Patient and Public Involvement: Discussion Guidance

May 2013
FOREWORD
from the Chair of the Council of Healthcare Science in Higher Education

I am pleased to present this discussion paper from the Council of Healthcare Science in Higher Education (CHS) considering how to integrate and embed Patient and Public Involvement (PPI) within healthcare science programmes offered by the Higher Education sector.

The healthcare science workforce uses robust modern scientific methods as part of the diagnosis and treatment of patients. These inform wellness monitoring, care plans and the disease management of patients. Whilst the members of the healthcare science workforce only make up 5% of the NHS staff, they are an integral part of 80% of all diagnosis\(^1\).

The NHS is responding to growing expectations and ensuring that PPI is at the core of Higher Education Institution (HEI) courses is essential to developing the capacity of the healthcare science workforce to meet increasing demands. HEIs consequently need to continue to work hard to ensure that the education and training of the healthcare science workforce fully engages with all those whom their profession supports. Patient involvement at all levels of a programme, from design through to implementation, assessment, monitoring and review will demonstrate a full commitment to PPI.

This document is intended to be a starting point for discussions between participants in PPI and HEIs. Further work will be carried out by a CHS PPI working group which will consider the issues raised in this discussion paper. Using this we will work to develop effective guidance for HEIs.

This discussion paper includes both key principles and suggestions regarding the implementation of PPI, along with examples of how HEIs have pursued PPI. It is important to emphasise that these are not prescriptive suggestions of how HEIs should structure their PPI. These examples are offered for further comment and discussion.

I do hope that this document will stimulate lively discussion. It is important that HEIs continue to come together to share learning and their experiences. The CHS provides HEIs with a forum in which to share these ideas. I would like to thank all my colleagues within the CHS and the wider higher education sector who supported the creation of this document by reflecting their experiences of PPI by contributing examples or commenting on successive drafts of the document. Furthermore, CHS would like to acknowledge the important contribution and dedication demonstrated by PPI participants, some of whom have taken the time to comment on this discussion paper. This generous contribution helps to enhance the learning experience of healthcare science students and academic staff alike.

You will notice that throughout this document there are key discussion points and questions and I would urge those who would like to comment on the discussion paper to please contact the CHS at admin@healthcarescience.ac.uk.

Introduction to the Council of Healthcare Science in Higher Education (CHS)
In recognition of the importance of the future role of the higher education sector in healthcare science education and training, the Chief Scientific Officer and the Modernising Scientific Careers (MSC) programme have supported the development and establishment of the Council of Healthcare Science in Higher Education (CHS).

The CHS provides a national voice for healthcare science higher education and will work to develop its profile within the sector, while also ensuring it influences and is informed of developments and opportunities in healthcare science education, research and innovation.

Purpose of this document
This document is a discussion paper which aims to inspire debate and comment. Patient and Public Involvement (PPI) in healthcare science programmes is a developing area and this discussion paper reflects current literature on the subject and suggests further areas that HEIs may need to consider.

As part of the CHS’s work to support HEIs to embed PPI, we will be hosting a working group with representatives from both HEIs and participants in PPI to develop and refine practical guidance that will be offered to HEIs. The CHS intends that this guidance will continue to be updated to reflect the development and experience of incorporating PPI within healthcare science programmes.

Throughout the discussion paper you will notice text boxes with key questions and points for further discussion. If you would like to comment on these areas, or any other parts of the discussion paper please email admin@healthcarescience.ac.uk.

Professor Wendy Purcell
Chair, Council of Healthcare Science in Higher Education
Vice-Chancellor and Chief Executive of Plymouth University
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BACKGROUND

This discussion paper has been developed following on-going discussions regarding the importance of PPI in healthcare science programmes from patient representative groups, regulators and HEIs themselves.

This topic is of increasing relevance given that, since 2009, all Modernising Scientific Careers (MSC) accredited academic providers have been required to demonstrate they have a PPI plan in place. Indeed, to gain MSC accreditation, HEIs must now have a formal strategy and action plan for PPI which should detail how the process and outcomes of involvement will be monitored, along with ensuring that patients and the wider public are part of a working partnership2.

Similarly, in December 2011 the Health and Care Professions Council (HCPC), as a regulator of some healthcare science professions, launched a consultation exercise on the introduction of a new Standard of Education and Training which requires PPI. The consultation proposed that all accredited programmes will have to demonstrate how they incorporate PPI. Subject to approval, this standard will potentially come into effect from 2015–20163.

This is happening in the context of increased public expectations. This is recognised by the NHS’s maxim of no decision about me without me, along with the increased emphasis on the choice agenda. The Francis Inquiry highlights that quality of care is the guiding principle for all healthcare professionals and the need for their focus to be patient-centred throughout their careers4. New working structures and technological developments will increase the level of patient contact of the healthcare science workforce, further demonstrating the need to be patient-centred5.

