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ORGANIZATIONAL PARTICIPATORY RESEARCH

Recommendations for Practice

Written by
Paula L. Bush, Marie-Claude Tremblay
and the OPR recommendations working Group*

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Canadian Institutes of Health Research

* OPR recommendations working group members, in alphabetical order

René Benoit
Mathieu Bouchard
Beatrice Débarges
Mario Di Carlo
Benjamin Gaudet-Fex
Catherine Lemyze
Vanessa Michaud
Shandi Miller
Philippe Ouaknine
Sharon Parry
Jennifer Reoch

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INTRODUCTION

Guidelines and principles for community-based participatory research and participatory evaluation exist (Israel, Schulz, Parker, & Becker, 1998; Mercer et al., 2008; Shulha, Whitmore, Cousins, Gilbert, & Hudib, 2016), but this Practice Guide address aspects of participatory research that are unique to Organizational Participatory Research (OPR). The hierarchy, power, and rules present in all organizations lend a context to participatory research that is different from that found in community settings. This Practice Guide is meant to help all stakeholders (academics, health organization members, and health service users) participating in an OPR to navigate this context successfully.

ACCORDING TO Friedberg (1997), AN **ORGANIZATION** IS A "CONTEXT OF ACTION IN WHICH RELATIONSHIPS OF COOPERATION, EXCHANGE, AND CONFLICT BETWEEN ACTORS WITH DIVERGENT INTERESTS ARE BEING ESTABLISHED AND MANAGED" (P. 43), AND WHICH FLUCTUATES IN RESPONSE TO CHANGES IN THE ENVIRONMENT.

HEREIN, WE CONCEIVE OF A **HEALTH ORGANIZATION** AS ANY ORGANIZATION OFFERING HEALTH-RELATED SERVICES. FOR EXAMPLE, THE ORGANIZATION COULD BE A HOSPITAL OR HOSPITAL WARD, PRIMARY CARE CLINIC, PHARMACY, LONG TERM CARE FACILITY, COMMUNITY ORGANIZATION, ETC.)

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Organizational Participatory Research (OPR) blends research and action to produce knowledge that can inform healthcare practices, services, and organizations. When **health organization stakeholders** act as decision makers *with* academic researchers, throughout the research process, the likelihood research findings are relevant to, and used by, the health organization, and its members, increases. Moreover, OPR often results in benefits for the organization and its members that go beyond the research aims. These extra benefits are four times as likely to occur when the organization initiates the OPR (Bush et al., 2014).

HEALTH ORGANIZATION STAKEHOLDERS REFERS TO ALL THOSE WHO DEVELOP, IMPLEMENT, OR ARE AFFECTED BY HEALTH ORGANIZATION PRACTICES. THIS INCLUDES ALL LEVELS OF **MANAGEMENT**, **ADMINISTRATION** AND OTHER STAFF (CLERICAL, SECRETARIAL, CUSTODIAL, ETC.), **PRACTITIONERS** (PHYSICIANS, NURSES, PHARMACISTS, SOCIAL WORKERS, ALLIED CARE PROFESSIONALS, ETC.), VOLUNTEERS, AND **SERVICE USERS** INCLUDING PATIENTS, THEIR FAMILY, THEIR CARE GIVERS, AND THEIR REPRESENTATIVES.

IN ANY OPR PROJECT, ALL HEALTH ORGANIZATION **AND** ACADEMIC STAKEHOLDERS ARE EQUAL. NO STAKEHOLDER GROUP HOLDS MORE INFLUENCE THAN ANOTHER OVER THE OPR PROCESSES AND DESIRED OUTCOMES.

This Practice Guide is addressed to all academic and **health organization stakeholders** who wish to work together to improve existing organizational practices or to design and implement new practices for the benefit of the organization, its members, its service users, and the academics. Specifically, this document is for managers, practitioners and staff working in health organizations; patients and their family, friends, representatives, or caregivers who use health organization services; academic researchers who come together as an OPR Working Group to collectively address a common concern regarding health organization practices and/or policies. Examples are provided for some, but not all, stakeholder groups, throughout. This has been done for the sake of parsimony and in no way implies that the stakeholder group for which an example is provided is more important or influential. All recommendations apply to all members of the OPR Working Group.

