the doctors.org website and copies of certificates are kept in the administrative office. Discussions are ongoing with the Professional Development team of the University to look into the possibility of a similar facility being available for academic, administrative and lay people.
Patient and public involvement in undergraduate medical education

Teaching

Warwick medical school and partners – modules on Health in the Community and Learning from Lives

”Health in the Community module (first semester, year 1), is taught one day a week, alternate weeks in the medical school and in the community. The sessions in the community are based in local medical centres and patients’ homes. Patients are volunteers who have been asked to participate by their community nurses. In the first week, working in groups, students explore the local area from different perspectives (that of a single mother, of a retired person and so on). As part of this work, students are encouraged to look at the physical environment, access to transport, health and other facilities. In the following weeks, the student groups interview a patient and three people from their support networks, including formal and informal carers, health and social services staff. Patients give feedback on the students who have interviewed them and are remunerated for their contribution. Then the students present their findings to the group. This enables them to see the differing perspectives and potential disagreements between various individuals involved in delivering care and support, as well as the doctor’s role. It also gives them an opportunity to think about how a patient’s life course might influence later health outcomes, and how different services in the community interact with each other and with the patient.

In the Learning from Lives module (year 2), members of UNTRAP (Universities/User Teaching and Research Action Partnership) are involved in group sessions with students, enabling them to learn in more depth about illness and its impact. Sometimes UNTRAP members deliver lectures to the whole student group, such as on their experiences of disability, medical professionals and the social model of disability. However, the core of the day is always the time when patients and/or carers discuss their experiences of health and social care with small groups of students, facilitated by a member of staff. These sessions usually last an hour and patients/carers are free to present their thoughts to students in any way that they feel happy with. However, they are encouraged to leave plenty of time for student questions. During discussions, students can be presented with complex healthcare scenarios and asked to make decisions on the way forward; patients and carers then comment on how they may have felt and reacted to these decisions. At the end students have a short time, perhaps 10-15 minutes, to discuss with the member of staff what they have heard after the patient/carer has left. This encourages students to think about the ‘lay perspective’ on health and also about the massive contribution of informal carers and the impact caring has on their lives.”

Cardiff medical school – extended oncology assignment

”As part of the Oncology Student Selected Component (SSC), students are assigned to oncology patients for four to five months. They accompany them to clinical appointments and treatment sessions, and talk to them about the psycho-social aspects of their illness. The Oncology Project allows the students to appreciate the varied dimensions of care of patients with cancer, through study of the social, physical and emotional aspects of long-term illness. It combines the powerful impact of the one-to-one interaction, with the active investigative and reflective approach to issues triggered from the patient’s cancer journey.”

Leeds medical school – Patient Voice Group’s involvement in teaching and assessment

”Members of the Patient Voice Group (PVG) are involved in design and delivery of teaching and assessment (formative and summative feedback) of students throughout the course (years 1-5). The areas covered are communication skills, team working, ethics, the reality and impact of living with a long term health condition, and the reality and impact of living with mental health issues. The PVG (themselves from different ethnic backgrounds) work with first and second year students who have English as a second language. They help to plan and run group sessions to discuss the difficulty of communication – medical, non-medical, local accents, dialect, humour, culture and how to become part of the community.

The PVG were involved in a research project ‘What Matters to US’ which led to assessment criteria..."
for communications skills teaching and informed the simulated patient mark sheet for the final year OSCE. The PVG also present the research findings as part of their lecture ‘What Patients and Carers want from Tomorrow’s Doctors’ during the first year’s introduction week.

The research group has developed into the Patient Voice Group Network. Network members include clinical and academic staff, students, patients and carers and together they continue to research, write and inform teaching and assessment.

Dundee medical school – ‘Doctors, Patients and Communities’ programme

The undergraduate degree delivered by Dundee University Medical School includes community-based teaching, known as the ‘Doctors, Patients and Communities’ programme. As part of the undergraduate degree, medical students visit a patient with a long-term condition in the patient’s home at intervals for the duration of the first three years of the curriculum. A small qualitative evaluation of the programme found that benefits to students included:

■ gaining an understanding of patients managing long-term conditions in the home context
■ having an understanding of patient-focused medicine
■ meeting patients early, which brought reality and continuity to their careers and a greater understanding of the patient’s condition
■ finding it an enjoyable method of learning.