This document, whilst recognising diversity in healthcare science programmes and that it is important that PPI should be targeted to the needs of individual programmes, attempts to address high-level considerations. This will maximise the benefit to students and staff, alongside potential benefits to patients and the wider public as recipients of healthcare science services.

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3 Health and Care Professions Council, About us, Consultations, Consultation on service user involvement in education and training programmes approved by the Health and Care Professions Council (HCPC), http://www.hcpc-uk.org/aboutus/consultations/index.asp?id=150 (date last accessed 13/03/2013).


DEFINING PATIENT AND PUBLIC INVOLVEMENT

PPI is a broad term which covers an array of activities. As described in the Health Foundation’s report *Can patients be teachers?*, not all patients currently receive care, at times the term ‘lay’ is used to acknowledge this, however this is seen to be inappropriate as it identifies those involved in PPI separately from a healthcare professional. Therefore, PPI is seen to be the best description to use as it allows the document to reflect the variety of contact that the public has with the services provided by the healthcare science workforce.

PPI in this document refers to a range of wider activities to involve and communicate with patients and the public. In this discussion paper, PPI is used to refer to a two-way, reciprocal relationship of equals between HEIs and those people who contribute to these processes.

People who participate in involvement will have a variety of knowledge and experience. Patients will be able to reflect on their current or previous experience of accessing treatment, whereas members of the public could be recruited to participate based on their own experience, for instance, that gained during their careers in education or healthcare management. It may be the case that those who have previously accessed services as a patient may be able to offer particular insights and expertise with regards to the delivery of a programme, whereas a member of the public may have specific experience and knowledge which could feed into the design of healthcare science programmes or curricula. However, it is important to be mindful that the distinction between patients and the general public is blurred; we are all very likely to access healthcare science services and so HEIs should consider what contribution the individuals involved in PPI activities are making and work to understand the effects of this on PPI activities.

For ease of reference, this discussion paper refers to ‘participants’; this is meant as an inclusive term and reflects those, both patients and the wider public, who contribute to involvement activities.

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BENEFITS OF PPI

PPI in healthcare science education offers a number of benefits for students, teaching staff and participants alike. Including:

- Helping students to understand their role as part of a wider healthcare team
- Injecting ‘reality’ into students’ experience by involving participants in training and teaching
- Offering the opportunity to address students’ pre-existing conceptions of people accessing services
- Allowing participants the opportunity to make an active contribution to students’ study
- Empowering participants and potentially increasing confidence when accessing healthcare services
- Allowing teaching staff to test and challenge their own assumptions and perceptions

PPI should develop a relationship of equals between patients and healthcare professionals. Engagement can allow students to reflect on the experiences of the patient (something they will be required to do throughout their careers) and can be helpful in preventing the development of divisions between the healthcare professional and the patient.

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7 General Medical Council (2011) Patient and Public Involvement in Undergraduate Medical Education: Advice supplementary to Tomorrow’s Doctors.
BRIEF REFLECTIONS:
RECENTLY PUBLISHED LITERATURE

The Professional Standards Authority for Health and Social Care (PSA) assess the performance of professional regulators and published a report in 2011 to identify effective methods for regulators to embed PPI. The report highlights that PPI helps to support public confidence in the actions of a regulator, as well as enhancing the development of policies and communications. Nevertheless, the report also suggests that regulators found the process of evaluating their PPI processes challenging and that approaches to develop involvement need to be focused and tailored to the needs of participants. The report also highlights the actions of the General Medical Council (GMC) in establishing a reference group to support involvement; this is stated to support the development of expertise and consistent advice which can be drawn on when needed.

Such conclusions demonstrate that it may be valuable to consider how PPI can be embedded within the management structure of healthcare science courses.

Discussion point:
- How can PPI be embedded within programme planning and budget setting for healthcare science programmes?
- How can we measure the impact of PPI on healthcare science courses?

In addition, the GMC’s Good Medical Practice highlights the professional standards they expect from their registrants, indicating the expected skills necessary to work in partnership with patients. This includes sharing information with patients on their care, as well as detailing the confidentiality of patient information. Such guidance also refers to the involvement of patients in teaching and research activities, highlighting the need to gain informed consent from patients. Further GMC guidance, Medical students: professional values and fitness to practise, also states that academic work should not identify the patient outside of their care team.

Guidelines produced by INVOLVE, an organisation which works to support active public involvement in NHS, public health and social care research, further suggests the need to respect the boundaries of participant privacy, along with clarifying how participant information will be used. This helps to demonstrate the breadth of experience and knowledge within other healthcare education programmes which healthcare science programmes could develop.