This Practice Guide has been developed with academics and health organization stakeholders. A systematic review of OPR (Bush et al., 2014; Bush et al., 2015) that identified, described, and explained OPR processes and outcomes was used to draft an initial version of this guide. Two meetings were then held with an academic, a clinician, two managers, and a patient, experienced in OPR to review, modify and refine the initial draft. Notably, the systematic review of OPR only identified 15 studies with patient or caregiver participation. The initial draft was, thus, missing an important element of OPR. To account for this, a group of seven patients and one academic met twice, and also worked collaboratively online, to develop recommendations for OPR that includes patients in the Working Group. This group began their reflection with a summary document based on patient engagement literature, prepared by the academic partner (Tremblay) (INVOLVE, 2013; Kotecha et al., 2007; Pollard et al., 2015; Telford, Boote, & Cooper, 2004). A final meeting was held with the two groups to discuss how to integrate the two sets of recommendations. The project lead (Bush) carried out the integration to produce a new version of the Practice Guide which was submitted to 18 experts for a Delphi.

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DEFINING ORGANIZATIONAL PARTICIPATORY RESEARCH

In OPR, all stakeholder groups are considered equally influential and important to the process and its outcomes.

Working Group members should seek to **balance power** relationships between service users, researchers, health care practitioners, managers, and any other stakeholder group involved in the OPR.

This involves enabling all Working Group members to engage and participate meaningfully in the OPR process, contribute their experiential, clinical, managerial, and research knowledge, and to promote the distinctive and complementary value of their knowledge to address the OPR objectives.

Among others, stakeholders may contribute knowledge regarding:

- the feasibility of implementing a new clinical practice
- how current practices are experienced by service users
- change management
- rigorous and systematic research methods

As equals, all Working Group members have the same rights, obligations, and responsibilities throughout the OPR process, including those related to raw data and dissemination of results.

SERVICE USER REFERS TO ANY MEMBER OF THE PUBLIC WHO ACCESSES OR USES HEALTH SERVICES. THIS INCLUDES PATIENTS, THEIR CARE-GIVERS, OR THEIR FAMILY MEMBERS, AS WELL AS INDIVIDUALS WHO ACCESS SOCIAL SERVICES WITHIN THE HEALTH SYSTEM.

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Working Group members may choose not to take advantage of some of these rights, or to distance themselves from certain obligations or responsibilities.

What is important is that Working Group members have the right to choose the extent to which they wish to be involved at various stages.

These decisions, and their rationales, should be discussed within the Working Group and agreed upon, and be transparent and respected.

According to a comprehensive systematic mixed studies review of OPR in health (Bush et al., 2014; Bush et al., 2015), OPR requires regular, structured Working Group meetings that assemble a broad variety of health organization and academic stakeholders and provide a supportive environment with the promise of confidentiality, such that Working Group members can voice their varied experiences, ideas for change, and fears and concerns; discuss and debate; accept compromises; gain confidence to effect change; effect change. Establishing objectives quickly helps to increase the unity of the Working Group for working toward the objectives, and circulating meeting notes (and other documents that may be produced) between meetings is crucial for subsequent deliberations, to correct misunderstandings, and to help engage Working Group members who are unable to attend some meetings.

The systematic review revealed that Working Group meetings are the crux of the OPR process. These meetings provide invaluable time and space for Working Group members, to present, discuss, debate, and reflect on various identified needs, and to share experiences and fears. These meetings:

- enable the Working Group to come to consensus regarding which issue to pursue, and to systematically reflect on and progress with their objectives. Through this systematic reflection and progression, Working Group members

identify needs, gain awareness of constraints to addressing those needs, gain confidence (which, in turn, leads to a drive to do the research and to take responsibility for decisions and actions), and effect change (e.g., improved clinical practices, reflective practice processes, other improvements/modifications/development of practices, procedures, policies, etc.);

- contribute to organization members' increased general awareness of work practices and processes, which in turn, this contributes to improved care practices;
- allow Working Group members to learn from one another;
- increase/improve communications. In turn, interdepartmental understanding is increased, organization members either improve or develop new skills (leading to feeling empowered), job satisfaction is improved, team work is improved/increased, staff gain confidence to effect change, resistance to change is diminished, and changes ensue;
- allow the Working Group to develop a cohesive identity, improve/increase the team-working and commitment of members. Working Group members' commitment contributes to their increased involvement in the project, improved understanding of one another, improved care and sustainable change;
- improve coordination among organization members.

