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Patient Engagement Resource Centre

Building Patient Engagement in Research
A Guide for Research Teams

Oct 18th , 2017

PERC Patient Engagement Resource Centre

The goal of the Primary Health Care Patient Engagement Resource Centre is to promote and support the meaningful and appropriate engagement of patients (meaning people with lived experience of a health issue, their families, friends and caregivers) in primary health care research in Ontario.

The Resource Centre provides information, resources and methods support to foster partnerships between researchers and patients to conduct research that addresses patients' needs, preferences and priorities for their health and health care.

PERC is sponsored by the following:

Innovations Strengthening Primary Healthcare Research in Primary Health Care - INSPIRE PHC

http://www.phcresearchnetwork.com/

The Ontario Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit - OSSU

http://ossu.ca/

This document was a product of work from PERC Advisory Committee:

Research Advisors	Patient Advisors
Simone Dahrouge	Karen James
Vikki Entwistle	Alies Maybee
Ian Graham	
Vivian R. Ramsden	

Contact Information:
Simone Dahrouge, Lead
613.562-6262 ext. 2913
SDahrouge@bruyere.org

Oct 18th , 2017

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How to Use This Document

This document is a resource intended to support authentic patient engagement in research as defined by Canada's Strategy for Patient-Oriented Research (SPOR). The content was developed by a team of research and patient advisors and relies heavily on pre-existing literature and guides.

This document as an effort of the Ontario SPOR Support Unit (OSSU) INSPIRE PHC was designed to support the primary health care research community incorporate meaningful patient engagement into their work. This document is intended to guide patients and researchers in establishing a fruitful and meaningful partnership. It provides general principles and guidance, but does not cover issues that should be in place when considering work with unique communities.

This document is endorsed by the Ontario Chapter of the Pan-Canadian SPOR Network in **P**rimary and **I**ntegrated **H**ealth **C**are **I**nnovations, or PIHCI (http://www.cihr-irsc.gc.ca/e/49554.html) – the **Be**tter **A**ccess and **C**are for **CO**mplex **N**eeds (http://www.beaccon.ca/).

This is intended as a living document. So, if you see the need for corrections or would like to make recommendations for change, please share these with us.

AUTHENTIC ENGAGEMENT WITH PATIENTS IN RESEARCH

Background

The benefit of integrated knowledge translation involving knowledge users, principally conceptualized as those upon whom the responsibility for funding and implementing innovations rests, has long been recognized, and has been a requirement by the Canadian Institutes for Health Research (CIHR) for over a decade (CIHR, 2012). The ultimate goal of health and medical research is to improve the overall health of Canadians, and as such, patients are, directly or indirectly, knowledge users. Until recently, with some exceptions, the engagement of patients and communities in studies has been principally limited to the end-of-study knowledge translation phase. However, when patient are effectively engaged as partners throughout the research process, using an integrated knowledge translation approach, the knowledge they have gained through their experiences can benefit future patients and community members. This approach has recently become an expectation of several funding agencies, including CIHR.[1] CIHR uses the term "patient partner" to include individuals who use the healthcare system, communities and organizations that represent these individuals, and informal caregivers such as family and friends. The term is not used in reference to study participants, even in the case of studies that seek to capture, understand and improve patient experience through the input from study participants.

CIHR's guiding principles for patient-oriented initiatives that involve patient partnerships are INCLUSIVENESS, SUPPORT, MUTUAL RESPECT, and CO-BUILDING. Several organizations, including CIHR and the International Association for Public Participation (IAP2), have proposed frameworks that can help guide discussions about approaches to involve patients in the decision-making process about matters that affect them. Both organizations have conceptualized this with five levels of involvement (Appendix A). To achieve adequate and meaningful engagement, a conscious effort must be made to involve patients not only in the exchange of information, but also the decision-making processes that take place throughout the research cycle: as the study is being planned; during its implementation and evaluation phases; and, in the exchange of knowledge that arises from the study. True collaboration or partnership is required to achieve authentic partnership. This are represented in the two levels right most levels on CIHR's framework. Researchers may wish to employ more than one strategy to achieve the desired contributions with patients. Strategies that are used in the three left levels can help complete the desired level of consultation. For example, public forums are useful for broad consultations on matters that require input from a wide variety of people; key informant interviews and focus groups can be helpful when specific issues need to be explored; forums or consensus conferences that gather together a variety of experts and patients to generate recommendations can be useful when decisions need to be made on subjects that may be more controversial. However, these do not substitute for ongoing partnerships in which researchers and patients work together to co-create research projects.

Each research project will have its own needs, and there may be challenges related to patient engagement specific to the context in which the study will be conducted. This document is not intended to be comprehensive or prescriptive, but rather to serve as a guide for how to establish a patient partnership strategy for research projects. As new evidence emerges, approaches to patient engagement will continue to evolve.