8 Professional Standards Authority, Patient and public participation in health professional regulation, 2011.
9 Ibid.
10 General Medical Council (2013) Good Medical Practice.
11 General Medical Council, Medical students: professional values and fitness to practise, Home, Education and training, Undergraduate education, Standards and guidance, http://www.gmc.uk.org/education/undergraduate/professional_behaviour.asp (date last accessed 03/05/2013).
Discussion Point:

- What can healthcare science programme providers draw from the experiences of PPI in other healthcare profession programmes?
- Is there the potential to share resources?
- Are there any barriers to this and how can they be resolved?
PROPOSED PRINCIPLES OF PPI

There are a number of key principles that HEIs may wish to take into account when pursuing PPI. This section offers a number of general considerations for HEIs:

- HEIs should strive to ensure participants both individually and collectively are treated fairly and consistently.
- Participant viewpoints should be seen in the very least as equally valid perspectives which are allowed to challenge the status quo. As part of this, every opportunity must be built in to ask participants what works for them and how they want to be involved and whether their involvement is working for them.
- HEIs should ensure regular and effective communication with participants to share the HEI’s plans. This will help to manage expectations.
- The value and achievements of involvement should be communicated to both participants and staff members alike. This will build momentum behind involvement and could help participants feel valued.
- Good practice should be shared between HEIs developing involvement.
- When planning, HEIs should take into account both the practical necessities of implementing involvement, along with working to ensure that a culture of involvement is embedded within an organisation.
- HEIs’ staff should deal with participant complaints promptly and effectively.
- HEIs should respect the boundaries of privacy and behave in an ethical manner. It should be made clear to participants from the start how their information will be used and the expectations placed on both staff and students involved in PPI.
- Students and participants alike should be clear about the behaviour expected during a session, it is important to highlight the importance of confidentiality, along with treating all parties as equal partners in the teaching experience.
- The relationship between HEIs and participants should be grounded in confidentiality, where the participant defines the scope of the confidentiality.
- HEIs should recognise that the extent to which participants are able, or choose, to engage may vary greatly based on the individual’s circumstances.
- HEIs must brief participants and students before any involvement session to ensure they each understand their role, and the learning outcomes the session will achieve. This should

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be done well in advance of the session to ensure any learning needs of the participant can be identified and met.

- HEIs may also want to consider whether participants’ reflections on their experience of accessing healthcare science services should be fed back to healthcare providers, along with how this feedback may be structured.

Discussion point:
- How can these principles be refined?
- Are there other principles that should be considered?
PRACTICAL CONSIDERATIONS

This section builds on the principles above by suggesting some practical considerations that HEIs may wish to take into account when embedding PPI by drawing on the literature to provide an overview of several different overarching topics, from the recruitment of participants to evaluation. The lists detailed in this section are neither exhaustive nor prescriptive, and the emphasis here is on enabling an exchange of information and practice to assist in the development of the approach to PPI.

Recruiting participants

Current literature on PPI suggests that recruiting participants can be a time and resource intensive activity; however, this should be done effectively in order to support the sustainability of involvement.\textsuperscript{15}

The following list proposes a number of considerations for HEIs when putting together recruitment strategies for HEIs:

- HEIs should first develop an involvement strategy which explores and defines where involvement will be embedded. This should inform the development of a role outline, detailing the knowledge and skills participants should have. From this, a recruitment strategy can be developed to ensure all participants are treated fairly and consistently.

- HEIs should establish how many participants they are likely to need. Adequate numbers of participants will also mean that PPI can continue if some participants decide they no longer want to be involved and will ensure that participation does not fall on one person.

- HEIs might wish to use social media to involve many different communities in planning and delivering healthcare science courses. HEIs should be mindful that it could take time to develop channels and keep them updated, but that this could offer a low cost solution to reaching out to the population. Nevertheless, some people do not have access to these facilities.

- Consideration should be made of placing literature in GP surgeries, parent and toddler groups, day centres or luncheon clubs to attract participants. Contacting a local radio station might also be another way of reaching potential participants.

- HEIs should be clear with participants about the amount of time they will be asked to give up, along with asking whether any support is needed. It is also important to use this early opportunity to communicate the purpose and importance of PPI.

- HEIs should understand the needs of participants and ensure that PPI activities take these needs into account. Participants should be asked how they prefer to be contacted.

\textsuperscript{15} M. Chambers and G. Hickey (2012) Service user involvement in the design and delivery of education and training programmes leading to registration with the Health Professions Council, HCPC.
HEIs should consider whether patients will require training to support their involvement, the level of training required will depend on the approach taken and can help patients feel valued\(^\text{16}\).

Staff too may need training, particularly when engagement is focussed on promoting accessibility\(^\text{17}\).

HEIs may wish to create a bank of participants and match them to the PPI activity, if a HEI should choose to do this, it is important that the contact details of participants are kept confidential, with access to the resource granted to a designated member of staff.

To create a bank of people willing to get involved, HEIs will need to make links with local community and patient networks and these may be extended to regional or national networks. This also offers an opportunity to maintain representative involvement.

