



**University of
Sunderland**

Faculty of Applied Sciences

**Staff Guidance
for
Patient, Carer and Public Involvement
(PCPI)**

Department of Pharmacy, Health and Well-being

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Definition of Patient, Carer and Public involvement (PCPI)

There is no one standard definition or term that represents patient involvement in either the National Health Service (NHS) or within universities (HEI's) (Towle et al., 2010). Terms that are used interchangeably across reports and journal articles can include any of the following: carer, client, consumers, family, patient, parents, service user, survivors or PPI (Patient and Public Involvement/engagement). Within the Department of Pharmacy, Health and Well-being service user and carer involvement is called **Patient, Carer and Public Involvement (PCPI)**.

PCPI Participants

We have an ongoing recruitment process, to recruit to the PCPI programme and the number of PCPI participants steadily grows. PCPI participants are recruited to participate in a number of areas and they can participate in as many or few as they like. The options they can choose from are:

- Recruitment and Selection
- Teaching
- Programme Management
- Curriculum Development
- Physical examination
- Assessment - Observed Structured Clinical Examinations (OSCE)
- PCPI reference Group
- Research

Majority of PCPI participants produce a case study which contains information about social background, medical history and medication history. PCPI participants' sign a consent form which allows us to upload their case studies onto Sunspace. Some PCPI participants have also recorded their sessions and these can be made available to the students (via Sunspace).

Some PCPI participants do not have any underlying medical condition and participate in a variety of the more generic activities, such as consultation and communication skills development, OSCE's, and recruitment and selection. We also have a number of PCPI participants who are willing to participate in practical clinical skills sessions, such as having an ECG carried out or undergoing a clinical examination (e.g. respiratory, cardiovascular or gastrointestinal examination).

How do I involve PCPI participants?

At present, all opportunities for involving PCPI participants is routed through Lesley Scott (L.Scott@sunderland.ac.uk). Initial enquiries can also be dealt with by Lynn Wansell (Programme Administration Officer (Nursing and Health) and (PCPI)) via fas-ccpi@sunderland.ac.uk. Ideally, we plan PCPI involvement one semester in advance, however, we can deal with a shorter notice period, although as much notice as possible is appreciated. There is quite a lot of background paperwork that needs to be completed for every session that includes PCPI participants, including completing risk assessment forms etc., therefore it is vitally important that you provide as much information as possible.

Information required

In order to ensure that we have the correct PCPI participant for the session, more information that you provide the better, will be used to match PCPI participant to your requirements. As well as using this information to match PCPI participants to sessions the information will also be used to brief the PCPI participant. In order to ensure the best possible experience, both for PCPI participants and for the students, then please provide as much information as possible. Please note that there are some rooms across the University that are not suitable when involving PCPI participants, so on some occasions it may be necessary to change rooms.

The table on the next page outlines as a minimum the information required for involvement of PCPI participants.

How many PCPI participants do you require?	
Week(s) number	
Date of Session (s) – if multiple sessions please ensure you provide all dates	
Time(s) of Session	
Degree Programme:	
No of students attending Seminar:	
Module Code:	
Room numbers and locations	
Briefly outline the role of PCPI participant (What are they required to do eg discuss in small groups any prevailing condition; use a standard case to develop communication skills; participate in an OSCE; have a physical examination carried out. Attend a meeting as a PCPI representative, being on an interview panel.)	

Additional information

Please can you ensure that you provide the relevant supporting paperwork depending on the type of PCPI activity. It is always useful to have some **background information about the course**, as well as:

Activity	Type of Information required
OSCE: Physical examination	Outline of what required from PCPI participant, eg abdominal examination, chest examination, knee examination, eye examination. How long does each station last, how many students will they see, what time are the breaks? Please provide as much information as you can.
OSCE: History taking station	Please provide the case/cases so that these can be sent on to the PCPI participants in order that they become familiar with them. How long does each station last, how many students will they see, what time are the breaks?
Teaching session:	What is the structure of the session, how many students, what size groups will the session be split into? Is it a generic communication skills session, is it condition specific, is it around MDT/IPL i.e. what is the focus of the session
Interviews	Structure of the interviews. Who will be on the panel? Is it University or a NHS panel? What is the focus of the interview? What questions will be asked? All papers (e.g. applications, person statements etc.) including timetable for the interviews need to be sent to the PCPI participant at least one week before the panel.
Programme Boards/other Meetings	Please provide an agenda for the meeting/board with minutes of at least the last meeting and if possible a couple of previous meetings. Please outline what you expect from the PCPI participant.

Please note if you have involved PCPI participants before and would like to request someone by name that is fine, but no guarantee can be made to provide the same PCPI participant.

