A GUIDE TO PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH

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CONTENT

ABOUT THIS GUIDE

There is growing recognition of the value of patient and public involvement (PPI) in health research (Boote et al., 2015; Pii et al., 2019; Skovlund et al., 2020). Patients can offer a unique perspective to healthcare development and improvement through their lived experiences. The incorporation of PPI in health research is particularly well established and supported by organizations and frameworks in the United States with the Patient-Centered Outcomes Research Institute (PCORI) (Frank et al., 2015), the UK with INVOLVE (INVOLVE, 2021), and Canada with SPOR (Greenhalgh et al., 2019; Manafo et al., 2018).

In Switzerland, PPI is still in its early stages of development, and hence not yet as well incorporated in clinical research. Nevertheless recent efforts have been pursued to promote PPI in health research. For instance, the Swiss National Science Foundation (SNSF) and the Swiss Clinical Trial Organisation (SCTO) developed in a collaboration the PPI Fact sheet and the PPI Guide for Researchers (Swiss Clinical Trial Organisation (SCTO), 2021). Furthermore, organizations such as the Swiss Group for Clinical Cancer Research (SAKK) and the SNSF have incorporated representatives of patients and the public in helping to foster the communication between patients and researchers (Swiss Group for Clinical Cancer Research (SAKK)) or evaluating the funding for studies submitted to the Investigator Initiated Clinical Trials (IICT) programme (Swiss National Science Foundation (SNSF), 2021).

This guide is intended to give a comprehensive overview about what PPI in research for patients, researchers, and health care organizations. The document provides definitions of the main PPI concepts, the values and principles of PPI, guidance about how to involve patients in a research project, how to evaluate the PPI process, or administrative and legal questions regarding roles, responsibilities, and remuneration. The structure of a training program for both, patients and researcher is also proposed, together with the description of how the SCCL-PPI* model can serve as a platform to facilitate and coach PPI in research projects.

To develop the SCCL-PPI framework, a review of the literature was conducted in order to identify established frameworks of PPI in cancer or in research (Greenhalgh et al., 2019). Nine models from seven different countries were considered: University of Montréal (CA) (Karazivan et al., 2015; Pomey et al., 2015; santé;, 2014), Strategy for Patient-Oriented Research (CA) (Canadian Institutes of Health Research, 2014), Patient-Centered Outcomes Research Institute (US)(Frank et al., 2015; Patient-Centered Outcomes Research Institute (PCORI)), National Institute for Health Research (UK) (Hickey et al., 2018; INVOLVE, 2015), Cancer Research UK (UK) (Cancer Research UK), Belgian Health Care Knowledge Centre (BE) (Cleemput I et al., 2019), Oncode Institute (NL) (Institute;, 2021), Cancer Australia (AU) (Cancer Australia and Cancer Voices Australia, 2011), and Patients Partenaires – HUG (CH) (Touveneau et al., 2018).

*SCCL = Swiss Cancer Center Leman
PPI = Patient and Public Involvement

PATIENT AND PUBLIC INVOLVEMENT (PPI)

Patients and Public Involvement (PPI) is defined by INVOLVE, the national advisory group that supports public involvement, as **“research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them**. In this definition, the “public” refers to patients, potential patients, caregivers and people who use health and social care services as well as people from organizations that represent people who use services (INVOLVE, 2015).

Terminology regarding PPI is still challenging, with little consensus as to whether relevant groups of individuals should be referred to as “patients”, “clients”, “consumers”, “service users”, “the public”, or by some other name.

Throughout this guide, they will be referred to as **“patient”**, a person who has (had) recourse to cancer care, in the course of which he or she develops experiential knowledge. “Patient” can include actual or former patients, caregivers and people who used cancer care services.

PATIENT LAB

WHY INVOLVE PATIENTS AND THE PUBLIC IN RESEARCH?

Despite each project might have specific reasons and objectives to involve patients and the public, there are some general principles that apply (adapted from INVOLVE, 2021).

- **Democratic principles.** A lot of research is supported by public funding. Public involvement in research is an intrinsic part of citizenship, public accountability and transparency. People who are affected by research have a right to have a say in it by providing the opportunity to influence research that is relevant to them.

- **Provide a different perspective.** Patients and the public will bring their own perceptions, expertise and lived experience (e.g. disease, impact of treatments) that may differ from those of the researchers and professionals.