Specifically, Working Group meeting processes include collective data analysis and discussion of findings and how to act on them. The collective data analysis process promotes dialogue and helps the group to gel. This process is also an opportunity to reflect and to make modifications to the project as needed. Discussing the findings within the Working Group is valuable in that findings often validate perceptions and raise awareness. They increase the motivation to make change and allow the group to

identify additional needs and/or modify project plans. Ultimately, they increase members' understanding of how to use research findings to inform changes and enable joint problem solving. Communicating the findings outside of the Working Group (to the rest of the organization) gives the Group legitimacy, enhances buy-in of other organization stakeholders, and stimulates reflection.

The changes the Working Group implements have a positive effect on the organization, and its stakeholders. Importantly, they pave the way for subsequent changes.

A diagram illustrating the processes and outcomes of OPR is included at the end of this Practice Guide.

THE **WORKING GROUP** MAY OR MAY NOT PARTICIPATE IN THE DATA COLLECTION.

SOME OPR WORKING GROUPS HELP ACADEMIC RESEARCHERS DETERMINE WHAT DATA TO COLLECT FROM WHOM, BUT LEAVE THIS PHASE OF THE OPR IN THE RESEARCHERS' HANDS. IN OTHER GROUPS, ORGANIZATION MEMBERS PARTICIPATE ACTIVELY IN ALL ASPECTS OF THIS PHASE.

THE DISCUSSION AND DEBATE THAT OCCURS DURING THE DATA ANALYSIS AND INTERPRETATION OF RESULTS PHASES ARE WHAT APPEARS TO BE IMPORTANT (REF BUSH ET AL REVIEW).

NOTABLY, THE WORKING GROUP DECIDES WHO WILL PARTICIPATE IN WHAT PHASES OF THE STUDY.

THE ACADEMIC RESEARCHERS DO NOT DECIDE FOR THE OTHER STAKEHOLDER GROUPS.

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RECOMMENDATIONS

This Practice Guide includes four sections of recommendations listed below.

Explanations of each recommendation follow the list.

1. FORM AN OPR WORKING GROUP AND COLLECTIVELY ESTABLISH WORK PROCESSES

1.1. Recruit stakeholder representatives known to work well in groups

1.2. Recruit working group members from all stakeholder groups, including management

1.3. Establish mechanisms for continuity

1.4. Assess and respond to Working Group members' training needs

1.5. Establish project management processes

1.6. Schedule and hold meetings at regular intervals

1.7. Ensure meetings are structured, focussed and evaluated

1.8. Agree upon communication mechanisms

2. COLLECTIVELY ESTABLISH OBJECTIVES, ANALYZE DATA AND DETERMINE HOW TO USE OPR RESULTS

2.1. Establish objectives quickly to help build the commitment of working group members

2.2. Analyze data and interpret results

2.3. Implement changes based on results

3. ADAPT THE OPR PROCESSES TO THE NEEDS OF THE WORKING GROUP MEMBERS

3.1. Adapt to schedules

3.2. Adapt to language and literacy needs

3.3. Adapt communication tools to needs of working group members

3.4. Adapt to Working Group members' skills

4. COLLECTIVELY ENSURE THE DEVELOPMENT AND NURTURING OF RELATIONSHIPS WITHIN THE WORKING GROUP

4.1. Ensure reciprocity, trust, and respect within the Working Group

4.2. Recognise, explicitely, what Working Group members learn from one another

4.3. Ensure potential, actual, or perceived power differentials among Working Group members are acknowledged and addressed

4.4. Ensure each Working Group member's expectations are expressed and understood

4.5. Discuss, define and clarify the OPR-related roles and responsibilities of each Working Group member

4.6. Discuss, define, and clarify ethical rules for collecting, using, and storing data

4.7. Discuss, define, and clarify rules for accessing and disseminating scientific research materials and publications

4.8. Discuss, define, and clarify rights and agreements regarding authorship and intellectual property

4.9. Discuss and clarify benefits of participation in the OPR, for all Working Group members, from the outset

4.10. Be transparent about challenges that may occur and determine how to address them

4.11. Discuss, define and clarify how Working Group members should be compensated

4.12. Draft an OPR guiding principles document at the outset of the OPR

1. Form an OPR Working Group and Collectively Establish Work Processes

Organizational Participatory Research (OPR) should to be carried out by a core Working Group of health organization and academic researcher stakeholders.

