Workbook to guide the development of a Patient Engagement In Research (PEIR) Plan

BENEFITS

PROCEDURAL REQUIREMENTS

CONVENIENCE

FEEL VALUED

MEANINGFUL PATIENT ENGAGEMENT IN RESEARCH

CONTRIBUTIONS

RESEARCH ENVIRONMENT

SUPPORT

TEAM INTERACTION

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THE UNIVERSITY OF BRITISH COLUMBIA

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This workbook is available free for download at the Arthritis Research Canada website, www.arthritisresearch.ca.

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PREAMBLE

Purpose

The purpose of this workbook is to facilitate high-quality partnerships between researchers and patient partners[1] undertaking research projects together by presenting guidance for research project teams to plan their activities. It uses the Patient Engagement in Research (PEIR) Framework as its starting point.[2] The PEIR Framework includes eight components that outline meaningful engagement in research from the perspectives of patient partners.

Although the term *patient* is used here, this workbook is equally applicable for collaborative projects in which the non-researchers are family caregivers, community members, or any other member of the public who wishes to collaborate in, or co-create, health research.

Evidence and experience

The information in this workbook is derived from three sources: 1) in-depth interviews involving patients with arthritis who have previously served as partners on research teams,[3] 2) peer-reviewed publications related to the topic of patient and public engagement in research, and 3) the collective perspectives of our team of patient partners and health researchers.[2] Additionally, it has been critically reviewed by Dr. Laura Nimmon (Assistant Professor at the University of British Columbia) and Colleen McGavin (*Patient Engagement Lead for the BC Support for People and Patient-Oriented Research (SUPPORT) Unit and patient partner herself*). Readers are encouraged to explore the references and resources cited in this workbook. Instructions on accessing journal articles are provided at the end of this workbook to help those less familiar with this process.

How to use this workbook

This workbook can be used flexibly to enrich research project team discussions in a variety of formats, including small group research meetings, formal and informal consultations, and team-building workshops. The ideal time to begin using it is when the research project team is still in the initial stages of developing a grant application and/or after the study has been funded but has not yet started.

The questions provided are intended to stimulate discussion between researchers and patient partners within the team. The questions are about issues that are important for establishing meaningful partnerships. They will guide team members through the process of identifying the key elements of meaningful patient engagement in research, from the perspective of all the members of a research project team. The workbook can be used throughout the study to document expectations and to critically reflect whether patients are being meaningfully engaged in the research process. The activities are not meant to be followed linearly, but rather used flexibly as a guide to prompt discussion when appropriate.

The responses to the questions can then be used to form the foundation for a work plan that includes who will do what and by when, and how and when success will be evaluated. This work plan will document the research project team's strategy around the patient-researcher partnership. Like the research methods, the plan can be revisited periodically as the team and the project evolve, always with the goal of ensuring meaningful patient engagement throughout the research process.

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[1] We use the term 'patient partners' to mean patients or their informal caregivers (family members or friends) who represent the voice of health services users on research teams.

[2] Hamilton CB, Hoens AM, Backman CL, et al. An empirically based conceptual framework for fostering meaningful patient engagement in research. Health Expect. 2018;21:396–406. https://doi.org/10.1111/hex.12635

[3] Tran B, Leese J, MacDonald G, et al. It is about us! Patient engagement in health research. Richmond, BC, Canada: Arthritis Research Canada; 2016.

Patient Engagement In Research (PEIR) Framework

There are eight key components in the PEIR Framework, which collectively contribute to meaningful patient engagement in research.

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Meaningful patient engagement in research

This is defined as the planned, supported, and valued involvement of patients and their surrogates (e.g., parents of sick children) during the research process. It involves an interactive team and positive research environment that not only facilitates patients' effective contributions to help to produce important outcomes but also ensures they benefit from the experience. Each of the eight components of the PEIR framework is explained on the pages that follow, with questions to encourage team discussion.

PROCEDURAL REQUIREMENTS

This component focuses on the procedural details of managing the inclusion of patient partners in a research project to ensure their experiences are both rewarding and productive.

Activity

Discuss within the research team ideas about how to support and include patient partners in the research project to ensure their experience is both rewarding and productive. In dialogue, focus on the essentials for launching the partnership and starting to work together on the project.

Recommended questions for discussion

- What are the patients' goals and the researchers' goals for working together on the project?

- What attributes and personal experiences are researchers seeking in patient partners for this project, and how many patient partners would be sufficient?

- What abilities or perspectives do the research project team members bring to the project?

- What stages of the research process can most benefit from the contributions of patient partners? (For example, study design, data collection, analysis, interpretation, and sharing of results.)

