

Patient and public involvement in research – 7,5 ECTS

Patient and public involvement (PPI) is defined as research being carried out **with** or **by** members of the public rather than **to**, **about** or **for** them. Well implemented PPI can facilitate the conduct of relevant and accessible research, resulting in innovative and impactful solutions to healthcare challenges.

The overall goal of the course is to build a basic understanding of PPI in health research. Further, the course will provide students with a simple toolkit to facilitate the application of the knowledge developed from the course in their own research.

Learning outcomes

After completing the course, the students should be able to:

- Explain what PPI is, what it is not, and its empirical basis
- Define and differentiate between different levels of PPI
- Apply existing frameworks and guidance for conducting PPI and develop an understanding of ethical considerations
- Practically apply PPI throughout the research cycle
- Identify and apply appropriate tools to facilitate PPI
- Identify barriers and facilitators for PPI and reflect on how they may overcome barriers and utilise facilitators
- Critically evaluate the impact of using PPI in their research
- Identify and apply approaches to evaluate the impact of PPI in their own research

Content

The course will adopt a “flipped classroom” approach. As such, more instructional and academic content will be delivered via online lectures and reading material – this will be done outside the classroom. A series of seminars will be used for activity based learning, for example, class discussions, debates, peer reviewing, and skill development. The aim with this approach is that more interactional seminars will help to facilitate students’ ability to apply the knowledge gained during the course into their own research.

Schedule

Time	Room	Theme	Teachers
11 October 13.15-17.00	Waldenströmsalen, Rudbeck	Introduction: What is PPI?	Chelsea Coumoundouros Joanne Woodford
18 October 13.15-17.00	Gregor Mendel Salen, Rudbeck	PPI throughout the research cycle	Chelsea Coumoundouros Joanne Woodford
25 October 13.15-17.00	Gösta Hultqvist, Rudbeck	Poster session on PPI through the research cycle Tools to facilitate PPI	Chelsea Coumoundouros Joanne Woodford
8 November 13.15-17.00	Waldenströmsalen, Rudbeck	Barriers and facilitators in carrying out PPI	Chelsea Coumoundouros Joanne Woodford
14 November 13.15-17.00	Waldenströmsalen, Rudbeck	Evaluation of PPI	Chelsea Coumoundouros Joanne Woodford
30 November 13.15-17.00	Waldenströmsalen, Rudbeck	Final seminar Examination	Chelsea Coumoundouros Joanne Woodford

Course outline

Seminar 1- Introduction: What is PPI?

Content:

In this seminar students will receive information about course learning outcomes, disposition, and examination. Discussion around what PPI is and what it is not and how it is related to the research of course participants.

Preparation:

Watch Film 1: *Patient and public involvement in research.*

Read the following papers:

Stephens, R., & Staniszewska, S. (2017). Research Involvement and Engagement: reflections so far and future directions. *Research Involvement and Engagement*, 3, 24.

Staniszewska, S., Denegri, S., Matthews, R., & Minogue, V. (2018). Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. *BMJ Open*, 8, e017124.

de Wit, M., Abma, T., Koelewijn-van Loon, M., Collins, S., & Kirwan, J. (2013). Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. *BMJ Open*, 3, e002241.

Seminar 2 - PPI throughout the research cycle

Content:

In-depth discussions regarding the implications of implementing PPI in different stages of the research cycle. Students will form teams and debate for and against PPI at different stages.

Preparation:

Watch Film 2: *Doing research right: PPI through the research cycle.*

Read the following papers:

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Garfield, S., Jheeta, S., Husson, F., Jacklin, A., Bischler, A., Norton, C., & Franklin, B.D. (2016). Lay involvement in the analysis of qualitative data in health services research: a descriptive study. *Research Involvement and Engagement*, 2, 29

Manafò, E., Petermann, L., Vandall-Walker, V., & Mason-Lai, P. (2018). Patient and public engagement in priority setting: A systematic rapid review of the literature. *PLoS One*, 13, e0193579.

McMillan, B., Fox, S., Lyons, M., Bourke, S., Mistry, M., Ruddock, A., . . . Van Marwijk, H. (2018). Using patient and public involvement to improve the research design and funding application for a project aimed at fostering a more collaborative approach to the NHS health check: the CaVIAR project (better Care Via Improved Access to Records). *Research Involvement and Engagement*, 4, 18.

Seminar 3 – Poster session on PPI throughout the research cycle & Tools to facilitate PPI

Content:

Poster session: Each student presents their poster in five minutes followed by five minutes of questions from both the audience and lecturers. Short lecture and exercise on tools and facilitation of PPI.

Preparation:

Prepare a Poster on how you can utilize PPI throughout the whole research process in your own research project, see separate instructions below.