Health organization stakeholders participating in the Working Group ought to be representative of all organization stakeholder groups. That is, representatives of those who will need to implement the changes addressed by the OPR, as well as representatives of those who will be affected by the changes (and their potential effects), should participate in research-related decisions, with the academic researcher(s), throughout the OPR.

Literature reviews suggest health organization stakeholders' participation in the decision-making may take the form of being consulted by the academic researcher(s) or co-constructing the OPR with the academic researcher(s) (Bush et al., 2015; Munn-Giddings, McVicar, & Smith, 2008). The decision regarding extent of participation should be that of the Working Group.

1.1. Recruit Stakeholder Representatives Known to Work Well in Groups

Working Group members should be effective collaborators.

Working Group members with divergent, or who challenge the objectives and processes of the OPR opinions may provide relevant contributions.

1.2. RECRUIT WORKING GROUP MEMBERS FROM ALL STAKEHOLDER GROUPS, INCLUDING MANAGEMENT

All stakeholder groups should be represented in the Working Group given the differing perspectives of Working Group members can increase the value and relevance of the outcomes for stakeholders.

Variety within stakeholder groups is also important. This may mean recruiting or patients with different socio-economic characteristics, age, and health status; or academic researchers from qualitative and quantitative backgrounds.

Stakeholder groups should e present in equivalent numbers.

It may be difficult to achieve such fair representation of all stakeholder groups, but this need not halt the OPR process. Some projects begin with a few individuals and recruit others as the OPR gains traction within the organisation.

Relevant management participation is required for the approval of the OPR and change implementation activities, and for the allocation of required resources.

1.3. ESTABLISH MECHANISMS FOR CONTINUITY

Competing obligations may make it impossible for some Working Group members to attend every meeting. Also, some may be more apt to get involved if they know they do not have to attend every meeting. Notably, some OPR studies report the value of allowing new members to join the Working Group during the OPR process, while others report this as disruptive. The Working Group should discuss and decide what is most appropriate for them and their OPR.

The Working Group should establish communication means to ensure all Working Group members remain abreast of activities and engaged in decisions.

Among other options, this may mean videorecording meetings and making them available online, or distributing meeting notes soon after meetings.

The Working Group should decide how to deal with loss of members (including academic members) in the midst of a project (due to, for instance, staff turnover, work constraints, dissatisfaction with the OPR).

Should the Working Group decide to replace members who leave, recruiting individuals with equivalent expertise, as well as from the same stakeholder group, is warranted.

TO RECRUIT SERVICE USERS TO THE WORKING GROUP, PATIENT GROUPS MAY BE A FRUITFUL AVENUE. MOREOVER, HEALTH ORGANIZATIONS MAY CONSIDER SETTING UP 'BANKS' OF SERVICE USERS INTERESTED AND APT FOR PARTICIPATING IN OPR ENDEAVOURS.

HEALTH ORGANIZATIONS COULD SET UP COMMITTEES OF ORGANIZATION STAKEHOLDERS, INCLUDING SERVICE USERS, TO RECOMMEND SERVICE USERS FOR OPR WORKING GROUPS.

SERVICE USERS MAY WANT TO ESTABLISH THEIR OWN COMMUNITY OF PRACTICE FOR OPR. IT MAY BE TO THE ADVANTAGE OF FUTURE OPR FOR THE ORGANIZATION TO SUPPORT THIS ENDEAVOUR.

1.4. ASSESS AND RESPOND TO WORKING GROUP MEMBERS' TRAINING NEEDS

It is crucial that all Working Group members have the necessary skills and knowledge to be able to contribute effectively to the OPR.

At the outset of the OPR, Working Group members should express their needs and determine how to address them.

This may mean providing a research literacy workshop for the non academic researchers on the team, OPR training for the academic members, meeting facilitation skills training, or a meeting decorum seminar, to name a few examples.

FOR OPR PROJECTS FOCUSED ON IMPROVING ORGANIZATIONAL PRACTICES ASSOCIATED WITH A **SPECIFIC HEALTH ISSUE**, IT IS RECOMMENDED TO RECRUIT SERVICE USER REPRESENTATIVES WITH RELEVANT EXPERIENCE REGARDING THE HEALTH ISSUE, BUT ALSO AN ABILITY TO TAKE A STEP BACK FROM THIS EXPERIENCE TO CONSIDER THE HEALTH ISSUE AND ASSOCIATED ORGANIZATION PRACTICES FROM A DISTANCE.