- **Improve research quality and relevance.** By consulting the end user, Patient & Public Involvement (PPI) ensures that research focuses on outcomes that are important to the patient and the public. Public involvement can make research more relevant for example through the identification of new research ideas or prioritizing topics, therefore ensuring that research is focused on what matters to people; or helping to redesign and clarify the research. These improvements can help foster recruitment and retention of participants by ensuring that the ways of communicating and research methods are sensitive to the needs, customs and circumstances of the community.

- **Make research ethical.** PPI plays an important role in producing good study participant information sheets and shaping the informed consent process. It is more likely that potential participants understand the research and potential risks thus making the consent genuinely ‘informed’. PPI improves the experience of participating in research by ensuring that the design of the study respects and meet the needs of the participants (i.e. avoid burden with lengthy questionnaires, reduce unnecessary appointments or tests, and assure coverage of travel or other expenses).

- **Major funding bodies and scientific publications encourage (if not require) PPI.** In an effort to help advance PPI in healthcare and health research, journals like the British Journal of Medicine (BMJ) request to include a Patient and Public Involvement Statement as part as their patient partnership strategy to promote the co-production of their content (https://www.bmj.com/campaign/patient-partnership). In Switzerland, the Swiss National Science Foundation (SNSF) involved representatives of patients and the public in the evaluation process of the Investigator Initiated Clinical Trials (IICT) program to ensure that the projects addressed questions that are important to society but not a priority to industry (https://www.snf.ch/en/7GJ99FdMjxpeGkc1/news/clinical-research-patients-and-the-public-have-their-say).

Cancer patients and researchers partner for better cancer research

MISSION

As affiliate of the Swiss Cancer Center Léman (SCCL), the Patient Lab will innovate and promote a transdisciplinary partnership with cancer patients, caregivers and public at all stages of research and development of new or improved models of support and care in Suisse romande. Initially, the Patient Lab will focus on the development of Patient-Reported Outcomes Measures (PROMs) and Patient-Reported Experience Measures (PREMs) in cancer research and care.

AIMS

Affiliating the Patient Lab with the existing SCCL research & clinical platforms aims to:

- empower each other's innovation through cutting edge interactions between researchers, patients and public;
- improve public and patient involvement in research activities, and thus their adherence to studies;
- develop/enhance joint Public and Patient Involvement (PPI) capacity;
- enable the development of transdisciplinary oncology research projects that deliberately and systematically involve public and patients, and, in the longer term, lead to quality improvement initiatives in clinical care;

This approach will position the Patient Lab at SCCL as an integrative approach of cancer research that will be recognized regionally, nationally and internationally.

RESEARCH

EDUCATION

Innovate and promote in Suisse Romande a transdisciplinary partnership with cancer patients, caregivers and public (PPI), at all stages of research and development of new or improved models of support and care.

CARE

MANAGEMENT

GOVERNANCE

ACADEMIC LEAD

IUFRS, FBM, UNIL, CHUV
Oncology Department CHUV

UNIGE, HUG
Oncology Department HUG

TRANSDISCIPLINARY RESEARCH MANAGEMENT

Research Co-management
Patient & Public Involvement (PPI)
IUFRS (UNIL/CHUV) representative

Research Co-management
Patient & Public Involvement (PPI)
HUG representative

RESEARCH PROJECTS

RESEARCH PROJECTS 1	RESEARCH PROJECTS 2	RESEARCH PROJECTS 3,4,...	FUTURE RESEARCH PROJECTS
Principal Investigator 1	Principal Investigator 2	Principal Investigator 3,4,...	Principal Investigator
Patients' representative 1	Patients' representative 2	Patients' representative 3,4,...	Patients' representative
Scientific collaborators	Scientific collaborators	Scientific collaborators	Scientific collaborators
Post-docs	Post-docs	Post-docs	Post-docs
PhDs	PhDs	PhDs	PhDs
Master students	Master students	Master students	Master students

GUIDING PRINCIPLES

Adapted from the National Standards for Public Involvement (INVOLVE recommendations) (NIHR, 2018a), the Patient Focused Medicines Development (PFMD; www.pfmd.org) launched the Patient Engagement Quality Guidance, a multistakeholder[1] co-creation of Public and Patient Involvement (PPI) guidance and good practice identification (Deane et al., 2019).

Seven guiding principles were established providing a framework for good PPI practice, reflecting on and improving the purpose, quality and consistency of PPI in research (Deane et al., 2019). These principles can be applied according to the unique needs of each organization and project.