**Securing Representation**

Related to the recruitment of participants is the question of how representative the group should be of the wider public. In line with this, HEIs could consider the following points:

- Are there physical barriers that prevent people getting to the venue?
- Are there non-physical barriers which inhibit involvement? This could include the over-use of jargon or participants not feeling confident about the expectations placed on them. This could be resolved through a close relationship with a named contact.
- Are there a range of involvement activities so participants can choose their level of commitment\(^\text{18}\)?
- Does the timing of the session preclude involvement by employed people? If people are paid for their time, would this cover potential lost earnings?
- Can the experience of an individual be applied to the wider community and other individuals\(^\text{19}\)? This may especially be the case if members of the public are involved in PPI activities because of their specific knowledge or expertise. Have participants become ‘professionalised’ through their previous involvement?\(^\text{20}\)?

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\(^{16}\) Trent NHS Strategic Authority, *Principles for Practice: Involving Service Users and Carers in Health Care Education and Training*.


\(^{18}\) Ibid.

\(^{19}\) NHS Confederation *Patient and public engagement in the new commissioning system*.

HEIs may want to work with participants to develop an access plan which would consider how any potential needs might be met. This could include providing support to travel, any mobility aids, hearing loops, additional breaks or dietary requirements.

Has easy to read material about the PPI activity been provided? This should also include directions to the venue, along with details on public transport.

Are there opportunities for new people to become involved in PPI? It may be that HEIs might want to consider whether a participant’s involvement is limited to a certain amount of time. Again, this should be clearly communicated at the start of involvement.

Should a nominated participant act as spokesperson to raise any concerns or issues to the involvement lead? This may help some individuals feel more comfortable in becoming involved.

Reimbursement

It is suggested that HEIs should consider that it is good practice to reimburse participants and that ideally those who wish to volunteer rather than be paid for their involvement should still have their expenses paid\(^\text{21}\).

Expenses can include childcare costs, travel and associated refreshment and sustenance costs. Reimbursement can be one of the more difficult barriers for HEIs to address and it is important to work with finance departments to establish processes with the required flexibility to reimburse participants quickly.

Related to the above, suggested points of consideration are:

- What processes could be put in place to facilitate prompt payment to participants?
- How will participants be informed of the payment processes?
- Will participants need to have their travel expenses paid before the session?
- Are participants concerned about the effects of cash payments on any benefits they may receive? This is a complicated area and participants should be asked whether the payment method proposed by the HEI is suitable for their own personal circumstance and recommended to seek further advice if necessary.
- Would gift vouchers be preferable for some participants? It will be important to communicate with participants that this may still be viewed as income and that participants who receive benefits need to disclose this information if requested.
- Do participants prefer to be paid in one go or for their payment to be spread over a period of time\(^\text{22}\)?

\(^{21}\) SCIE, *The Participation of Adult Service Users, Including Older People, in Developing Social Care*.

\(^{22}\) Tew et al. *Learning from Experience: Involving service users and carers in mental health education and training: a good practice guide*. 

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Evaluation of PPI

Evaluation of PPI is crucial to help programme designers understand the strengths and weaknesses of their approach, along with the impact it has had. Evaluation is a multi-faceted approach and can involve looking at aspects including:

- the quality of the content
- the delivery process
- the impact of the activity or programme on the audience(s) or participants.

Carrying out an evaluation can be challenging for HEIs as it will involve creating a criterion for judging involvement. With this in mind HEIs should note that often the most effective method of policy evaluation depends largely on what an ‘evaluator’ is looking to measure and, as a result, there is no unique formula which offers a single way of carrying out this process.

In spite of this, when considering evaluation there are a few principles of evaluation which HEIs might wish to reflect on:

- **What are the aims and objectives of engagement?** Having clear aims and objectives will help HEIs start the process of developing both the activity and an evaluation strategy. While involvement in healthcare science programmes is targeted towards improving the experience of students, it is important not to forget that ultimately the aim of involvement is to promote better outcomes for those accessing healthcare science services.

- Are the above objectives SMART:
  - Specific
  - Measurable
  - Achievable
  - Relevant
  - Time-bound

- **What monitoring and evaluation tools will be used to inform the aims and objectives?** E.g. questionnaires, interviews, focus groups, observational exercises. NB. When using focus groups, HEIs may want to consider whether participants feel comfortable to contribute. Caution should be exercised to ensure teaching staff do not dominate the group and assume an overt identity of an ‘expert’ which could limit discussion.

- **How will the findings be reported?** HEIs might wish to consider reporting findings in different ways to a) teaching staff b) regulators c) participants d) students. Sharing the results of the evaluation will also provide one way of validating the results.

**Discussion point:**

- Are there other principles of evaluation that HEIs should consider?
A Framework for Evaluation

It is important that HEIs work to develop a framework for evaluation in which they can assess themselves; this can help support the reliability of results by providing some consistency to evaluations. Involving staff, participants and students in the development of the framework may help ensure it measures what it intends to, helping to enhance the validity of the evaluation.

One potential way of progressing this approach may be to consider the ‘Ladder of Involvement’ as developed by Tew et al. to describe different levels of involvement. PPI may develop at a different pace within some programmes, nevertheless, using a framework can help to identify areas for improvement.