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Building the Team

The earlier patients are engaged in the research cycle, the greater their input, and therefore the more significant their impact throughout the researcher-patient partnership in the research process. The strength and viability of a partnership transforms and evolves over time. It is therefore desirable to engage partners early, when the research idea is being developed, and to start building a meaningful and enduring relationship that, where feasible and appropriate, may even continue after the original project has ended, engaging them in informing the planning and conduct of future research. Early engagement of patient partners in the research process will also promote a sense of ownership, allowing them to contribute more meaningfully to the team's efforts. However, even if a research study is in its later stages, it is never too late to invite contributions from patients that may lead to the building of a partnership.

Inclusiveness

The intent is to develop partnerships with patients drawn from the population that the study is intended to impact (directly, for instance in the case of intervention studies, or indirectly, for instance in the case of studies that analyze data to inform policies). It is desirable to engage patients who may have had different experiences in life so as to maximize the breadth of experiential knowledge garnered.

The severity of a patient's medical condition (where applicable), their socio-economic profile, their cultural beliefs, the geographical setting in which they live, gender, age, and other factors can influence a patient's healthcare experience and therefore their contribution to a research project.

It may not be feasible for the partnership to include all forms of diversity. If engaging a small number of patients is insufficient in meeting the study's information and/or decision making needs, the team could also consider engaging organizations that formally represent patients and their breadth of voices. In addition, researchers may also want to consider undertaking other strategies that allow for greater engagement, such as participating in discussion forums, cafés, and other deliberative structures; however, these strategies are not covered in this guide.

Recruitment

Researchers may find some of the following strategies helpful in identifying patients who may be interested in participating in their study:

- speaking with healthcare professionals who work in the subject area of the study
- seeking engagement at public forums, including online forums such as patient panels and/or networks at both the provincial and national level
- seeking the assistance of health authorities with active public and patient engagement portfolios
- inquiring whether healthcare delivery, teaching, research and other organizations relevant to the area of study have active patients and/or family advisors from where they can draw partners
- consulting various organizations that support patient engagement by establishing a list of individuals interested in contributing their lived experience to a research project. These organizations help link researchers to the appropriate individuals interested in informing research. The resource guide entitled *Patient Engagement and Canada's SPOR Initiative*, which was produced for the Ontario SPOR Support Unit in 2015, provides a list of such programs by Abelson et al. (2015).

When considering the suitability of a partnership, both the researcher and the patient partner should reflect on the alignment between the patient's lived experience and interests with the project focus. This helps maximize the opportunity for patient partners to contribute authentically to the project. The following are examples of items to consider:

- Does the patient's lived experience align well with the project direction and its intended target population?Are the project's broad objectives relevant to the patient and his/her experience with the healthcare system?
- Is there a good alignment between the patient's abilities and availability to contribute and the research project's engagement need, and if not, is the project team willing to accommodate this ?
- Is there a willingness and commitment from the research team and the patient to learn together about how to form an effective partnership?
- Does the patient understand the constraints imposed on the team that may predetermine part of the work being planned (e.g., the funding agency's limitations on scope, methodological requirements, issues of feasibility, etc.)?Does the research team have a clear plan for ensuring the patient's voice is elicited and appropriately considered in the decision making process?

Patients interested in participating in dialogues about the health care system are often motivated by the opportunity to make an improvement in the current status, addressing deficiencies they've experienced. Being part of a research team provides patients with such an opportunity; but the process is different from consultations they make take part in for regional healthcare planning or policy making. The process through which research can make a positive change in how healthcare is delivered is by definition longer and requires several steps. It's a process of gathering evidence to inform decisions. The role of the patient partner during the research period is therefore not that of advocacy, but rather the patient should view their role as an equal member of a team working towards a common goal of finding the right answer. The patient partner's role in the dissemination phase of the study, however, is a clear opportunity to advocate for changes informed by the study results.

The "fit" of the partners is an important ingredient in the success of any working relationship, and this should be taken into consideration by both parties when making the decision about developing a partnership.

Project Management Considerations

This section highlights strategies that can be built into the project management plan and which can help mitigate potential challenges/opportunities for change with researcher-patient partnerships.

The value of effectively engaging patients and community members in healthcare planning and policy making has long been recognized. Similarly, public engagement in research is not a new concept. Participatory research is a well-established model of research grounded in the authentic engagement of patients and communities in the co-creation of innovation and knowledge.[2.] However, patient engagement in health and medical research initiatives is relatively new, and we can draw many best practices from those that adopted and integrated various patient engagement models into practice. Thus, it is important to minimize potential risks while and establish strategies to avoid these.