Arrangements for meeting/greeting and refreshments

The standard arrangement is that when you are involving a PCPI participant, then you (or nominated representative) will meet the PCPI participant at the Reception Area in Dale Building of in the Patient Flat area of the Living Lab. Majority of PCPI participants arrive about 10 minutes (or earlier) before the agreed time. If they are contributing to a teaching session that lasts a number of hours, there is either a refreshment crate that you should take into the session or bottles of water will be provided. If PCPI participants are here all day, if catering is not being provided as part of the activity to which they are contributing then we need to ensure that we have requested hospitality vouchers for them. We have developed some principles of how we work together please see appendix A for these. We need to ensure that we look after our PCPI participants as they make a vital and valued contribution to all our courses across the Department.

Support for students/PCPI participants

In the unlikely event that students become distressed during a session, we need to ensure that the student is supported. In the first instance this support is provided by the academic member of staff delivering the session. If the academic member of staff has concerns regarding the student then they can refer them to the University Student counselling service. If the PCPI participant becomes distressed, then please support them in the same way as you would support a distressed student, but please inform the PCPI lead as soon as possible after the event so that they can follow up and ensure that the PCPI participant is fine.

Feedback

Feedback is collected from PCPI participants on a regular basis, informally at the end of involvement sessions as well as more formal structured feedback sessions. PCPI feedback is extremely important in order to shape future engagement activities. More formal feedback and suggestions are also fed through activities around curricular development and programme boards.

If you have any feedback with regard to PCPI participants, this should be sent to the PCPI lead in the first instance. If you have suggestions or would like to discuss future opportunities

for involvement of PCPI participants or have particular groups you would like to recruit to for future involvement, the PCPI Lead would be more than happy to meet up with you to discuss this. Also if you have any concerns or reservations regarding the input of the PCPI participants to activities, these should also in the first instance be fed back to the PCPI Lead. This feedback is very important, as some PCPI participants are more suited to certain activities than others, but we need to have this fed back in order to ensure that the right PCPI participants are being matched to the right activities.

Appendix A - Principles of how we work together

As PCPI participant you are part of the team and have a valued contribution to make. Therefore we need to ensure that you feel included and involved. As part of an annual review, we will look at what we have done and see if we are still doing things that have been agreed. *The contribution you are making is important to us and therefore we will be:*

1. Open, consistent and clear about the purpose of involving PCPI participants within the Department of Pharmacy, Health and Wellbeing.

The PCPI Reference Group will:

- Identify the benefits to the organisation and PCPI participant of being involved in the work;
- Negotiate the boundaries to involvement.

2. PCPI participants will identify as part of the team the way in which they are involved.

This means:

- PCPI participants will help plan their involvement and develop their own evaluation of this, including what has been important to them in their role.
- PCPI participants will be enabled to identify their own needs as part of the project.
- PCPI participants will be involved in understanding and identifying the boundaries of this involvement – including understanding when they act as representatives and when solely from their personal experience/skills.

3. We will support and encourage PCPI participants to choose the way they become involved.

This will include:

- Making sure PCPI participants fully understand the reasons for the types of activities they can be involved in.
- Making sure PCPI participants have the information they need to make informed choices.
- Making sure conditions of involvement are clear, including support, training and payment.
- Making sure PCPI participants are comfortable and clear about what they are doing and are in control of the level of their involvement.

4. PCPI participants will, as part of the team, identify methods of feeding back information on how the involvement develops and its outcomes.

This will include:

- Identifying PCPI influence on the project and the personal outcomes PCPI participants have gained from their involvement.
- Explaining how your involvement has influenced the education of future healthcare professionals
- Receiving feedback from staff and students regarding your involvement

5. We will make sure that everybody is supported to come to the meetings and are able to participate.

This means:

- Making sure that rules and ways of working are understood by PCPI participants and there are no barriers to joining in.
- Working together and understanding each person's skills so that everybody can join in by breaking down information, conversation and by avoiding big words and jargon.
- Encouraging everybody to take part by making sure they understand. This might mean asking people how they learn best.

6. The group will make every effort to include the widest possible range of people in the work.

This will include:

- Developing opportunities to include groups that are 'rarely heard'.
- Developing opportunities to include groups who it is hard to communicate with.
- Acknowledging and attempting to address the difference in power relationships.

7. The group will value the contribution, expertise and time of PCPI participants.

This will include:

- For those PCPI participants who would like to be paid, this will include being issued with a casual worker contract from the University of Sunderland (example contract - see appendix C)

- For planned activities (not meetings) PCPI participants will be issued with a letter which outlines the hourly rate of pay and the dates and times for this work (assignment schedule). (Appendix G)

8. We will use what we have learned from working with PCPI participants to change things for the better.

This will include:

- Asking PCPI participants to share their experiences of being involved to influence planning and change;
- Setting up audit and monitoring systems to make sure involvement can be formally assessed;
- Ongoing reporting back to PCPI participants about how their contribution was used and how it has influenced healthcare professional education and practice
- Sharing learning internally (University of Sunderland) and with other external organisations with appropriate consent from the reference group.

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