- What are reasonable time commitments from patient partners?

- What funding resources are available and required to cover the cost of engaging patients as research partners?

- At what points during the research process will there be opportunities for patient partners to be involved?

- What parts of the project are most interesting or relevant to the patient partners?

- How will decisions be made? (For example, by consensus?)

Items identified for Procedural Requirements

List the procedural requirements the team identified from the discussion.

Example: The project will include four patient partners with different forms of arthritis who will be consulted monthly to provide guidance on issues that arise (i.e., as an advisory committee).

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CONVENIENCE

Emphasizes the importance of choice and accessibility, including sufficient time to engage, and the flexibility for patient partners to choose how and when to contribute.

Activity

Discuss ways to make engagement convenient for all team members, with special attention on the patient partners' perspective(s).

Recommended questions for discussion

- What are the preferred days or times for meetings? (For example, consider other commitments, such as regular work hours or parenting responsibilities.)

- How frequently will meetings be held?

- What methods are preferred by patient partners to engage in discussions? (For example, in-person meetings, teleconference, videoconference, emails, informal phone calls.)

- What are the best locations for patient partners to participate face-to-face? (For example, think about the general accessibility of buildings, elevator access, and distance from public transit.)

- What are the patient partners' preferred ways of receiving updates about the project or key information if they miss a meeting? (For example, a brief one-on-one phone call to update a patient partner or a general email update to all team members.)

Items identified for Convenience

List the items that would make it convenient for everyone on the project team to engage in the research.

Example: All team members will receive an agenda by email a week prior to each formal meeting.

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CONTRIBUTIONS

Focuses on patient partners' roles and project-related activities. This addresses the recognition that patient partners contribute both their perspectives and their experiences to the research project.

Activity

Discuss the potential, expected, and ongoing contributions of patient partners to the research project. Depending on the patient partners' prior experiences, the lead researcher may want to explain a typical research process and possible contributions by different team members. This would be done in order to help patient partners identify opportunities that match their skills and interests.

Recommended questions for discussion

- In what ways will each team member contribute to the project? (For example, do patient partners want to offer up their experiences with or perspectives on their health and the health care system, or their life experiences in general, or do they have relevant personal or professional expertise that could be valuable?)
- How will the roles and tasks vary among team members?
- Will the team member's roles and tasks change over the lifetime of the project?

Items identified for Contributions

List the anticipated contributions of the different team members.

Example: Patient partners will work with the rest of the research team to analyze the data and interpret the results. Researchers will provide summaries of the data and invite patient partners to ask questions and to discuss possible explanations for the results.

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SUPPORT

Focuses on the resources offered to support patient partners as researcher team members.

In particular, this component addresses the importance of using both financial and non-financial resources to support and encourage patient partners' contributions.

Activity

Discuss support for patient partners that would help make the partnership successful.

### Recommended questions for discussion

- What, if any, training would help patient partners to effectively work on the research project team?

- What, if any, training would help researchers to effectively work together with patient partners and lay audiences?

- What financial support do patient partners expect/appreciate? (For example, consider expenses like travel, parking, internet access, and childcare.)

- What non-financial support do patient partners expect or need in order to participate? (For example, access to a workspace or to equipment like a computer.)

- What items are "deal-breakers" and what items are appreciated as "nice to have if possible"? A candid discussion between patient partners and other team members puts everything on the table.

- At what points in the project should supports for patient partners be re-evaluated to ensure the research project team is working effectively together?

- Are there any other considerations regarding support from the patient partners' perspective(s)? Or from the researcher's institution? (For example, are there rules or limitations relating to payments by cash, cheque, or gift card?)

Items identified for Support

List the items identified to address how to support the research project team members.

Example: Patient partners will be trained on the basics of ethics in human research, which is required for academic researchers.

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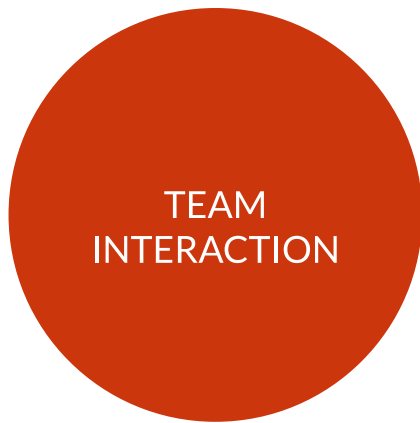
TEAM INTERACTION

Focuses on aspects of interactions on a research project team, including communication style and rapport, which are important to patient partners and other team members.

Activity

Discuss considerations for maintaining clear communication and positive interactions within the team.

Recommended questions for discussion

- How do team members prefer to be addressed? (For example, on a first-name basis.)