<table>
<thead>
<tr>
<th>Level 1:</th>
<th>No involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 2:</td>
<td>Limited Involvement</td>
</tr>
<tr>
<td></td>
<td>Some contact with local community or patient groups, involvement is at the discretion and invitation of HEIs. Involvement is primarily through the delivery of the programme rather than the way the programme is structured.</td>
</tr>
<tr>
<td>Level 3:</td>
<td>Growing Involvement</td>
</tr>
<tr>
<td></td>
<td>Involvement is established but decisions are often made without the involvement of participants. There is little consistency to the delivery of training and debriefing sessions.</td>
</tr>
<tr>
<td>Level 4:</td>
<td>Collaboration</td>
</tr>
<tr>
<td></td>
<td>Participants are seen to be a member of the team and contribute to key areas of decision making with regards to the content and delivery of the course, along with its evaluation.</td>
</tr>
<tr>
<td>Level 5:</td>
<td>Partnership</td>
</tr>
<tr>
<td></td>
<td>Participants and staff work together across all dimensions, with participants potentially being an employed member of staff, with infrastructure in place to support the participant in their involvement.</td>
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</tbody>
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The following proposed questions may help inform the application of the evaluation framework.

- How far has PPI been embedded into the structure and culture of the HEI? What was involvement like before?
- Will the process of involvement lead to improved service provision and outcomes? What sort of evidence could be used to demonstrate this idea?
- Were participants representative of a wider community? Was this considered important to the success of the involvement activity?
- What impact has the activity had on relationships between staff, students and participants?

Discussion point:
- How can the validity and reliability of PPI be enhanced?

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23 Ibid. p.54.
• Did the activity change staff and student’s understanding/knowledge or attitudes?
• Has the activity impacted on programme delivery?
• Has the activity impacted on policy and strategy at the HEI?
• Were participants, staff and students clear about what they were being asked to get involved in?
• Were participants supported appropriately?
• How much did participants enjoy the activity?
• How should HEIs respond to the findings of an evaluation to support the sustainability of involvement?

**Key discussion point:**

- **Are there other questions HEIs should be asking to inform their PPI?**
STAGES FOR PPI

There are a number of different stages of designing and delivering a healthcare science programme. The subsequent signposts are subject to further discussion and have been included to broadly represent the participant and student journey.

1. Programme design
Programme design considers how a programme will be structured, including the approaches used to teach students. It is the first stage in delivering a programme and so it is likely that the early stages of design will coincide with the development of a PPI strategy or plan.

The following proposals maybe areas HEIs would like to consider:

- Would the development of a reference group provide initial input on how involvement in programme design should be structured? Such a group may help support the sustainability of involvement and it may be particularly useful for this group to include patient representative organisations and expert patients who would be able to contribute to PPI at this early stage.

- Would this reference group report into an overarching HEI PPI development group?

- How will HEIs ensure the contributions of participants are given the same importance as the input of staff members?

- How will HEIs consider and respond to the needs of participants? For instance, HEIs might consider whether participants will require access to facilities such as photocopying or printing.24

- What role can expert patients play in contributing to programme design sessions?

- The GMC highlights the specific viewpoint offered by patients with a long-term condition, how can HEIs consider the contribution offered by this patient group?25

2. Putting the curriculum into practice
Part of developing a healthcare science workforce responsive to the needs of participants is ensuring this subject is effectively covered within the curriculum. It is suggested that participants should be asked what the curriculum should incorporate in order to support the development of a healthcare professional responsive to their needs.

The following proposals maybe areas HEIs would like to consider:

24 Ibid.

25 General Medical Council (2011) Patient and Public Involvement in Undergraduate Medical Education: Advice supplementary to Tomorrow’s Doctors.
Could PPI be embedded in a curriculum review exercise to make sure the curriculum is relevant to the needs of participants?

Does the revalidation of an accredited programme offer the opportunity to consider whether programmes are matching the expectations of participants?

Could participants contribute to reading lists to offer students alternative resources which could potentially give further insight into the experiences of participants?²⁶

3. Student recruitment

There is also the potential to incorporate PPI in the recruitment of students as participants can reflect on their previous experience of accessing treatment to consider the personal qualities, skills, knowledge and abilities which improve the experience of accessing services.²⁷ Furthermore, this can also support students to see the programme actively valuing the contribution of individuals’ experience of healthcare science services.²⁸

There are a number of suggested considerations when developing PPI in the recruitment of students, including:

- What level of involvement would participants like to have?
- Is there the opportunity for participants to be involved in the development of the selection criteria and contribute to shortlisting activities?
- Could participants sit on the interview panel?
- Is there a particular question participants feel should be asked?
- How can the HEI ensure that candidates for healthcare science programmes are treated consistently?
- Are there any quality assurance processes that can be implemented to support this?²⁹

4. Programme delivery

It is suggested that PPI in programme delivery can encourage students to value the experience of patients, highlighting that often patients have a wealth of knowledge regarding their own conditions.


²⁷ Trent NHS Strategic Health Authority, Principles for Practice: Involving Service Users and Carers in Health Care Education and Training.