PPI = Public and Patient Involvement

Table 1. Public and Patient Involvement (PPI) quality criteria summary and description (Deane et al., 2019)

QUALITY CRITERION	DESCRIPTION	RATIONALE
Shared purpose	Importance of all stakeholders agreeing on the project's aims and outcomes before starting the project.	Early involvement is a key factor for quality of the process and includes the consideration of all perspectives in the early phase of planning.
Respect and accessibility	(1) respecting each other, and respectful interactions within the project to be established among partners, and (2) openness to and inclusion of individuals and communities (to the project) without discrimination.	A key quality aspect is the importance of securing a supportive culture that reflects that all stakeholders acknowledge the patients' perspective as equally important to that of other professional or authoritative stakeholders.
Representativeness of stakeholders	Mix of people involved, which should reflect the needs of the project, and the interests of those who may benefit from project outputs.	Ensuring optimal representativeness is demanding but essential for any PPI activity and involves careful consideration of the selection of patient representatives.
Roles and responsibilities	Refers to documentation of agreed and ideally co-created roles and responsibilities, indicating that all aspects of project needs will be established upfront and revisited regularly.	Clarity on roles and responsibilities of all partners is essential for the implementation of equitable working practices that ensure PPI opinions and expertise are respected and incorporated where possible into the projects.
Capacity and capability for involvement	(1) capacity as having relevant and dedicated resources from all stakeholders and (2) capabilities for all stakeholders to enable meaningful engagement.	It is essential that patients and researchers have sufficient resources (knowledge, skills, time, and budget) to contribute effectively.
Transparency in communication and documentation	Refers to the establishment of communications plan and ongoing project documentation that can be shared with stakeholders. Communication among stakeholders must be open, honest and complete.	Transparent communication throughout the project both internally and externally is essential to ensure credibility of process and findings.
Continuity and sustainability	Refers to the smooth progression of the project and efforts to maintain relationships with stakeholders beyond a single project.	Involvement of patients throughout the process as much as feasible, including aspects such as evaluation, dissemination and implementation can be very beneficial for the quality of the process. Additionally, ongoing commitment to PPI and development of long-term relationships will enhance quality.

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[1] Nine Working Group, Task Force or Core Team meetings were held (November 2016–June 2018) involving 76 unique participants, representing 51 organisations (including patient charities, academic researchers, funders, pharmaceutical companies) Deane, K., Delbecque, L., Gorbenko, O., Hamoir, A.M., Hoos, A., Nafria, B., Pakarinen, C., Sargeant, I., Richards, D.P., Skovlund, S.E., and Brooke, N. (2019). Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. BMJ Innovations 5, 43. 10.1136/bmjinnov-2018-000317.

PPI IN RESEARCH – THE SCCL-PPI MODEL

PPI in research is the development of an active partnership where researchers, patients and the public work together to develop research which is relevant and useful to patient and public needs (NIHR Research Design Service (RDS), 2018b).

STAGES OF INVOLVEMENT

Patients and the public can be involved in all stages of the research process, and in one or more phases of a research project:

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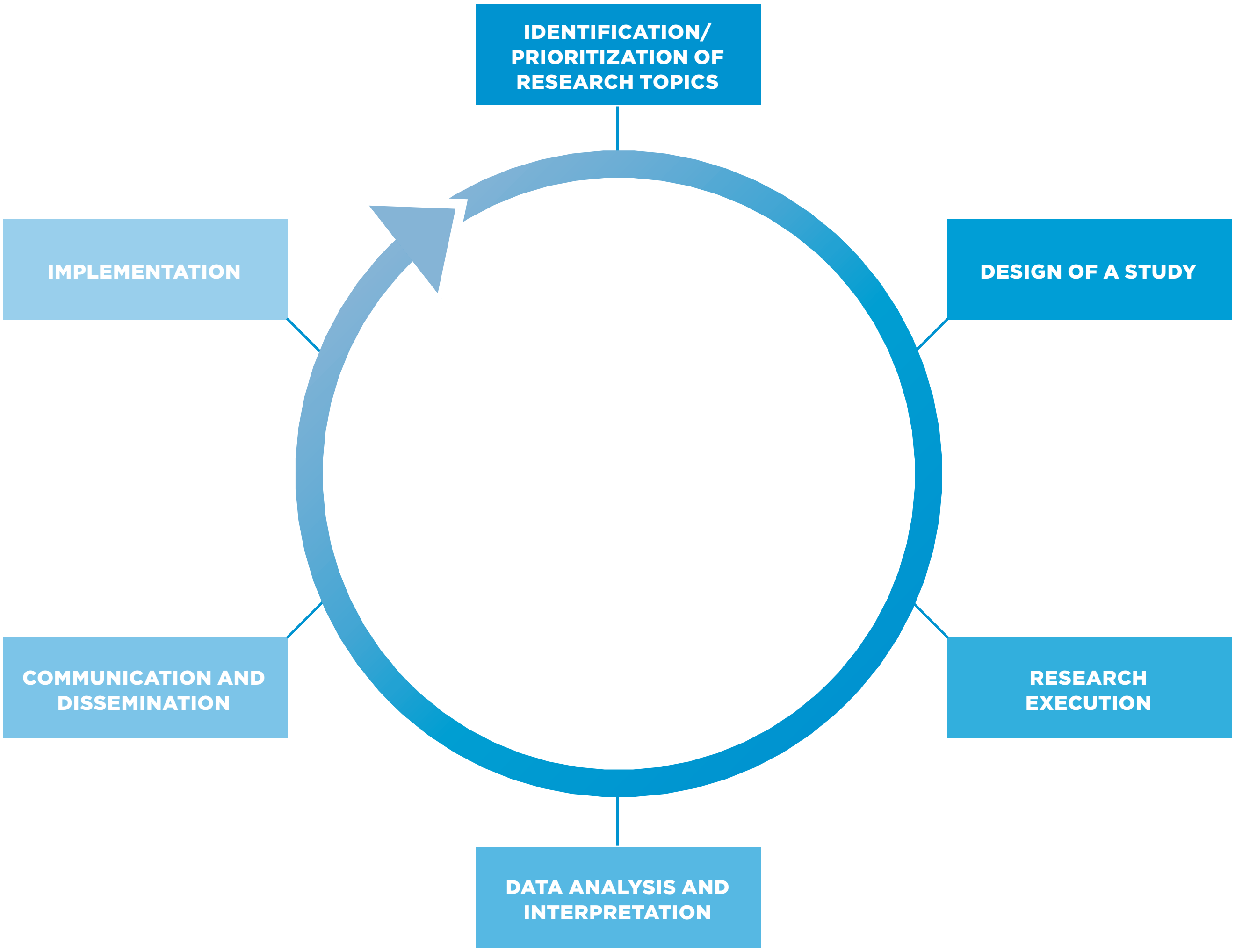
PPI = Patient and Public Involvement



Examples of objectives for each stage

IDENTIFICATION / PRIORITIZATION OF RESEARCH TOPICS:

- Help define research priorities
- Be consulted on research topics and priorities that are important to them as service users
- Collaborate with researchers to identify research topics
- Identify research topics themselves
- Develop and revise grant proposals

DESIGN OF A STUDY

- Inform the design of the research study
- Clarify the research question and affirm its importance
- Assist in ensuring that the research is ethical and acceptable to patients
- Ensure that the methods chosen are appropriate for the patients
- Assist in the design of the detailed protocol, including comprehensible consent forms
- Draft contracts and other guidance documents
- Assist in creating a recruitment strategy
- Review and comment on proposed questionnaires and data collection methods

RESEARCH EXECUTION (DATA COLLECTION / RECRUITMENT)

- Provide guidance throughout the research process
- Assist in the completion of patient information and consent forms
- Produce patient-friendly research updates
- (Assist in) conducting interviews and surveys and other data collection methods

DATA ANALYSIS AND INTERPRETATION

- Assist the research team in developing themes from the data (e.g. in working, focus or steering groups)
- Be consulted to see if they interpret the data in the same way as the research team
- Analyse data and compare with existing literature

COMMUNICATION AND DISSEMINATION OF RESULTS

- Advise on the different ways to disseminate results
- Present research results in conjunction with researchers
- Write information or summarize results for local patient groups, hospitals, etc;
- Be co-author in the publication of research results
- Draft and proof read of documents, especially lay versions
- Help to disseminate research results within their formal/informal networks

IMPLEMENTATION

- Ensuring that research leads to action
- Establishing relationships with key agencies and policy makers

LEVELS OF INVOLVEMENT

Based on the literature, the level of patient involvement can range from “information”, where the patient is informed about the research (passive subject) (Pomey et al., 2015) to patient-led research.

In the context of the SCCL-PPI model, and based on the type of research envisioned, we define 4 different levels of patient involvement in research:

Participation: to obtain information, opinions, advice, experiences. Establish priorities, identify research topics and participate to the dissemination of results, etc.