Values and Principles

Research team members will enter the partnership with various experiences working in teams, and they may have different expectations for how this group will function. The team should therefore consider

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discussing the foundational principles and values of working together, such as developing a shared vision and purpose; exploring how to foster mutual learning; identifying the team structure and the role of each team member; instituting processes to ensure respect, equity and transparency; and establishing a list of values prioritized by team members.

The team members' joint efforts to develop a list of team values at the outset of the project can contribute to better team cohesion and enhance the likelihood of a successful collaboration. This work is important for any team, but it is especially important in facilitating patient engagement in and with a research project, which will then optimizeg their ability to contribute. Important values include kindness, equity, honesty, transparency, appreciation of diversity, and respect.

There are a variety of resources that teams can draw on as they discuss what they value and how they will work together. For instance, it is often helpful to adopt commonly agreed-upon guiding principles for team function processes, and there are a variety of deliberative processes that can support consensus building. Some select ones are listed in Appendix B.

Clearly Articulated Roles and Expectations

The intent of patient engagement in research is for patients to contribute to the co-creation of knowledge in partnership with health care providers and researchers. Their role description should define not only how and when they will contribute but also how their contribution will be used to enlighten the team's decisions. The team members should negotiate the most appropriate areas of contribution for each member of the research team including the patient partner, considering availability, abilities, and interests. Ideally, each stage of the study will be enhanced with patient partners. There is value in having the same individuals involved throughout the study, although this may not always be feasible.

The expected level of engagement should be clearly defined for potential patient partners, including the time commitment and the anticipated duration of the project. For each component of the project to which patients have been invited to contribute, it is important to be explicit about the activities associated with the component, the rationale for the work, and the goal(s) expected which in turn will help to answer the research questions in a meaningful way. Specific goals are helpful; broader ones can leave a lot of ambiguity. Setting up a "role description" based on the decisions made together regarding how the patient partner will work within the project helps to ensure that all members of the research team will have a common understanding of the expectations. If the team is large, it is worth considering providing all team members with a description of the background and role of each member to enhance team functioning. If the team members find it acceptable, a photograph can also help facilitate interactions.

Material and Training Resources

Team leaders should consider the background and research experience each patient partner brings to the team and identify the areas in which they will need additional training and guidance. Patient partners new to the field are likely to need support understanding various aspects of research, such as funding cycles, ethical terms that guide research, the various constraints of the project, the agencies/organizations to which the project team is accountable, and the importance of rigour in producing credible evidence and how this may appear to slow down the process. The research team including the patient partner can benefit from orientation to project-specific issues such as ones relating to the specific topic being addressed or the context in which the study is conducted.

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Researchers (and other team members) should also seek the appropriate support to inform their role in this partnership. They may benefit from mentorship from experienced researchers, participating in informative workshops and/or reviewing documents that would enhance success in the patient-researcher partnership. They may wish to consider how best to empower patients and community members in this environment, approaches to deliberative dialogue for consensus building, the various roles that patient partners can play in a research project and beyond, and other ways to maximize the viability and benefits of that partnership.

There are many leaning resources available to research teams. These range from "how to" guides, to scientific literature, webinars, and workshops. Mentorship can also provide an enriching experience for both the mentor and mentee. Appendix B lists selected patient engagement resources, including comprehensive all-in-one resources, patient resources (on topics including recruitment and compensation), and training and supports for researchers and patients. This is not intended to be a comprehensive list, as new resources continue to emerge. The INSPIRE-PHC Ontario SPOR Support Unit (http://www.phcresearchnetwork.com/) has established the Primary Health Care Patient Engagement Resource Centre to support (https://www.patientengagement-phcresearch.com/) such initiatives in primary health care.

Project Management

Setting up explicit processes for team functioning can help ensure that important steps required for optimal collaboration are not overlooked. When the patient partners are involved in developing these processes, the approach will more likely be effective in facilitating and integrating their contribution. The team should consider each step in the study and consider the strengths; as well as, evaluate the risk of potential barriers and how these can be mitigated.

PROJECT PLAN AND MANAGEMENT

Having clear study timelines, milestones, and deliverables allows the team members to better understand their contributions over time. Team leaders should provide regular updates, maintaining consistent internal communication with the team. These updates should be more frequent when patient-partners are involved.

APPROACH TO DECISION MAKING

A fundamental aspect of patient-oriented strategies is the involvement of patients in decision making. The team should clearly establish a process by which decisions will be made, and the strategies that will be used to ensure that contributions of the study partners (patient partners, decision making partners, and potentially other involved stakeholders) are valued, and that the decisions being made are transparent. It is important that team meetings be set up to promote the contribution of all members, especially meetings in which decisions and knowledge translation are being considered.

Team leaders should report back on the actions taken following each team meeting and how any decisions made by the team have been implemented. If the team made recommendations, the group should be informed of the decisions made in response to their recommendations and how the decisions were informed by the recommendations.