Glasgow medical school – the Longitudinal Care Project (LCP)

The LCP was introduced in 1998 to Year 3 of Glasgow University’s new medical curriculum. Through their participation in this project, students are able to demonstrate an understanding of the patient’s journey of ill health, and to evaluate the quality of care, applying both patient and evidence-based medicine perspectives.

By regularly clinically reviewing several patients, each with chronic disease(s), over a period of six months, the project aims to enable students to:

1 Understand the natural clinical history of several chronic conditions, their effects upon patients and their consequences for those patients.
2 Assess the quality of clinical care using an evidence-based approach.
3 Identify the aims and objectives of care from the patient’s perspective, and consider how these compare with those of their relevant health professionals. This should include an assessment of the extent to which the care is holistic and patient-centred.
4 Explore the patients’ perceptions of their diseases and treatments, and consider how this may affect their care.
5 Explore the different responsibilities of, and the extent of communication and cooperation between, health professionals, and discuss how these interact to affect the quality of patient care.
6 Explore the potential problems posed at the boundaries of health care, whether between primary and secondary care, or between social care and health care.
7 Develop their ability to reflect on clinical experience. Their analysis should contain a critical reflection on both cognitive (skills and knowledge) and affective (attitudes and emotions) learning.

During the LCP, students work cooperatively with their peers to evaluate the care of selected patients. This evaluation is summatively assessed, and is submitted in two parts, of 8,000 words overall.

The LCP is 10 years old, and its enduring value is in providing students with direct engagement in the long-term care of real patients, thereby equipping them with vocationally important perspectives, and enhancing their ultimate fitness to practise.

A similar project runs in the third year of Newcastle undergraduate programme called the ‘Long Term Condition project’.

Southampton medical school – a Virtual Patient resource

A series of interactive Virtual Patients have been developed and implemented across the BM5
programme (five-year undergraduate medical degree course) in Southampton. Students ‘meet’ Virtual Patients in the Nervous and Locomotor, Gastrointestinal (GI) and Endocrinology courses, and during their Mental Health attachments. The Virtual Patients are supported by a wealth of interactive learning packages and online quizzes.

### Assessment and feedback

#### UCL medical school – informal feedback from patients

During clinical attachments in general practice in years 4 and 5, patients who participate in student led consultation are invited to provide informal feedback – either immediately or later by telephone. Additionally, simulated patients give feedback to students focusing on shared decision making and management planning. As part of the Professional Development Spine communication skills sessions (in Years 2, 3 & 4), role players are also asked to give feedback to students informally during their first attempts at history taking and examination.

#### Sheffield medical school – Patients as Educators programme

For its Patients as Educators programme, the school has recruited over 750 members of the public, many of whom have been patients, by word of mouth from a wide range of sources, including patient support groups, voluntary agencies, hospital clinics and GP surgeries. The recent expansion of the programme has successfully focused on linking with groups in Sheffield which were previously underrepresented and now includes members from the Somali, Turkish, Chinese, Pakistani and Kurdish communities. A standardised training session is provided for all new recruits, supplemented by session-specific training.

The participants in the programme assist the School and medical students in a wide range of activities aimed at developing and assessing students’ clinical skills, including community attachments, ‘patient encounters’ in the early years, simulated ward rounds, clinical skills training and clinical assessment and feedback. For example, some patients have been trained to understand how an abdominal examination should be carried out and what it should feel like as a patient. These patients are then able to provide feedback directly to students on their performance carrying out abdominal examinations. Patients contribute to the quality assurance of the programme and also provide the School with guidance on professionalism within medicine.