²⁹ Ibid.
Current literature highlights the importance of informed consent. Participants should consequently be given time to consider whether they want to participate and should be given the chance to ‘opt out’\(^{30}\). It is suggested that part of this also involves being clear with participants whether their case will be discussed further in the module, perhaps when they are not present\(^{31}\). It is also proposed that HEIs need to communicate how students will be involved in the session, including the level of skills students have obtained.

It is suggested that involvement in programme delivery could be through:

a) Taking an active role in teaching (the presence of participants may positively affect the way students interact with teaching and influence students’ subsequent perceptions of participants).

- Are there opportunities for participants to collaborate with teaching staff to deliver sessions? Here, both teaching staff and participants can agree on their specific role during the session.
- Would teaching staff be able to role model effective communication and partnership working to the student?
- Is there an opportunity to review whether the language (particularly jargon) used by teaching staff and students inhibits the involvement of some participants?

b) Developing teaching materials

- Is there the opportunity for a participant’s story to be used to highlight the integration and involvement of healthcare professionals? Could this be shared across different faculties? Could this help support a range of healthcare science specialities with varying patient contact?
- Could participants be involved in role playing to support students in developing clinical skills?
- Is there any value in using technology to support participants to become involved remotely\(^{32}\)? What support might be required for participants to do this?

It is proposed that considering the following practical points can help ensure involvement in programme delivery runs smoothly:

- What are the training needs of participants?
- Teaching staff should be easily accessible and should stay in the room during the session.
- Sessions should be structured to provide adequate breaks and access to refreshments.


\(^{31}\) Ibid.

\(^{32}\) Ibid.
After the involvement session participants should be asked their opinion of how the session went, a full debriefing should also be provided by teaching staff which will allow any queries or concerns to be answered\(^{33}\). There is also the opportunity for teaching staff to respond in writing to any suggestions as to how the session could be improved.

5. Assessment and feedback to students

There is also the opportunity for participants to be involved in assessing and giving feedback to students. The literature on PPI highlights some questions as to whether this is appropriate and so careful consideration is needed in regards to this. The British Medical Association reports that, depending on the nature of involvement, it can validate assessments as it demonstrates how students interact with patients\(^{34}\). It may also provide an alternative perspective which is valuable to students.

The points below are proposed questions HEIs may wish to consider:

- What role will participants play? Is there the opportunity for participants to work with teaching staff to create assessment strategies and guidelines, along with involvement in Objective Structured Clinical Examinations (OSCEs)\(^{35}\)?
- Is there the opportunity for participants to be involved in the design of some questions or the marking scheme for an assessment? How can participants contribute to the marking of reflective work?
- What training is required by participants? How is this to be identified and how will HEIs respond to this? Guidance produced by Trent Strategic Health Authority suggests there is a need to consider who delivers the feedback to students, do participants feel comfortable in doing this or should teaching staff deliver this feedback\(^{36}\)? It is also important to consider how to maximise the value of this to students.
- There is the opportunity for participants to be allocated a learning mentor who will support the participant when giving feedback to students.
- What weight should be given to participants’ assessments? How will differences between the opinion of teaching staff and participants be resolved\(^{37}\)?
- What processes need to be in place to ensure students are treated fairly and equally in assessments?

\(^{33}\) Trent NHS Strategic Health Authority, *Principles for Practice: Involving Service Users and Carers in Health Care Education and Training*.


\(^{35}\) Ibid.

\(^{36}\) Trent NHS Strategic Health Authority, *Principles for Practice: Involving Service Users and Carers in Health Care Education and Training*.

\(^{37}\) Ibid.
Do HEIs’ wider assessment policies need to be reviewed to ensure alignment?

6. Programme review and feedback to staff
Programme review helps to make sure a healthcare science course meets its aim to select, develop and graduate students who practise as part of a patient-centred healthcare science workforce and participants have a unique status which can help inform this process.

HEIs might wish to consider whether there is the opportunity for participants to contribute feedback by sitting on module and course review committees as well as whether participants could sit on faculty boards.

Programme leads should communicate the outcomes of programme reviews and highlight the difference participants’ contributions have made to the programme.
CONCLUSION

This discussion document has attempted to provide a starting point for HEIs to develop their PPI strategy. HEIs are independent bodies and their involvement strategy must respond to their own individual needs. This document is only the start of a process to support HEIs develop their approach to PPI and the CHS looks forward to working with participants and HEIs to develop future guidance on this topic through the PPI CHS working group.
APPENDIX:

Examples of Patient and Public Engagement and Patient and Public Involvement in healthcare education

Below are examples gathered from HEIs and training providers on their involvement activities across different healthcare profession programmes. These examples have been included to further inspire discussion on how HEIs could and should embed PPI rather than offering a prescriptive approach.

Middlesex University: Cardiac Physiology

Middlesex University has embedded Patient and Public Involvement throughout its Cardiac Physiology programme. The Partnership Board includes participants who make recommendations that inform the development of the curriculum, along with the provision of programme reviews and feedback and recommendations to address identified issues. Participants will also be part of the programme design team during the next programme review.