FACILITATING PARTICIPATION

There are several ways to facilitate participation. At meetings, an important consideration is the role of a facilitator to help promote equitable contribution of participants. Meetings are common and

important forums for discussion and decision making. The following are examples of the logistical aspects of meetings that could be considered to optimize patient participation:

- Is the venue adequate in terms of physical access, distance, and accommodations?
- Is the venue adequate in terms of being able to facilitate having coffee/tea, cookies, etc.
- What transportation is available to the site? What is the patients' ability to travel? Do they need special arrangements?
- How suitable are the meeting times? Schedules that may be appropriate for those whose paid work includes participation in the study may not be feasible for patient-partners if these conflict with their work hours.
- What other potential barriers might patient partners face in being able to fully engage in this work, such as childcare or potential loss of income? How might these be addressed?
- Would it be useful to allow team members to attend the meetings virtually?

The information needs of team members should be considered, including their preference for written versus electronic materials, their desire to receive the materials ahead of meetings versus at the time of meetings, etc. Creating a safe environment, demonstrating cultural humility will promote transparent interactions and maximize the contributions of all participating.

Patients will bring a wealth of experiential and tacit knowledge that stems from positive and painful experiences. Discussing matters that carry intense memories may trigger feelings of sadness or anger in patient-partners and/or all members of the research team and may be expressed through strong emotions. Listening with patience and empathy is often the most appropriate response.

WORKING WITH SPECIFIC COMMUNITIES

In some cases, the partnership will be broader than between researchers, health care providers and individual patient-partners; it may be intended to involve a unique community in a participatory approach. In these cases, it may be relevant to develop a data-sharing agreement so that everyone is aware of the principles of Ownership, Control, Access and Possession (OCAP), which enables self-determination of the research. These principles offer a way for First Nations, Métis and Inuit peoples to make decisions regarding what research will be conducted, for what purpose information or data will be used, where the information will be physically stored, and who will have access. This document does not address the specific requirements of conducting participatory action research and the associated expectations; however, this information can be found in Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS - 2).

SUSTAINING ENGAGEMENT

Teams will need to consider whether remuneration or some other form of compensation is appropriate for patient partners. Some teams offer patient partners a flat stipend intended to cover a specific period of time. Others provide compensation based on an hourly rate or an honorarium for specific tasks. When deciding what is appropriate for the research to be undertaken, teams should engage the patient-partners in the discussion and decision-making process, and should also consult the funding agency's guidelines for compensation.

Providing ongoing recognition for patients' unique expertise, contributions and encouragement for their efforts is an important way of acknowledging the importance of their contributions and building a sustainable partnership.

There may be periods when the contact of patient partners with the research team may be infrequent. During such times, updating all team members on the progress of the study can help to maintain their interest and facilitate engagement.

Budgetary Considerations

It is important to ensure that the research project is resourced to support adequate patient engagement throughout the research processes. Funding needs should be built into the grant proposal to ensure that the costs associated with co-creating the research project with patients-partners is appropriate.

Here are some examples of possible project costs related to patient engagement:

- costs related to developing relationships (such as meetings with partners, training, travel as a part of knowledge translation)
- compensation (whatever its form, probably has budgetary implications)
- costs related to project implementation
- requirements for technical information and expert advice related specifically to the engagement of patient-partners in the project
- travel and accommodation costs
- increases in hospitality funds (for coffee, snacks, lunches, etc.) to create an environment more conducive to patient engagement
- costs related to team meetings such as patient transportation, long-distance phone charges, caregiver costs to free the person to attend, and loss of income/compensation costs related to community mobilization and engagement, including culturally relevant promotional items (i.e., tobacco, cloth, and cash reimbursements) in an acceptable reimbursement method to compensate patient partners and communities for their participation
- costs associated with the preparation (including editing, translation, and printing) and distribution of relevant materials (discussion documents, background materials, meeting summaries, etc.)
- additional administration costs to support and manage patient partners
- patient partners' costs associated with participating in knowledge translation activities

In preparation of the grant proposal, the budget should be discussed with all team members, including patient-partners to avoid oversight and increase transparency.

Developing a Project

Patients can contribute meaningfully in all aspects of the research project, including planning the study, conducting the study, and disseminating the study results (see CIHR's Research Cycle in Appendix C). The examples provided below are adapted from the Patient-Centered Outcomes Research Institute (PCORI) engagement rubric. This rubric serves as a guide to help applicants for research funding show and describe their work with engaged patient-partners throughout the entire research process.

Planning the Study

All team members should be involved in planning the study. This includes developing the research question with a perspective ensuring that it is relevant to patient-partners, and establishing the study

methods, especially for the purpose of optimizing feasibility and acceptability to the population whose care the work is intended to enlighten or change practice with/for.