IT IS NOT NECESSARY FOR SERVICE USERS REPRESENTATIVES TO HAVE EXPERIENCED THE SPECIFIC HEALTH PROBLEM, BUT RATHER, TO HAVE HAD EXPERIENCE WITH IT.

A CARE GIVER FOR AN INDIVIDUAL AFFECTED BY THE HEALTH ISSUE ADDRESSED IN THE OPR COULD ACT AS A SERVICE USERS REPRESENTATIVE

1.5. ESTABLISH PROJECT MANAGEMENT PROCESSES

OPR projects require a certain amount of management to call meetings, prepare agendas, write and circulate meeting notes, follow up with people regarding their OPR-related tasks, etc.

These responsibilities should be shared between an individual embedded in the organization and a service user, with the relevant skills, knowledge, and desire to champion the OPR. This is particularly important for OPR projects that lead to subsequent OPR in the organization.

Managing OPR in this way is not always possible, nor practical, and academics often assume the project management. Developing a succession plan to transfer project management responsibilities to an individual embedded in the organization and a service user is recommended to facilitate the continued work.

Management needs to support the organization champion to ensure s/he has the time and resources to do the work.

Support for the service user champion is also required in the form of financial compensation and material resources (office space and supplies, computer-related resources, etc.).

1.6. SCHEDULE AND HOLD MEETINGS AT REGULAR INTERVALS

Working Group meetings are central to OPR as they provide valuable opportunities for members to discuss, debate, reflect, and develop relationships, helping to drive the OPR and to ensure its relevance to the organization and its members. Scheduling and holding meetings regularly can be an important part of the overall process, and help to generate benefits over and above the initial OPR project objectives.

1.7. ENSURE MEETINGS ARE STRUCTURED, FOCUSSED AND EVALUATED

Working Group members need to feel the meeting time is productive. This may mean, among other possibilities, beginning each meeting by reviewing OPR actions and results, followed by making informed decisions for subsequent actions.

Meeting agendas should be set and circulated prior to each meeting, and all members should have the opportunity to modify or add to the agenda.

Produce and circulate a summary of the Working Group's discussion and reflections following each meeting.

Include a summary of decisions and action points that provide precise instructions for specific people, and a timeline

Ensure Working Group members regularly complete an OPR process evaluation survey, reflect on results, and implement means to improve their Working Group processes, including meetings.

1.8. AGREE UPON COMMUNICATION MECHANISMS

All OPR-related decisions and actions need to be made explicit, written down, and verbally validated with all Working Group members. Do not assume that because information has circulated, it has been understood the same way by all members.

Continual checking for understanding is necessary. This may mean beginning each meeting by reviewing the notes from the previous meeting.

Means to communicate with Working Group members who miss meetings, or with organization members not engaged in the OPR, should also be determined. Among other possibilities, this may mean making a log book available in the organization, or posting information on an online message board.

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2. COLLECTIVELY ESTABLISH OBJECTIVES, ANALYZE DATA AND DETERMINE HOW TO USE OPR RESULTS

A comprehensive and systematic review of the OPR health literature suggests that participatory decisions regarding OPR objectives, data analysis and use of results are crucial (Bush et al., 2015). Other research phases, while not addressed explicitly in this document, can be addressed collectively by the Working Group, as well. This may mean, for instance, that the Working Group discusses which research participants to recruit and how, or which data to collect and how.

2.1. ESTABLISH OBJECTIVES QUICKLY TO HELP BUILD THE COMMITMENT OF WORKING GROUP MEMBERS

A systematic review of the OPR health literature suggests that if the impetus for the OPR stems from the organization, the likelihood the OPR will lead to benefits beyond those sought, is quadrupled (Bush et al., 2014). Yet, all Working Group members should contribute to defining the precise nature of the OPR to ensure objectives are pertinent to all stakeholders who will be affected by the changes or who will need to implement the changes.

2.2. ANALYZE DATA AND INTERPRET RESULTS

This is a crucial part of the OPR process. The diversity of the Working Group members will lend depth and rigour to the process. The academic members contribute, among other things, data analysis expertise, whereas, other members contribute, among other things, practical expertise.