#### Aberdeen medical school – patient involvement in teaching and OSCEs

The School of Medicine at the University uses volunteer simulated patients, volunteer real patients and actual patients in its clinical exams (OSCEs). The type of patient required is generally determined by the exam question. A simulated patient, for example, would be used for an OSCE station that tests history taking skills, for which the patient is required to learn a specific script. Simulated patients receive training and provide significant support for the teaching or practice of history taking and communication skills in the early years of the curriculum. A database of volunteer real patients is maintained and these patients may be used when a student is examining a specific system or disease, such as demonstrating how to examine a patient’s abdomen or a rheumatoid joint. Real patients are used in the final year assessment when specific clinical signs or symptoms are required for a particular OSCE station e.g. a diabetic foot problem or a heart murmur. Patients contribute to the mark awarded at each ‘live’ OSCE station based on their view of the student’s consultation skills.

Informal feedback during teaching is encouraged, including feedback from simulated patients following video recording of history or communication interactions with students. Volunteer real patients, who are accustomed to being examined as part of their clinical care, also provide feedback on clinical examination technique. Volunteer real patients complete a more formal written evaluation for the programme manager, to help identify issues or training needs.

A new Year 1 curriculum was introduced in Aberdeen in session 2009/10. Students initially learned basic history and examination skills for the Respiratory
Inclusion of patients in this way allows teaching to be planned well in advance to address specific topics, rather than the opportunistic style of clinical teaching which has been the norm. The SP programme and EPPSAT support virtually all clinical assessments in the undergraduate curriculum, including OSCE exams, the Clinical Practice element of the final exams, and both summative and formative assessments during modules and attachments. Patients are routinely asked for feedback about the examination process, and in some assessments are involved in rating the student performance. Both programmes have developed progressively since they were initiated, and now support a growing range of undergraduate and postgraduate teaching and assessment activities.

Imperial medical school – the Volunteer Patient Programme

The programme invites members of the public to take part in Year 1 communication skills sessions. In brief, each Year 1 student has the opportunity to interview 3 patients (5 minutes each) one after the other. The volunteer patients complete brief rating forms indicating their satisfaction with various aspects of the student's communication skills (including introductions, questioning, listening, warmth and professionalism) and return the rating forms to the students immediately.

Members of the public are recruited by advertising in hospital and GP waiting rooms. In selecting the volunteers, the School aims for diversity in demographics as well as clinical condition presented at the sessions, excluding as few applicants as possible.

Volunteers receive written information about the aims and structure of the session, including guidelines on how to prepare their 'role', for example: 'imagine that you are at your GP surgery, and a medical student asks to talk to you for five minutes about why you are visiting'. They are asked to make up the reason they are at the surgery based on their own experiences or experiences of someone they know well enough to realistically talk about their condition. They are also briefed at the beginning of
the session and faculty are available throughout the session to provide support.

The impact on the students is very positive. They very much enjoy this real patient contact only a few weeks into their course. The impact on the volunteers is also anecdotally positive, with many volunteers returning each year. They speak of ‘giving something back’ after good experiences with healthcare. Some have reported becoming more aware of the process of medical education and the emphasis on communication skills, or becoming more tolerant of their own doctors after considering the challenges the doctors face. A number of volunteers say they have become more proactive in their own consultations – for example, volunteering their ideas and concerns more readily, taking lists of questions they want answering, ensuring they know what medications they take and so on.

Warwick medical school – patient and public contribution to the future curriculum

Through UNTRAP (‘Universities/User Teaching and Research Action Partnership’) the School has recruited two members of the Steering Group that is advising staff on the shape of the future curriculum. These people already have experience of working in committee environments and/or have received training for such a role. In addition, members of UNTRAP (and their networks) were invited to attend a consultation day (held on a Saturday) to comment on and discuss what they perceive as important to cover in a medical curriculum. Thirty people attended and highlighted the importance of partnership and communication with patients, the importance of long-term conditions, recognising that cure is not always the most important outcome, seeing patients as individuals (and understanding their personal background) and acknowledging mistakes.

Newcastle medical school (Durham University Queen’s Campus) – Clinical Skills Partners’ input into teaching and curriculum planning

Clinical Skills Partners (CSPs) are members of the public used in anatomy and clinical skills classes. They are paid sessionally, so represent ‘simulated’ patients rather than current patients, but, inevitably, they have experience of the NHS. Students practise clinical skills on each other, but it is invaluable to have non-peers to provide further feedback on the performance of these skills in practice. Some skills (breast examination, palpation of femoral artery, placing 12 lead ECGs in females etc) are not generally carried out by students on each other. The CSPs are essential for these.