DEVELOPING THE RESEARCH QUESTION - RELEVANCE

While the researcher often brings his or her past work to bear on the development and design of a new study and may need to work within specific constraints imposed by a funding agency, all team members should help to define the research question(s) and specific study objectives; thus, ensuring that these align with patient priorities in some way.

THE STUDY METHODS – FEASIBILITY AND ACCEPTABILITY

Patient partners can significantly contribute to the success of the study by helping to shape the methods. For example, involving patient-partners in the following study strategies can help improve the project's feasibility and acceptability to potential participants, or to those who might be impacted by the study results/findings. The study strategies include:

- establishing eligibility criteria and recruitment strategies for study participants
- identifying and confirming the roles of patient-partners in data collection, data analysis, and report writing
- designing the study to minimize disruption to patients and other stakeholders participating in the research study activities so that the activities are consistent with ongoing care
- creating study materials, including information sheets and data collection tools such as survey and qualitative study guides (this helps to ensure that the material's literacy level is appropriate, the terminology used to describe sensitive matters is acceptable, the information needs of the patient are met, and the burden to the participant is acceptable)
- facilitating communication within the research team by planning and adjusting a reporting schedule to the main group by subgroups formed around activities and/or locations
- defining relevant patient-reported outcome measures (PROM) and patient-reported experience measures (PREM), and other meaningful patient-oriented outcome measures
- developing plans to evaluate the team's partnership strength, the extent of patient engagement, and the impact of patient engagement on study outcomes

Conducting the Study

This phase of the study cycle entails the recruitment of participants into the study, data collection, data analysis; as well as, the interpretation of the study results/findings.

Recruitment of Participants and Data Collection

Patient partners can optimize the recruitment of study participants and data collection. Since the patient partners may be members of the study's target population, they can help develop recruitment strategies, including identifying the most appropriate sites for participant recruitment and developing a patient-centred approach to recruitment. It may also be appropriate for the patient partners to participate in the recruitment of study participants. Because they have been intimately involved in developing the study, they can describe the study and its potential risks and benefits to potential participants. Furthermore, potential study participants may be more receptive to the information they receive from the study's patient partners by virtue of their shared history. This may be especially important when working with unique populations. The same is true for data collection, as study

participants may relate to the patient partners, and therefore may feel safer in sharing their information.

Data Analyses and Interpretation

Some patient-partners may be interested in participating directly in the analysis of the data. They will provide especially valuable insights during the interpretation of the results. Their tacit and experiential knowledge can help the team understand the results/findings, such as why some measures were influenced whereas others were not, or why the results are different across settings.

Special consideration: When working with a community using participatory processes, it is important that research teams provide the community with the raw data and the results of analysis to support decision making in and with the community. Analysis of the results by local people is an essential part of community action for health, and healthcare practitioners and researchers should work with individuals, patients and/or communities in ways that are meaningful to them (i.e., taking a patient-centred approach).

Knowledge Translation

DISSEMINATION STRATEGY

Patient partners can contribute in various ways to the strategies for disseminating the study results/findings. They can co-create the approach for whom (target audience) and in what ways (the message) the knowledge is disseminated.

Patient partners are especially knowledgeable about opportunities for dissemination within their communities. They may help identify key public audiences and how to reach them (e.g., via social media, the press, or public forums). They can help shape the message so it is clear and relevant to these specific stakeholders. The patient's voice is an increasingly important vehicle for knowledge-to-action decisions, and their participation in dissemination efforts is a significant way in which to increase the reach of the message and the impact of the results/findings.

Dissemination Activities

Patient partners may be directly involved in knowledge exchange activities. In taking an active role in generating the study data, they also are co-owners of the data and should have opportunities to help in the dissemination of the study results/findings in meaningful ways.

Consideration should be given at the inception of the study as to how to support patient partners in these activities. It may be desirable for patient partners to present the study findings and conclusions at academic conferences, public consultations, policy forums, or in other venues. They may organize and participate in or lead public communication activities including workshops, seminars, roundtables, webinars, and public lectures. They should be offered the same opportunity as other team members to contribute to the various forms of knowledge translation, including the scientific write-up.

Patient partners are ideally positioned to reach certain stakeholders, including patient communities and health planners. If patient partners are interested in organizing efforts to communicate the study findings to the general public, such as taking on a leadership role in a specific aspect of the study, they should be encouraged to do so and be provided with the necessary support. The research team should identify conferences and groups that serve key academic and public policy audiences and should

determine which team members, including patient partners, will be engaged in the presentations. It is useful to create a potential timetable for the team's participation in various conferences.

Some patient partners may be interested in helping to write up the study findings; the research team can target different publications for each of the documents that will be produced, depending on who will be on the writing team for each one. Some patient partners may want to take a lead role in authoring manuscripts.