Notably, collective data analysis does not, necessarily, mean that all Working Group members participate in the technical work of the analysis (e.g., coding qualitative data, performing statistical analyses). With the support of the academic members, the Working Group may decide which types of analyses are needed (e.g., comparison of groups of participants, changes in variables over time) or comment on preliminary qualitative categories or themes to help direct the analysis which may be performed by the academics.

Working iteratively, discussing, debating, and reflecting as a group, is necessary. This entails hearing/validating and understanding different points of view, and documenting reflections and decisions.

2.3. IMPLEMENT CHANGES BASED ON RESULTS

One advantage of the OPR approach, is that practice improvements may be made in the organization as soon as the Working Group has research results.

Depending on the study design, it is possible for the Working Group to take actions to improve practices based on preliminary results.

The OPR process can induce changes in the practice environment and the organization members, which may in turn, influence the OPR.

The Working Group should document changes that are made or occur; reflect on their impact on the organization, its members, and the research; reassess the OPR objectives, and determine new ones if necessary or desired.

3. Adapt the OPR Processes to the Needs of the Working Group Members

All Working Group members must be able to express themselves equally. This means the Group should implement processes to ensure all members feel apt to do so. Adapting OPR-related work to the knowledge, skills, and needs of all members is necessary.

3.1. Adapt to Schedules

The Working Group should negotiate how best to accommodate their differing schedules.

Among other options, this could mean holding each meeting twice to maximise participation, or using video/teleconferencing platforms to enable participation of Working Group members who are not onsite.

3.2. Adapt to Language and Literacy Needs

It is important to be cognizant of use of jargon; not all stakeholders will understand each other's technical lexicon.

Steps should be taken to ensure all group members understand and can, thus, participate fully.

This may mean discouraging the use of acronyms; adapting written and oral language for those whose first language is different than the one used by the Group, or who may have low literacy; or other options the group deems necessary.

3.3. ADAPT COMMUNICATION TOOLS TO NEEDS OF WORKING GROUP MEMBERS

Some members may have functional limitations (e.g., visual, hearing, or cognitive impairment), others may not have access to computing equipment or the internet.

3.4. ADAPT TO WORKING GROUP MEMBERS' SKILLS

It is not necessary for the non-academic members to have research skills, but the capacity to analyze and synthesize ideas is an asset.

While skills are not a pre-requisite to participation, they are important to the OPR process.

It may be pertinent to support the development of all Working Group members' skills in these areas.

This may mean offering 'OPR literacy' training to ensure all Working Group members understand key concepts, general research processes and methods (e.g., basic statistics, qualitative themes), ethical considerations, publication processes, and requirements for academic promotion.

Academics may need to learn the value of working with non-academics as well as how to respectfully and meaningfully engage with all Working Group members.

4. COLLECTIVELY ENSURE THE DEVELOPMENT AND NURTURING OF RELATIONSHIPS WITHIN THE WORKING GROUP

Developing and nurturing relationships among Working Group members can be a lengthy process and it requires conscious work. Schedules, funding timelines, and expectations may not make it possible or plausible to take extra time to develop relationships. Incorporating relationship building processes into the OPR is necessary.

4.1. ENSURE RECIPROCITY, TRUST, AND RESPECT WITHIN THE WORKING GROUP

The Working Group members should cultivate and nurture an atmosphere of awareness and understanding of one another.

The Working Group climate must be such that members feel safe to express any thought or feeling they may have regarding the OPR.

To help achieve this, options include signing confidentiality agreements; conducting team building exercises; holding get-togethers for food, fun, and fellowship (even if only before or after meetings); or using given names, rather than titles (e.g., Dr.).

4.2. RECOGNISE, EXPLICITELY, WHAT WORKING GROUP MEMBERS LEARN FROM ONE ANOTHER

To foster engagement, Working Group members should regularly express their appreciation for members' contributions and explicitly state what they have learnt from one another.

Among other options, this may mean allotting specific time for this in meeting agendas, tasking a group member to note particular strengths of other members and sharing these at selected meetings, or ensuring regular expression of thanks via greeting cards and phone calls.

4.3. ENSURE POTENTIAL, ACTUAL, OR PERCEIVED POWER DIFFERENTIALS AMONG WORKING GROUP MEMBERS ARE ACKNOWLEDGED AND ADDRESSED

Power differences among Working Group members, be they actual or perceived, may be inevitable. Yet, the Group should strive to achieve equity.