- What are the preferred communication styles and methods of the research project team members? (For example, bulk emails, online forums.)

- What is the preferred format for meetings? (For example, a presentation followed by team discussion.)

- How could the research project team members demonstrate mutual respect? (What does mutual respect look like for each team member?)

- How could the research project team establish and maintain trust within the team?

Items identified for Team Interaction

List items that would help to ensure the research project team interactions are positive.

Example: Meetings will be chaired by the research team lead, who will ensure that the views of all members are invited, considered, and appropriately incorporated in discussions.

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RESEARCH ENVIRONMENT

Emphasizes the importance of having an inclusive organizational/team culture that encourages patient partners to feel comfortable and accepted as equal team members working together.

Activity

Discuss considerations for creating and maintaining an inclusive team culture.

Recommended questions for discussion

- How does the team create an environment that not only supports the goal of the research but also values all participants as contributors?

- What are the team's ground rules and expectations for working together? (For example, how do the team members share decision-making power?)

- What should the team do to ensure that status and hierarchy do not discourage members from full participation in the research project?

- Are there cultural or historical issues (e.g., systematic marginalization) to be considered before proceeding, or to revisit during the project?

Items identified for Research Environment

List items identified for the research environment in which your project takes place.

Example: Team members will not be judged on their level of education when contributing opinions. This will be enacted through listening respectfully to each person's contributions.

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FEEL VALUED

Focuses on ensuring that patients and researchers feel equally valued on the research project team by ensuring everyone receives appropriate recognition and respect.

Activity

Discuss preferred options for recognizing patient partners' contributions and showing that they are appreciated and valued.
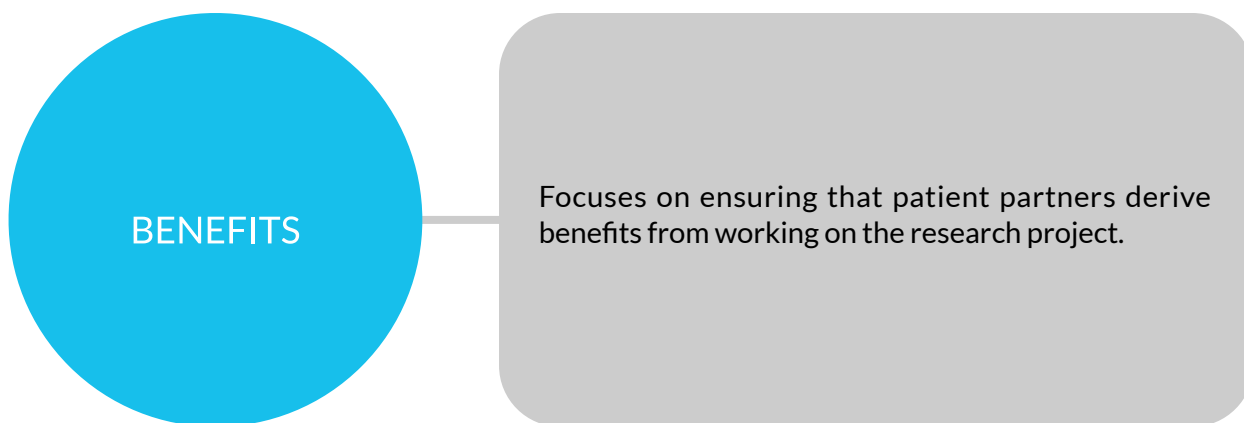
Recommended questions for discussion

- How could the contributions of patient partners be appropriately recognized? (For example, acknowledgement of their involvement on printed media or publications—including their being listed as co-authors or co-presenters—gifts, project business cards, honoraria or fee for service, formal ways of thanking individuals or groups.)

- At what point in the project should the team get together to revisit and discuss ways to ensure that they all feel their perspectives and contributions are valued?

- Are there any actions or behaviours that should be avoided because they could be inferred as suggesting that any team member is less valued? For example, if researchers request feedback within unrealistic timelines, this could be interpreted as suggesting that some team members' time and priorities are more important than others'.

- Are there other ways to ensure that patient partners feel valued?

Items identified for Feel Valued

List two or more items identified for patient partners to feel valued on your project.

Example: Patient partners will be invited to join as co-authors on manuscripts. The team will collectively decide on the degree of participation for all co-authors, including patient partners, in the development of the manuscript.

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BENEFITS

Focuses on ensuring that patient partners derive benefits from working on the research project.

Activity

Discuss what could be done to ensure the team members benefit from being part of the research project, and place emphasis on benefits to patient partners.