Evaluating Patient Engagement in Research

It is important to assess the success of the partnership during the study; as well as, at the end of the study. A developmental evaluation, or formative assessment of the partnership's likelihood of success and lessons learned is important to help address gaps and redress opportunities for change. All team members should be asked to evaluate their experiences in and with the partnership. Team leaders may choose to distribute a short survey to team members following a specific activity, such as a team meeting, to assess their experience during that activity. Feedback unrelated to specific encounters or activities can also be collected periodically from team members.

There is a dearth of scientific knowledge about patient partnerships in research. Iterative formative assessments, as well as a summative evaluation are helpful in demonstrating the authenticity of the partnership. These evaluations can also contribute significantly to the understanding of the strengths and opportunities for change related to engaging with patient-partners throughout the reseach process. It is important that the formative evluations be viewed as an opportunity to redress gaps and optimize the current partnership not as a measure of team members' performance or commitment.

While looking at the desired outcomes of the partnership, the research team should assess the creation of inclusive mechanisms for the research team's activities; the appropriate inclusion of the patient partners' tacit and experiential knowledge in the research process; the establishment of respectful collaboration amongst team members, including patient partners, researchers, and healthcare providers; and the extent to which study decisions were informed by the various members of the research team.[3.] According to the CIHR's SPOR Framework, the six conditions for successful patient engagement are: inclusive mechanisms and processes, multi-way capacity building, multi-way communication and collaboration, experiential knowledge valued as evidence, patient-informed and -directed research, and a shared sense of purpose.

Some tools are available that can be used or adapted to co-create a program evaluation related to authentic engagement in research. A group of lead scientists in this area have assembled a helpful toolkit of different approaches that can be applied to evaluate various dimensions of patient engagement in research (www.ceppp.ca/toolkit). In addition, it may be valuable for members of the research team to co-develop success measures of their partnership that address the specific expectations of their research project.

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Resources Consulted

- **Change Foundation's PANORAMA Panel**
  http://www.changefoundation.ca/panorama/
  A standing panel of 31 Ontario residents exchanging views, experiences and advice that helped The Change Foundation in its work to improve the patient/caregiver experience.

  http://www.changefoundation.ca/patient-compensation-report/
  The Foundation has designed an easy-to-use tool, to help us decide on a case-by-case basis, whether to pay patient-engagement participants.

- **Canadian Institute of Health Research (CIHR)'s Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework**
  http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf
  The SPOR Patient Engagement Framework is designed to establish concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

- **Health Quality Ontario's Capturing the Patient Experience Instruction Sheet**
  http://www.hqontario.ca/Portals/0/Documents/qi/qi-capturing-patient-experience-instruction-sheet-en.pdf
  The NHS formulated the theory of Experience Based Co-Design (also known as the EBCD approach™). Experienced based co-design is essentially a set of principles implemented with a variety of tools that capture the experiences of patients, carers and staff through discussion,

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observation and filmed interviews.

- **INVOLVE's Briefing Notes for Researchers**
  http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
  This is a new edition of the briefing notes for researchers. Whilst some of the content is drawn from earlier editions this document is substantially different in both its format and its content, reflecting the changing environment since the original briefing notes were written in 2004.

The number of resources for public involvement in research have increased substantially, including those provided by INVOLVE such as the online Evidence Library and Putting it into Practice Database, those available through other National Institute for Health Research (NIHR) funded initiatives, and through the Research Councils and various research charities.

- Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research – An International Perspective by Nass, Levine & Yancy (2012)
  http://www.pcori.org/assets/Methods-for-Involving-Patients-in-Topic-Generation-for-Patient-Centered-Comparative-Effectiveness-Research-%E2%80%93-An-International-Perspective.pdf
  The objective of this white paper is to provide PCORI with an evidence-based review of best practices, processes, and methods for patient engagement that have been studied and implemented internationally, and that could be adapted and used to promote patient involvement in research topic generation in the United States.

- National Health Service (NHS) West Midlands (University of Birmingham)'s Guide to Capturing and Using Patient, Public and Service User Feedback Effectively

  http://pure-oai.bham.ac.uk/ws/files/10495118/A_guide_to_capturing_and_using_patient_.pdf
  This Guide has been produced as part of Investing for Health Project 4 to assist PCTs, Practice Based Commissioners and Trusts with the effective commissioning, analysis and use of patient, public and service user feedback. It highlights the need for engagement to be meaningful, embedded within each organization and understood and valued by staff. It gives a simple guide to each of the different methods for collecting feedback, as well as top tips, case studies and useful resources.