The Group should address, explicitly, that all Working Group members hold the same degree of power, control, expertise, and influence in the context of the OPR, regardless of the roles, power, control, expertise, or influence they hold outside of the OPR.

The Group should conduct assessments of its transparency and equity, with validated tools, during the OPR to learn how it is doing in this regard, and to improve, as needed.

4.4. ENSURE EACH WORKING GROUP MEMBER'S EXPECTATIONS ARE EXPRESSED AND UNDERSTOOD

All Working Group members' expectations should be explicit and understood. This may include transparent discussions and decisions about project timelines, required time commitments, and how OPR activities will fit into the schedules of all those involved. The funding source and associated requirements should be made explicit, together with expected outcomes or deliverables. Setting milestones and circulating them in writing, may be useful. It may be necessary for Working Group to be open to modifying or prioritising initial OPR objectives to meet the Group's expectations.

4.5. DISCUSS, DEFINE AND CLARIFY THE OPR-RELATED ROLES AND RESPONSIBILITIES OF EACH WORKING GROUP MEMBER

The Working Group should define the roles needed for the OPR and their associated responsibilities.

This may include, among others, deciding who will take meeting notes and when they should be distributed; deciding who will analyse data and how results will be communicated; or deciding who will disseminate results, to whom, when and how.

Overlapping or competing roles should be made explicit, together with conflicts of interest, if present.

4.6. DISCUSS, DEFINE, AND CLARIFY ETHICAL RULES FOR COLLECTING, USING, AND STORING DATA

The Working Group should define and understand how to handle sensitive or confidential data. Clinical data may need to be anonymized before being shared with the Working Group, or made available to only select Group members.

4.7. DISCUSS, DEFINE, AND CLARIFY RULES FOR ACCESSING AND DISSEMINATING SCIENTIFIC RESEARCH MATERIALS AND PUBLICATIONS

All Working Group members should have access to research tools, documents, data, and other materials. It is up to their discretion whether or not they take advantage of this access.

Guidelines for publishing OPR findings should be addressed.

4.8. DISCUSS, DEFINE, AND CLARIFY RIGHTS AND AGREEMENTS REGARDING AUTHORSHIP AND INTELLECTUAL PROPERTY

All Working Group members deserve equivalent recognition for their contributions to the OPR.

Requirements for co-authorship and acknowledgement in publications and presentations (academic or otherwise) should be defined.

All Working Group members' contributions should be described in publications and presentations.

4.9. DISCUSS AND CLARIFY BENEFITS OF PARTICIPATION IN THE OPR, FOR ALL WORKING GROUP MEMBERS, FROM THE OUTSET

Patients may benefit regarding their participation in the patient-provider relationship or the knowledge they acquire through the OPR regarding their health condition and rationale for certain care practices.

Health care professionals may improve their working relationships with other organization members.

All members may experience improved confidence or leadership skills.

Addressing what cannot be achieved through the OPR is also important. Among other things, this may mean clarifying that the OPR is not a context for addressing clinical or social issues of Working Group members.

4.10. BE TRANSPARENT ABOUT CHALLENGES THAT MAY OCCUR AND DETERMINE HOW TO ADDRESS THEM

Define a mechanism for Working Group members to express concerns or grievances ethical or otherwise, they may develop as the OPR progresses.

Among others, challenges may include potential for conflicts of interest regarding patient-provider relationships, strained work relationships, or disagreements about the meaning of results.

Options for addressing challenges include using reporting more than one possible interpretation of results in publications, or using the Institutional Review Board (ethics committee), if the OPR has ethical approval, or the ombudsman, if not.

The Working Group should determine mechanisms for dealing with dissension. Enlisting the help of an arbitrator may be required at times.

4.11. DISCUSS, DEFINE AND CLARIFY HOW WORKING GROUP MEMBERS SHOULD BE COMPENSATED

Compensation should be fully addressed in the research funding application.

Among other options, this may mean budgeting for service users to receive financial compensation for their time, as well as costs incurred for participation (e.g., parking, child care, meals); budgeting for honoraria or costs associated with clinicians who are granted leave from professional duties to allow for time to participate in the OPR activities.

Notably, compensation for different types of Group members may be governed by institutional regulations and this should be made explicit at the outset.