Recommended questions for discussion

- What benefits do team members perceive as meaningful in terms of their being partners on the project? What benefits can patient partners expect?

- How will patient partners realize those benefits?

- For patient partners with prior experience of engaging in research, what benefits did they appreciate most? Are those, or similar, benefits possible in the current project?

- What benefits can researchers propose based on their past experiences of partnering with patients on research project teams? (For example, access to the latest information or publications, access to university libraries for journal articles, and first opportunity to try a resource or tool developed through the research process.)

- Who will be responsible for ensuring that benefits are realized?

Items identified for Benefits

List the items identified that would ensure team members benefit from working on the project.

Example: Patient partners will have access to research-based information about their diseases or health condition that they would otherwise not have access to.

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STEP 1. Key Action Items

From the list of items identified in response to the questions above, identify, as a team, the key actions for a work plan (and terms of reference) that will ensure a high-quality patient-researcher partnership.

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STEP 2. Establishing Roles and Responsibilities

Team member	Title (e.g. researcher, patient, family member researcher)	Expected level of engagement (e.g., consult, collaborate, or lead)	Contact details

STEP 3. Work Plan

Action item	Team member responsible	Desired outcome and completion date	Evaluation: How will the team know this has been achieved?
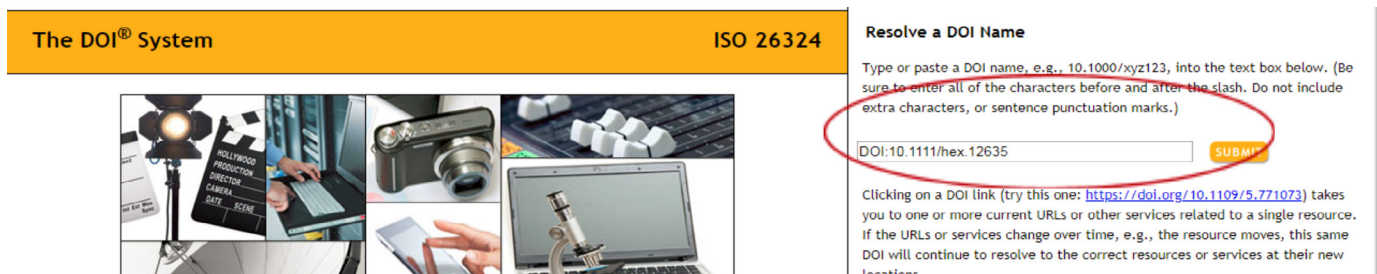
ACCESSING JOURNAL ARTICLES

Most recently published journal articles can be accessed online. Some articles are published in open access platforms, which make articles immediately available for free online, or delayed open access, which makes them available for free one year after publication. When articles are not published open access, users have to pay to read them. An article that requires payment for access may be made available at university libraries or health research institutes. Depending on the university, a patient partner may access articles at no cost through a university library by being sponsored for a library card from a university-affiliated researcher or applying for a card as a community borrower. There may be an annual fee for a community borrower card. If so, researchers may be able to pay this fee for patient partners as a research expense.
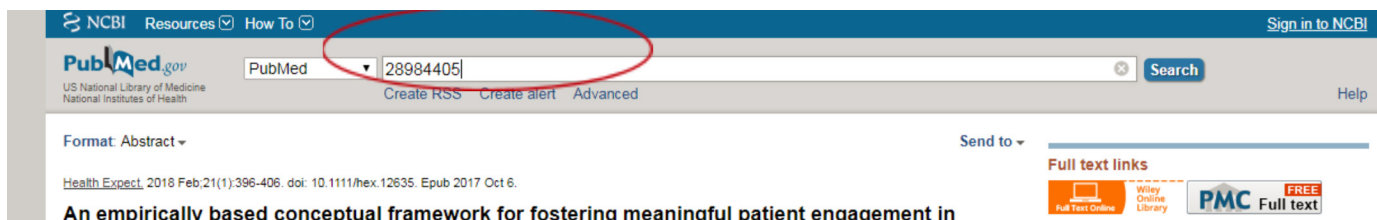
Each published journal article has a unique identifier, DOI or PMID, which can be used to quickly locate the article online.

A Digital Object Identifier (DOI) number can be entered on the DOI System website, doi.org, or directly into a search engine (like Google) to locate a journal article.

A PubMed Identifier (PMID) is assigned to each article archived in the PubMed database. A PMID number can be entered on the PubMed website, ncbi.nlm.nih.gov/pubmed, to locate a journal article.

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SEEKING YOUR FEEDBACK

We would love to hear about your experience using this workbook and would appreciate your feedback on it.

Please feel free to contact us with any comments, questions, or other feedback at:

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