- **INVOLVE's Budgeting for Involvement**
  http://www.invo.org.uk/wp-content/uploads/2014/11/10002-INVOLVE-Budgeting-Tool-Publication-WEB.pdf
  This guide provides practical advice on how to budget for involving patients, carers and the public in research. It will be helpful for working out the costs of involvement at any stage of the research process – whether that's a planned focus group in a study underway or putting together an entire budget for a study.

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Acknowledgements

We would like to acknowledge the support and help of our patient partners Roger Stodda, Lynne Mansell, and Ron Beleno in contributing suggestions for this document.

We would like to thank Jennifer Thomson for the editorial work on the document.

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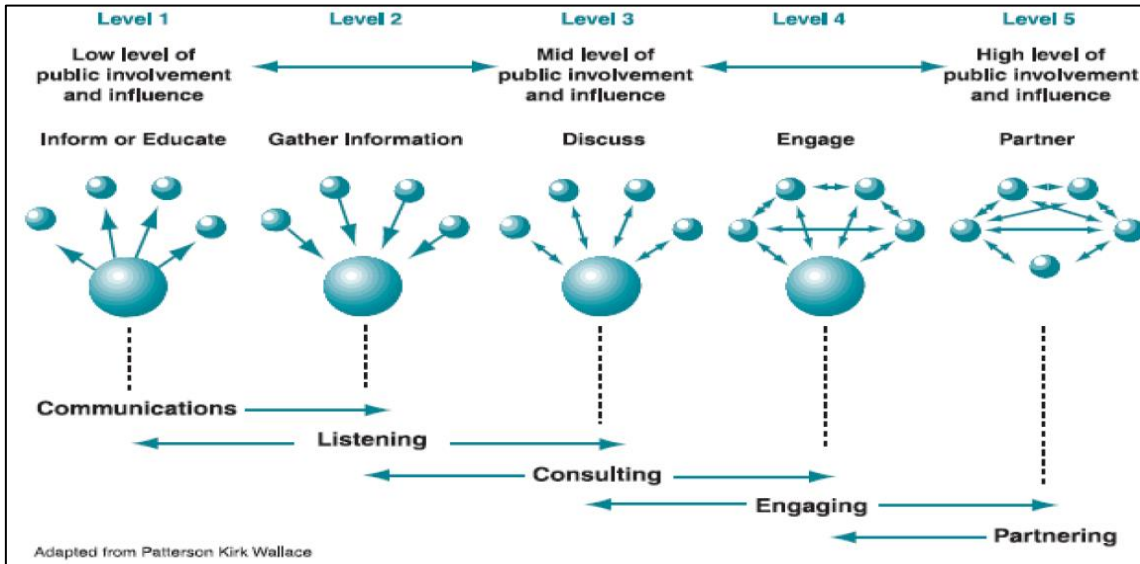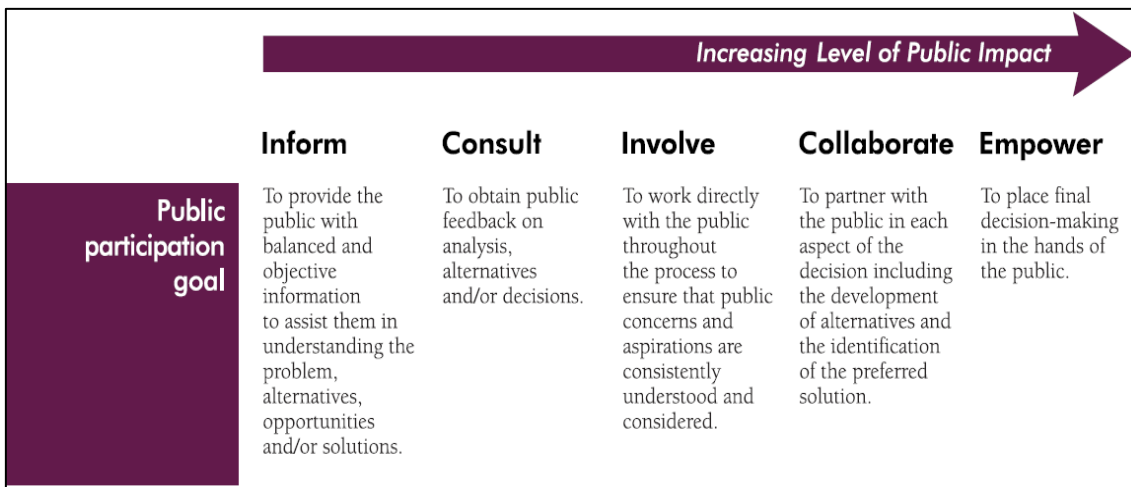Acknowledgements

Appendices

Appendix: A – Frameworks

Fig. 2: The Five Levels of Public Involvement

CIHR's Summary Table of Citizen Engagement Approaches[4.]