The School also takes the opportunity of engaging these members of the public who have observed the curriculum at first hand in discussion on curriculum planning and medical education/training from their lay but informed perspective. These discussions are deliberately informal in nature, taking place during the briefing/debriefing for the Clinical Skills Sessions, rather than through formal committee structures. Instead, staff members report the discussions to the formal curriculum committees.

Sheffield medical school – patient involvement in Placement based assessment

Placement based assessment (PbA) has been introduced in Phase 3a for Women’s Health, Child Health, Psychiatry and Community. Previously in the end of phase OSCE it was not possible for students to demonstrate their clinical skills with patients who were pregnant, psychiatrically ill or with young children and their families. The new assessment structure allows this to occur and the OSCE has been dropped. Whilst it had been anticipated that the reliability of the assessment would fall the reverse has occurred with the assessments having a greater validity than previously.

Development of curricula and assessments

Sheffield medical school – involvement of the Patient Council in curriculum development

The Council has members from Foundation Boards of NHS Trusts where students undertake clinical placements. They comment enthusiastically on attributes they wish doctors to have and this helps develop our curriculum. Recently, Patients as Educators have started to contribute in a similar way and the two groups will be linked.
Aberdeen medical school – patient involvement in developing teaching materials
““The Personal and Professional Development (PPD) group has been developing and implementing a thread of portfolio based teaching, but with some plenary sessions, which will run through all five years of the MBChB programme. A patient representative, contacted via our local Health Board, has contributed to and supported the work of this group. Individual patients have given their own perspective on illness and interaction with the NHS during PPD sessions in the first year of this new curriculum."

Royal College of Physicians, London – lay involvement through Specialty Advisory Committees (SACs)
““Every SAC at the College has a lay member, usually recruited through the College Patient and Carer Network. They are expected to participate in every discussion and work programme of the SAC, and therefore have regular involvement in and influence on:

- specialty curriculum implementation and review
- quality management
- trainee support
- specialty certification (UK programmes and equivalence routes)
- academic training
- workforce planning and
- recruitment.

The College made a real effort to involve all the lay representatives on the SACs in the process of the latest curriculum review. The documents have been developed mainly by clinicians but then were clarified and improved in terms of usability by the lay members. The Joint Royal Colleges of Physicians Training Board (JRCPTB) employed a lay coordinator who worked closely with all the lay members to ensure that their views and opinions were made clear in the final curriculum documents. Many of the clinicians on the SACs commented about how helpful they found the lay input to the curriculum rewrite process, this has subsequently boosted lay participation in the SAC meetings."

Birmingham medical school – Focus Group meeting on curriculum design and content
““At the first meeting of the Focus Group we presented our curriculum to a panel of 12 patients (approached through Patients Association) and asked for feedback. They had difficulty focusing on the curriculum rather than general points about medical services, but the main points that they raised were the importance of communication with patients and the importance of planning discharge and return to the community.

They felt that this latter point was one that was rarely addressed in detail and we have taken that on board as we plan to re-design our Community Based Medicine (CBM) curriculum.

We plan to reconvene this group to comment on our admission and fitness to practise processes."

Leeds medical school – Patient Voice Group’s involvement in developing teaching scenarios and assessments
““The Patient Voice Group (PVG) members inform the development of the school’s education programmes by being involved in each stage; from conception and delivery right through to assessment and evaluation. Some members become part of focused workshops with clinicians and students, creating an expert partnership to produce high validity methods of formative and summative assessment which are authentic and clinically relevant.

Patients and carers were crucial to the development of an electronic assessment tool piloted by year 3 medics in practice settings. The students used the tool to reflect on skills such as giving information, explaining a procedure and gaining consent. They also had to gather feedback from healthcare professionals, students, patients and carers. Each member of the PVG paired up with a member of the communication skills team, and each pair was allocated 20 students. They were able to access the written/audio exercise online to discuss and feedback direct to the student.