The experience of Middlesex has indicated that clear terms of reference should be developed to clarify the role of participants on the Partnership Board. This will also be supported by running a one-day induction programme during the summer.

Participants also support the delivery of a programme through:

- Telling life stories, discussing experiences or role-play
- Developing learning resources, such as case histories and patient experiences through the use of video, audio or written means
- Contributing to the assessment and provision of feedback to students
- Contributing to a research project steering group, which provides ongoing feedback and helps to formulate research questions
- Being involved in a student research project

Middlesex University has found that a dedicated Patient and Public Involvement champion needs to be identified. This person should be responsible for not only developing a strategy to embed Patient and Public Involvement in the curriculum, but also ensuring that it is implemented.

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Newcastle University: Voice North

Hosted by Newcastle University’s Initiative on Changing Age, Voice North is a Research and Engagement panel for the North East. Established in 2009, currently over 3,000 members of the public and patients are involved in a wide range of research and teaching activity, largely focused around ageing and chronic disease.
Members have been involved in a range of teaching activity within the Biomedical Research Centre and there are plans to further develop within the MSc in Clinical Sciences as part of Modernising Scientific Careers.

Training and support on Patient and Public Involvement in research is offered to Voice North members in a series of workshops using INVOLVE resources. The impact of this activity is being evaluated and early findings suggest that it is helpful to students in understanding their role as part of the wider healthcare team and in gaining valuable insight into the patient experience. It allows patients and the public to make an active contribution to students’ study and learn in depth about the science involved:

“We have really valued the opportunity to learn more about the exciting work that the students are undertaking. As a patient, we see the end product, the new treatment and so on, and it has been so interesting and lovely for us to appreciate the scientists and their often painstaking and detailed work that lies behind all and to feel in some way we are contributing to that”

Voice North member

“I hope through taking part in [this kind of activity] we can show students first hand just how much we – as older people who are effectively benefitting from the fruits of their labour – appreciate their work. I hope we can communicate just how much this is valued, and let others know and encourage them to get involved too”

Newcastle Biomedical Research Centre PPI member

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St George’s: Cardiac Physiology
St George’s University of London Healthcare Science programme in Cardiac Physiology, Respiratory and Sleep Physiology involves visually impaired patients taking the role of tutor to come in and lead the students through a range of interactive activities, as well as working to consider legislative requirements. A session on communication skills is also held with a group of ten hearing-impaired students who volunteer to run sessions designed to highlight what the student should be aware of when working to support people with a hearing impairment.

St George’s also runs a session whereby students interview a patient who is about to undergo a test and has consented to be interviewed. The interview is designed to allow the student to reflect on the patient’s perspective of undergoing a test, with particular reference to how much information the patient has received, how much has been understood, along with giving an insight into the patient’s concerns.

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University of the West of England

UWE held a session recently which involved an individual with a learning disability co-teaching a session on communication.

Before the session, teaching staff met with the individual to explain what will be involved and fully plan for the session. The individual was encouraged to bring up anything she wanted discussed, with the teaching staff member taking notes which were subsequently validated by reading through what was written. A PowerPoint presentation was designed which would be used to help facilitate the session.

During the session the individual presented for almost two hours and had control of the whole session, from the content of the session, to how it was paced and their relationship with the students. The individual was happy to give advice, information, as well as suggestions for the students to reflect on. The member of teaching staff was there to provide prompts if necessary and ask further questions, along with checking whether the individual was happy to answer potentially personal questions.

These key aspects were identified as being crucial to session running successfully:

- Teaching staff were present during the session and supported the facilitation of the session but the individual directed the session.
- At every stage of the process the named contact worked to check the level of understanding from the individual and whether they would be happy to answer questions from students-informed consent is vital and should be confirmed regularly.
- Payment was received at the rate of an Associate Lecturer, with payments and needs assessments managed through a single administrator.

Experience from UWE shows the importance of building a trusting and therapeutic relationship with those involved in engagement activities. Time before the start of a session needs to be allocated to the development of this relationship.

Quotations from students:

“Just a quick message to say thank you for organising the visit of xxx to our lecture today. It was lovely to talk to her and definitely gave a better understanding of learning disabilities. We would love to see her again soon and I would recommend the same sort of set up with the following year”

“...thought I should let you know how useful today's lecture was. We had xxx come in who is an individual with learning disabilities. It was her first time teaching but she was very helpful, she was happy to answer our questions and was great at giving us advice. I feel this was one of the most useful lectures we've had in this module. xxx said that she enjoyed teaching
today and that she would like to come back to teach us again in the future, I think that would be very useful for us...”

Thoughts from a participant:

The following comments summarise how the individual who co-taught a session felt about their involvement

I believe that it is really important that the public, including students understand the lives of people with learning disabilities including a range of adversities that I face on a day-to-day basis. I am a sociable person, I enjoy meeting new people and finding out about who they are and this helps me feel relaxed.