IAP2's Spectrum of Public Participation[5.]

Appendix: B – Patient Engagement Resource Guides

WORKSHOPS AND TRAINING

- **INVOLVE's Report on Developing Training and Support for Public Involvement in Research**
  http://www.invo.org.uk/wp-content/uploads/2015/06/8774-INVOLVE-Training-Support-WEB2.pdf
  This publication offers advice and guidance to help you develop your own training and support packages suited to different situations and contexts. It is part of a larger online resource which holds a collection of full case studies and also provides detailed information about planning training and support for five common ways of involving the public in research: (1) research panel member, (2) project advisory group member, (3) project steering group member, (4) public reviewer, and (5) peer interviewer.

1. **Masterclass on the Conduct and Use of Patient-Oriented Research**
   http://ossu.ca/training/masterclass/

   The Masterclass on the Use and Conduct of Patient-Oriented Research aims to prepare individuals to champion the conduct and use of patient-oriented research (POR) in Ontario's health system. POR, in a nutshell, is research that engages patients as partners in the planning and conduct of health research and in efforts to support the use of health research. Individuals such as patients, family members and caregivers, healthcare providers, policymakers and managers, and researchers are critical participants in ensuring that the health system in Ontario is based on high quality, relevant research evidence.

2. **Patients Canada**
   http://www.patientscanada.ca/
   Patients Canada is part of a national coalition funded by the Canadian Institutes of Health Research (CIHR) that is putting patients and family caregivers at the centre of health research, and we're eager to share our progress.

   20–40 active members meet once a month to review patient stories and identify areas to target for health system improvement; strong web presence; 1000–2000 members;
   Chair: Michael Decter

- *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (*TCPS2) Core Tutorial
  https://tcps2core.ca/welcome

  The online tutorial TCPS 2: CORE (Course on Research Ethics) is an introduction to the 2nd edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)*. It consists of eight modules focusing on the guidance in TCPS 2 that is applicable to all research regardless of discipline or methodology.

<u>LITERATURE AND GUIDES</u>

1. **CIHR Glossary of Funding-Related Terms**
   http://www.cihr-irsc.gc.ca/e/34190.html
   The CIHR Glossary includes the definitions of the most commonly used funding-related terms in an easy to use alphabetical list.

2. **INVOLVE Briefing Notes for Researchers**
   http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
   This is a new edition of the briefing notes for researchers. Whilst some of the content is drawn from earlier editions this document is substantially different in both its format and its content, reflecting the changing environment since the original briefing notes were written in 2004.

   The number of resources for public involvement in research have increased substantially, including those provided by INVOLVE such as the online Evidence Library and Putting it into Practice Database, those available through other National Institute for Health Research (NIHR) funded initiatives, and through the Research Councils and various research charities.

<u>WEBSITES</u>

1. **Canadian Foundation for Healthcare Improvement: Patient Engagement Resource Hub**
   http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx

   The Canadian Foundation for Healthcare Improvement is a not-for-profit organization funded by the Government of Canada, dedicated to accelerating healthcare improvement. CFHI plays a unique, pan-Canadian role in spreading healthcare innovations.

   Hub resources include Canadian and international open source tools. Use them in patient and family engagement initiatives to improve health and healthcare.

   You can:
   - Search by keyword, category, or source organization.
   - Browse the newest additions.
   - Narrow your results by language or country.

2. **Health Quality Ontario: Patient Engagement Tools and Resources**
   http://www.hqontario.ca/Engaging-Patients/Patient-Engagement-Tools-and-Resources
   Health Quality Ontario plays a role in facilitating patient engagement throughout all aspects of the health system. Working with patients, families and health providers, we gather and develop tools and resources to support their engagement efforts.

3. **Patient Engagement Resource Centre (PERC)**
   https://www.patientengagement-phcresearch.com/

PERC

The goal of the Primary Health Care Patient Engagement Resource Centre is to promote and support the meaningful and appropriate engagement of patients (meaning people with lived experience of a health issue, their families, friends and caregivers) in primary health care research in Ontario.

The Resource Centre provides information; resources and methods support to foster partnerships between researchers and patients to conduct research that addresses patients' needs, preferences and priorities for their health and health care.

4. **The Centre of Excellence on Partnership with Patients and the Public – Evaluation Toolkit**
   https://nouveau.ceppp.ca/en/our-projects/evaluation-toolkit/
   The research team of the Patient and Public Engagement Evaluation Toolkit project proposes to various health system stakeholders a wide range of tools to assist them in the evaluation of patient and public engagement initiatives, both in health research and in health care.

   The Evaluation Toolkit is a resource designed for practitioners of the health sector, produced after the completion of a rigorous systematic review of patient and public engagement evaluation tools.

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Appendix C : CIHR's Research Cycle