The PVG have been instrumental in the design of the Patient Mentor Pilot. Patient Mentors will
lead sessions for all first years in term 3 of the new curriculum. Students are required to write a number of short reflective pieces chosen from 16 topics, such as patient safety, complaints, carer experiences, health promotion or medical jargon. One of these will be assessed by a Patient Mentor, who will mark the written piece and run small groups to discuss and give feedback to the students.

A collaborative approach is taken to scenario generation. For example, a new year 2 communications skills scenario was written by a team which included 3rd year medics, patients, carers, clinicians and simulated patients from the highly skilled PVG pool. The starting point was based on a difficult situation experienced by one of the students on a year 2 placement. The group were able to share their clinical knowledge and lived experience to create a scenario both authentic and clinically relevant. The PVG bring their patient/carer perspective to the scenario, enhancing the student’s feedback in their role as simulated patients and out of role as themselves.

The same collaborative method contributes to the blueprint and design of the final year OSCE. Matching the PVG experience with the clinician’s knowledge of assessment produces a realistic and robust station that along with the SP marks improves validity and reliability.

**Newcastle medical school – Patient feedback at Final MB.BS examination**

The School revised its final MB.BS clinical examination in 2009, which continues to involve real patients from the volunteer database. The School incorporated detailed patient feedback and evaluation, including aspects such as the realism of the encounters with students compared with previous medical consultations, and the treatment of the candidates by the examiners. It is planned to integrate this evaluation routinely.

**Quality processes and governance**

**Warwick medical school – lay/carer involvement in strategic and policy decision-making**

Through UNTRAP (‘Universities/User Teaching and Research Action Partnership’) the School has recruited a member of the public to its Undergraduate Studies Committee. This Committee, a sub-committee of the Board of the Faculty of Medicine, makes recommendations to the Faculty Board on all key strategy and policy decisions relating to the School’s undergraduate courses (for example, approving course content and assessments). All members have equal voting rights on the Committee. The current lay member has very significant experience as a carer and brings the perspective of a service-user to decision-making at the Committee.

**Liverpool medical school – patient input into programme oversight, development and quality**

We have patient representatives on both the Board of Studies, which is the senior committee in the school for oversight and development of the programme, and also on the Quality Management Group, which is the lower-level committee dealing with programme quality issues, and which reports to the Board of Studies.

The patient representatives were both appointed from patient representative groups from two local hospital trusts, and received personal induction before they accepted and took up their posts on the committees. They were required to sign undertakings about confidentiality, but there has been a tension concerning which course-related information can be used by the patient representatives. The presence of a patient representative, especially on the quality group, provides another perspective and has also enabled us to enhance the methods through which patients give feedback to students on clinical placements.

**Royal College of Ophthalmologists – Lay Advisory Group**

The Lay Advisory Group meets quarterly, and its members are involved in all the College standing Committees and most Sub-committees. The Group
comments on matters of interest to the College and related to its work, and contributes to the College publications. These include comments on the UK Vision Strategy and aspects of its implementation; support for the concept that trainees should perform a minimum number of certain surgical procedures; concern about the suggested ending of the Certificate of Visual Impairment (CVI) data collection; and issues of confidentiality during College examinations. It is currently involved in development of a document on ophthalmic services for people with learning disability for the Professional Standards Committee.

Some members have also trained as Lay Examiners to help with the communications station at FRCophth exams. The Lay Advisory Group members are recruited for the variety of skills and expertise that they can bring, thus there is a lawyer, and IT expert, a disability case worker etc.

GMC – lay input into strategic and operational matters and quality assurance work

There is lay representation on the GMC Council, its Boards, committees and working groups. Lay members are appointed to reflect a wide range of experience of regulation, the health sector, education and the patient perspective.