Read the following papers:

Devonport, T.J., Nicholls, W., Johnston, L.H., Gutteridge, R., & Watt, A. (2018). It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement in the Development of Health Research. *International Journal for Quality in Health Care*, 30, 152–156

Supple, D., Roberts, A., Hudson, V., Masefield, S., Fitch, N., Rahmen, M., . . . Wagers, S; U-BIOPRED PIP group. (2015). From tokenism to meaningful engagement: best practices in patient involvement in an EU project. *Research Involvement and Engagement*, 1, 5.

Vat, L.E., Ryan, D., & Etchegary, H. (2017). Recruiting patients as partners in health research: a qualitative descriptive study. *Research Involvement and Engagement*, 3, 15.

Seminar 4 - Barriers and facilitators in carrying out PPI

Content:

Exercise on identifying barriers and finding solutions to overcome them. Reflections from a person with lived experience talking about their experience of being both a patient and their experience of being involved in PPI.

Preparation:

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Watch Film 3: *Doing the right research*

Read the following papers:

Chambers, E., Gardiner, C., Thompson, J., & Seymour, J. (2019). Patient and carer involvement in palliative care research: an integrative qualitative evidence synthesis review. *Palliative Medicine*, *33*, 969-984.

Johnston, J. N., Ridgway, L., Cary-Barnard, S., Allen, J., Sanchez-Lafuente, C. L., Reive, B., Kalynchuk, L. E., & Caruncho, H. J. (2021). Patient oriented research in mental health: matching laboratory to life and beyond in Canada. *Research involvement and engagement*, *7*(1), 21.

Grading, F., Britten, N., Wyatt, K., Froggatt, K., Gibson, A., Jacoby, A., . . . Popay, J. (2015). Values associated with public involvement in health and social care research: a narrative review. *Health Expectations*, *18*, 661-675.

Keenan, J., Poland, D., Boote, J., Howe, A., Wythe, H., Varley, A., . . . Wellings, A. (2019). 'We're passengers sailing in the same ship, but we have our own berths to sleep in': Evaluating patient and public involvement within a regional research programme: An action research project informed by Normalisation Process Theory. *PLoS One*, *14*, e0215953.

Optional:

Video of talk on soft power. https://www.youtube.com/watch?v=Ymrpqyy_w5M&t=2s

Timestamps of sections of the video to focus on:

13:50-23:07 – public contributor perspective on research, healthcare and PPI *I especially recommend listening to this section

3:20 – 13:50 – academic perspective on power, patient healthcare and PPI (also interesting comments on the language used around these topics at 8:55)

Seminar 5 - Evaluation of PPI

Content:

Short lecture plus group exercise on how to write an evaluation plan for PPI

Preparation:

Watch Film 4: *Evaluating public and patient involvement*.

Read the following papers:

Collins, M., Long, R., Page, A., Popay, J., & Lobban, F. (2018). Using the Public Involvement Impact Assessment Framework to assess the impact of public involvement in a mental health research context: A reflective case study. *Health Expectations*, *21*, 950-963.

Gibson, A., Welsman, J., & Britten, N. (2017) Evaluating patient and public involvement in health research: from theoretical model to practical workshop. *Health Expectations*, *20*, 826-835.

Russell, J., Fudge, N., & Greenhalgh, T. (2020). The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Research involvement and engagement*, *6*, 63. Popay, J., & Collins, M. (2014).

The Public Involvement Impact Assessment Framework Guidance. Universities of Lancaster, Liverpool and Exeter.

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Seminar 6 – Final seminar

Content:

Each student will present their own PPI and evaluation plan proposals, followed by a group discussion. Each student is also assigned one PPI and evaluation plan proposal to act as main reviewer and thus begin the group discussion as main reviewer.

Preparation:

Watch Film 5: *Top tips for PPI*

Read all PPI and evaluation plan proposals. Prepare a 10 minute presentation of your own PPI and evaluation plan. Prepare discussion questions on the plan you are assigned.

Examination

Active participation

Active participation at all occasions as per below is required. Students are expected to prepare well before seminars and read three core articles before each seminar. Attendance is mandatory.

Poster session

Each student will individually create a Poster to present during seminar 3. Building on their own research students should think of ways of how utilize PPI through the research life cycle and present it with a Poster. Please reflect on whether you want to put emphasis on a particular part of the cycle or wish to distribute it equally during the cycle. At the Poster session, each participant will present their Poster in five minutes followed by a five minute discussion. The Poster session is an opportunity to present your ideas and gain feedback on how to apply PPI to you project as a preparation for the final examination.

Examination paper

Each student will individually write a paper presenting a PPI plan for a grant proposal related to their own research utilizing PPI during the whole life cycle. The paper should also include a public involvement evaluation plan. Students will be provided a separate template for the paper according to what a funding application template could actually look like including headings and specified number of characters.

The paper will be around 6 pages (approximately 3-4000 words) + references. Deadline is 21st November (midnight). Teachers will then share the papers with other students for peer review. Each student will be main reviewer on one proposal.