

Patient and Public Involvement in Research Course Plan (English) 2023

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| Course title: | Patient and Public Involvement in Research |
| Course credits: | 7,5 ECTS |
| Level: | Third-cycle education |
| Course coordinator: | Joanne Woodford |
| Responsible department: | Department of Women's and Children's Health |
| Language: | English |
| Research track: | Not applicable |
| Course content: | <p>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.</p> <p>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.</p> |
| Learning outcomes: | <p>After completing the course, the students should be able to:</p> <ul style="list-style-type: none">• 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 utilize 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 |
| Teaching methods: | <p>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.</p> |
| Examiner: | Joanne Woodford |
| Mandatory elements: | Attendance of all seminar is mandatory. Up to two sessions can be missed, however these will be replaced by written assignments |

Examination:

Active participation: Active participation at all occasions 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. 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 for students to present their ideas and gain feedback on how to apply PPI to their 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. Students send the paper to each other for peer review. Each student will be main reviewer on one proposal.

Course literature:

Course literature detailed below is subject to change as will be updated, where appropriate, with more current resources prior to the course being run.

Seminar 1: Introduction: What is PPI?

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

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

Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., & Chant, A. (2019). Frameworks for supporting patient and public

involvement in research: Systematic review and co-design pilot. *Health Expectations*, 22(4), 785–801.

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. *Research Involvement and Engagement*, 4, 18.

Seminar 3: Tools to facilitate PPI

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

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.

Goedhart, N. S., Pittens, C. A. C. M., Tončinić, S., Zuiderent-Jerak, T., Dedding, C., & Broerse, J. E. W. (2021). Engaging citizens living in vulnerable circumstances in research: a narrative review using a systematic search. *Research Involvement & Engagement*, 7(1), 59.

Gradinger, 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.

Seminar 5: Evaluation of PPI

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.

Popay, J., & Collins, M. (2014). *The Public Involvement Impact Assessment Framework Guidance*. Universities of Lancaster, Liverpool and Exeter.

Shahid, A., Lalani, I. N., Rosgen, B. K., Sept, B. G., Longmore, S., Parsons Leigh, J., Stelfox, H. T., & Fiest, K. M. (2022). A scoping review of methods to measure and evaluate citizen engagement in health research. *Research Involvement & Engagement*, 8(1), 72.

Prerequisites: Admitted to postgraduate studies in the field of science for medicine and pharmacy.

Maximum number: 20 participants

Selection: Not selection, however possible to control numbers if there is more interest than the number of places available

Other information: Online options can be offered for students not located at Uppsala University

Contact: Joanne Woodford, Assistant Senior Lecturer, joanne.woodford@kbh.uu.se

Preliminary schedule: Teaching schedule detailed below.

| Date | Time | Theme | Hours |
|-------------------------------------|----------------|---|-------|
| Wednesday 6 th December | 13:00 – 17:00 | Introduction: What is PPI? | 4 |
| Thursday 7 th December | 13:00 – 17:00 | PPI throughout the research cycle | 4 |
| Wednesday 13 th December | 13:00 – 17:00 | Poster session on PPI through the research cycle Tools to facilitate PPI | 4 |
| Wednesday 14 th December | 13:00 – 17:00 | Barriers and facilitators in carrying out PPI | 4 |
| Monday 18 th December | 13:00 – 17:00 | Evaluation of PPI | 4 |
| Wednesday 10 th January | 09:00 - 17:00* | Final seminar examination | 4-7 |

*subject to be shorter, dependent on number of student examinations scheduled