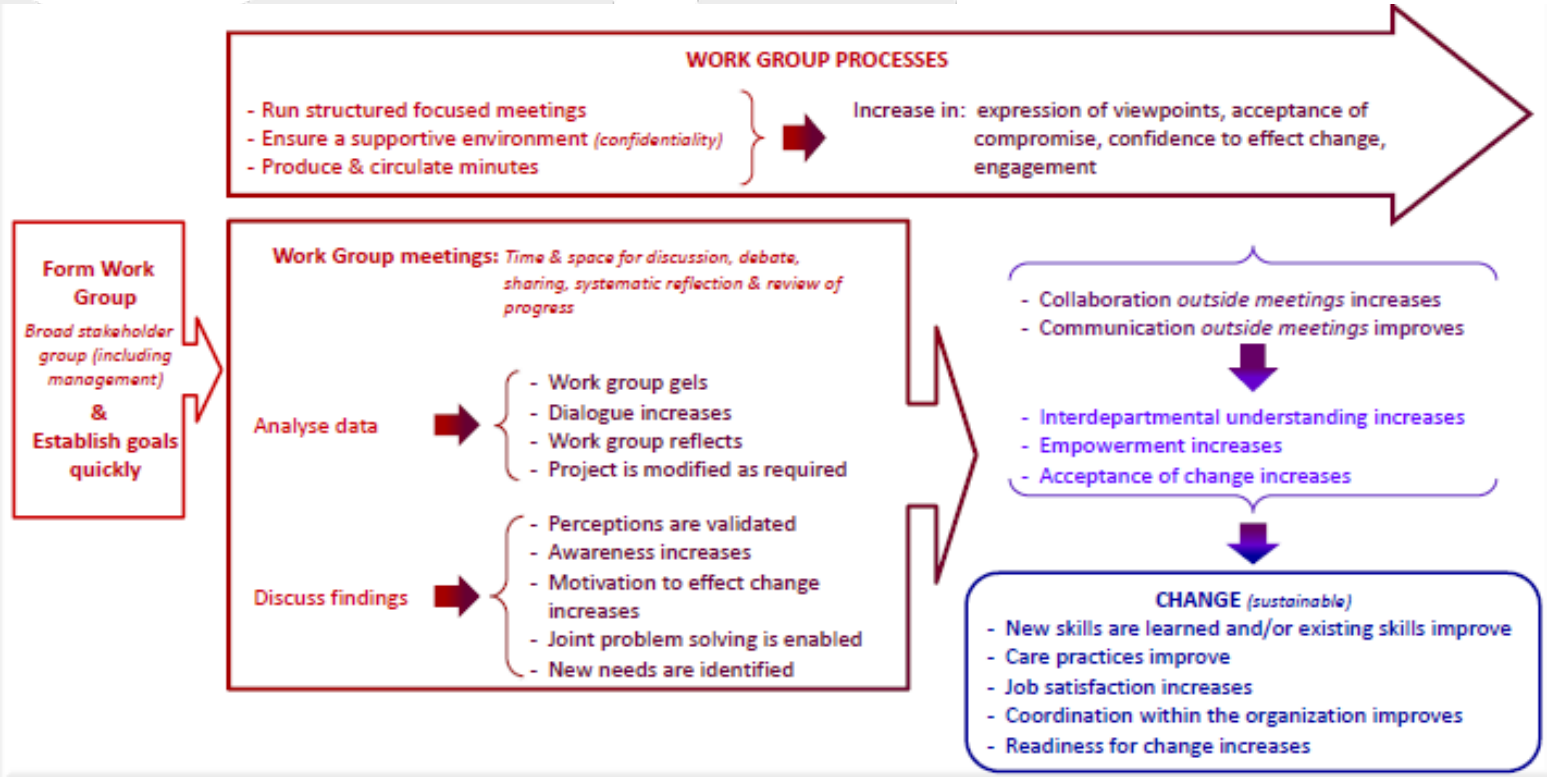
4.12. DRAFT AN OPR GUIDING PRINCIPLES DOCUMENT AT THE OUTSET OF THE OPR

The Working Group's decisions regarding the recommendations in this Practice Guide should be written in an OPR Guiding Principles document.

All Working Group members should agree to the principles, in writing.

While guiding principles may be amended during the OPR, it is important for the Working Group to produce a written document of principles, at the outset.

MODEL OF ITERATIVE PROCESSES AND OUTCOMES OF OPR



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