I was tense and nervous to begin with but the teacher and the students made me feel relaxed.

The responses from the students are important to me; they respected, listened and were interested in what I had to say and this made me feel good too. I felt valued. I enjoyed answering their questions.

Because I had good experiences with my teaching I would be happy and motivated to teach again. However, I would need someone to guide and help me through the process again, someone I like and can trust.

I would like to teach again in a bigger room with more students. I would find this challenging but with the right support I would look forward to that.

The money is important to me as I can spend it on what I want.

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Plymouth University:

Plymouth University organises an NHS Service Users Group which is used as a forum to disseminate views from both patients and the public to programme teams as appropriate.

In addition, direct contact with the general public is facilitated through a series of outreach events such as the Hi-tech Health Events held annually at the University’s Knowledge Spa at the Royal Cornwall hospital in Truro and the Science and Technology Showcase events held in September in the graduation marquees on Plymouth Hoe.

Plymouth University intends to increase student contact with patients and the public through the setting up of an outreach clinic for respiratory function testing and through healthy heart and lung days in the clinical physiology teaching laboratory. These initiatives will bring our students in close contact with patients and public and provide valuable opportunities for dialogue with healthcare
science students and educators. Outreach is a key priority for programme managers and academics in the School of Biomedical and Biological Sciences.

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Brunel University: Physiotherapy
When members of the local osteoporosis and breathe easy group were approached to help with the design of the Physiotherapy BSc programme they not only provided invaluable insight into how student education could be improved but also offered to be involved in the delivery of the students’ education. In response, physiotherapy lecturers at Brunel University have recruited people with a variety of neurological, respiratory and physical conditions to come into the university to deliver tutorials with first year physiotherapy students.

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Buckinghamshire New University: Nursing
Bucks New University incorporates Patient and Public Involvement throughout the student journey, beginning with the interview and selection process for pre-qualifying nursing students.

Representatives from “People’s Voices” (http://www.peoplesvoices.org.uk) are regular members of interview panels; participate in simulated learning activities and contribute to teaching sessions.

Participants are also involved in the development of courses and curricula as part of a curriculum development team. As well as regular attendance at the Patient in Partnership (PiP) meetings held at one of the university’s partner Trusts, members of the curriculum development team meet separately with PiP attendees and a local Carers Association to ensure these voices are also included in curriculum development.

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Manchester Academy for Healthcare Scientist Education
Manchester Academy for Healthcare Scientist Education (MAHSE) is a partnership between the University of Manchester, Manchester Metropolitan University and the University of Salford, as well as leading healthcare scientists from partner Trusts.

MAHSE is working to involve patients and members of the public within every healthcare science programme it supports and will work to facilitate links between healthcare science educators and the wider public. MAHSE will also promote healthcare science and the opportunities to become involved throughout the region.
As part of this, a patient and public forum is being established. This is an interested group of patients and the wider public who will form an autonomous committee that will feed into the MAHSE Board on topics such as the development of teaching tools and materials, assessment through practical exams, programme planning and evaluation. As required, the forum will provide input and support for individual healthcare science programmes developed under the MAHSE umbrella. Once set up, the patient forum will be held around four times a year to fit into key times when trainees are in Manchester as well as at suitable times to feed into the MAHSE Board.

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The West Midlands Regional Genetics Laboratory working with UNIQUE
UNIQUE is a charity which provides information and support to families and individuals affected by any rare chromosome disorder. Collaboration between UNIQUE and the West Midlands Regional Genetics Laboratory (WMRGL), a large diagnostic genetics laboratory based at Birmingham Women’s NHS Foundation Trust, has allowed Genetic Scientist Training Programme trainees to volunteer to gain first-hand experience of the effects that various genetic anomalies have on the individual and their families.

UNIQUE holds a Family Conference where families affected by chromosome disorders are invited and encouraged to get together and meet others who may be encountering similar difficulties, listen to presentations on a range of issues and provide access to information on benefit entitlement and genetic counselling. Families are encouraged to bring their children along and a crèche is available to allow parents the opportunity to attend meetings and for some ‘time out.’ Volunteer participants from WMRGL, including trainees, are encouraged to sign up to offer additional support to the crèche. The success of the Family Conference has led to further collaboration with UNIQUE and the provision of syndrome specific days. Again trainees are able to volunteer at the crèche and gain further insight into the effects of these syndromes.

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The University of Southampton
The University of Southampton’s BSc programme in Cardiac Physiology, Respiratory and Sleep Physiology invites an expert patient to come in to share his experiences of living with diabetes. This session maps onto the programme when students learn about the anatomy and physiology of the endocrine system, the pathology of diabetes, as well as the psychosocial science relating to the patient’s response to illness and psychosocial influences on health behaviours.

Feedback from students on the session was positive; it helped to bring the theory of the course to life and added to students’ enjoyment of the session, offering the opportunity to interact with a “real” patient.

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