The GMC ensures patient and lay input into every quality assurance process, such as the Quality Assurance of the Basic Medical Education (QABME), Quality Assurance of the Foundation Programme (QAFP), specialty visits and the review panels for the specialty curricula and assessment systems. Lay visitors and lay members of panels are drawn from a pool of ‘associates’, who are highly experienced members of the public with relevant expertise in a range of backgrounds. The GMC associates are trained for the role they undertake, and their performance is monitored. The standards and requirements set by the GMC are all consulted on publicly in writing and through events and meetings. Also, there is a Reference Community – a pool of individuals interested in the GMC’s work, half of whom (26) are members of the public. The opportunity to be part of the Community was promoted with the help of a number of patient and public organisations, aiming to reach people from diverse backgrounds to maximise the extent to which the Community reflects the diversity of the wider population. Appointments were made through an open process. The purpose of the Community is to enable the GMC to access the individual perspectives of a diverse group of members of the public and doctors on a range of issues so as to inform its policy and decision taking. Members are involved through a variety of methods of working, including remote (e-engagement) exercises, deliberative discussions (face to face or by phone) and, less frequently, by appointment to boards or working groups.

The benefits of the Reference Community relate to flexibility. It enables the GMC to get a public perspective on key issues when it is needed using a variety of methods. The earlier model, the Patient and Public Reference Group, operated in a ‘committee style’ through quarterly meetings. Also, the Community complements rather than duplicates the GMC’s continued engagement with representative organisations and groups. However, 26 members of the public are a small group and there is a risk over time that public members lose independence. The GMC intends to mitigate this by periodically refreshing the membership.

Academy of Medical Royal Colleges – Patient Lay Group

The Academy Patient Lay Group (APLG) has been established to inform Academy discussions, and to ensure that the generic interests and perspectives of patients and the general public are taken into account within the work of the Academy. Its membership consists of the Chairs of the Colleges’ and Faculties’ Patient and Lay Groups, and coopted members invited to attend by the Chair.

Its main responsibilities are to:

- respond to requests for comment from the Academy and its committees
- offer advice on generic issues that directly affect patients
- consider the effect of actual or proposed government policy on the delivery of care
- share common policy and processes
- disseminate successes, good models and share good practice.
References

1. www.expertpatients.co.uk
   www.eppwales.org (accessed 10 August 2010)


4. South Central WCC Collaborative PPI Programme. Undated. Patient and Public Engagement Toolkit for World Class Commissioning


12. Repper, J., Breeze, J. 2004. A review of literature on user and carer involvement in the training and education of health professionals www.shef.ac.uk/content/1/c6/03/21/77/Finalreport.pdf (accessed 17 September 2010)


24. UK Biobank Ethics and Governance Council workshop. 2009. Involving publics in biobank research and governance

31
25 Postgraduate Medical Education and Training Board. 2008. Patients’ Role in Healthcare – the future relationship between patient and doctor


29 Williamson, C. 2007. How do we find the right patients to consult? Quality in Primary Care, 15, 195-9


31 General Medical Council. 2009. Confidentiality


35 Faculty of Medical Sciences, University of Newcastle. 2009. Patients and Undergraduate Medical Students: Consent for Involvement in Teaching /Medical Education. Code of Practice for the Faculty, NHS Trusts and General Practice

36 Royal College of Paediatrics and Child Health. 2005. Coming out of the shadows: a strategy to promote participation of children and young people in RCPCH activity


38 www.alps-cetl.ac.uk/essen/player.html (accessed 17 August 2010)


40 Department of Health. 2006. Reward and Recognition. The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers

41 www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/untrap/ (accessed 6 August 2010)


43 www.healthtalkonline.org (accessed 16 August 2010)

44 www.patientvoices.org.uk (accessed 5 August 2010)

November 2010)
www.untoldstories.org.uk (accessed 1 November 2010)
storiesforchange.net (accessed 1 November 2010)
www.youthhealthtalk.org (accessed 1 November 2010)
www.youtube.com/results?search_query=patient+story
(accessed 1 November 2010)


50 www.rethink.org/how_we_can_help/campaigning_for_change/stigma_and_discrimination/time_to_change/education_not_discri.html
(accessed 5 August 2010)

51 Barton, P. 2009. Evaluating 10 years of the Longitudinal Care Project. The Clinical Teacher, 6, 38-43