Consultation: to obtain feedback and advice on specific research activities: comments on forms and surveys, study design, data collection methods, outcome measures, analysis of results, relevance of results, etc.

Collaboration: working directly with patients throughout the research process - particularly at the planning stage - to ensure that their expectations and concerns are understood and addressed, and that the research process responds to those aspirations and concerns.

Partnership: Active partnership with the patient in all aspects of the research process, including: research priorities, research question, research design, data collection methods, outcome measures, analysis of results, relevance of results, dissemination of results, etc. Decisions about the research process are shared. Research grant application, being a member of the study advisory group, and collaborating with researchers to disseminate the results of a research project.

Within a single project, different levels of involvement may coexist, independently or as a continuum throughout the research process.

To note that in the SCCL-PPI model,

1.- The lowest level of involvement will correspond to an already active involvement by participating in the research process. This level, named in our model “participation” differs with the concept of Participation as defined by INVOLVE or NHS where people take part in a research study (passive subject).

2.- Research led by patients as defined by other models, will not be conducted. Instead, an active partnership or co-creation will represent the highest level of involvement in the SCCL-PPI model.

TYPES OF INVOLVEMENT/ROLES

Patients' roles vary according to the contributions a patient is able to offer. To use patient knowledge to the best effect, ways must be found to convert the diversity of individual experience into the closest representation of a typified patient perspective. The patient voice must be a blend of collective and personal experiences. A way to overcome this is to include more than one patient and covering more than one type of involvement.

PERSONAL ENGAGEMENT

Actively participate in raising awareness from a personal perspective and provide feedback from direct experience. Engagement occurs through patients sharing their stories and participating in focus groups, surveys, and targeted work groups.

ADVISOR

Provide opinion and guidance from the perspective of both individual and collective experience, making recommendations based on the best available evidence. When the views of a diverse range of patients are sought to provide advice and to influence the final decision.

EXPERT

Participate on organizational boards or are involved in advisory committees or major projects and are invited for their high-level expertise knowledgeable across a broad range of cancer care. They are supported by a network of patients/peers who advise their work (e.g. patient associations, umbrella organizations). Patient experts have a longstanding experience in patient involvement in research.

PARTNER/CO-RESEARCHER

Patients are considered as equal partners with essential knowledge necessary for research and most importantly to effectively support the implementation of PPI in research.

RESOURCES: CAPABILITY & CAPACITY

Furthermore, the decision regarding the the stage, level, and type of involvement requires a careful evaluation of the capabilities of the patients as well as the capacity of the research group/organization.

PATIENTS' CAPABILITY

Patients have a range of capabilities based on their experience, skills, knowledge, interest, or time. Patients have developed knowledge from their own experience and are able to transpose this experience to represent the views of others.

In the SCCL-PPI model, patients are supported, trained and categorized for their capabilities (defined by the patient) to engage meaningfully and represent effectively for people affected by cancer.

Capabilities refer to:

- Experience: participants have an experience of cancer as patient, survivor, family member, or informal caregiver
- Motivation: participants show an interest to engage in research
- Understanding the setting: participants will develop an understanding of the research context
- Adaptation: participants will develop their skills to meet the requirements of their role
- Availability: participants define their availability and commitment possibilities
- Knowledge: participants have or lack knowledge regarding research or the research topic
- Learning: participants undertake learning to build their expertise
- Support and networking: participants seek support to perform their role through involvement in patient's organizations, support groups, networks, etc.

CAPACITY OF THE RESEARCH ORGANIZATION

Estimation of resources available in terms of PPI experience and knowledge, time, and costs. Resources may determine the number of patients, their level of involvement, or the selection of methods. All these factors might have an impact on the PPI outcomes that researchers have to consider.

In the SCCL-PPI model, researchers are trained and coached on their requests based on their specific needs and resources.

METHODS USED IN PUBLIC AND PATIENT INVOLVEMENT (PPI)

The selection of a methodology to involve patients will depend on the research question, on the purpose of involvement, on the research stage, on the number of patients involved, and on the capacities of the researchers. A range of various qualitative and quantitative scientific methods exists. Methods can also include process-oriented[2] or mixed approaches (e.g. the James Lind Alliance priority setting method).

Among the most commonly methods used in PPI in cancer research we find (Pii et al., 2019):

- Interviews
- Focus groups
- Group interviews
- Nominal group techniques
- Surveys
- Expert groups / Delphi
- Steering groups / advisory boards

Or processes involving workshops, and discussions and feedback sessions, to reach consensus on a specific issue (e.g. identification of research priorities).

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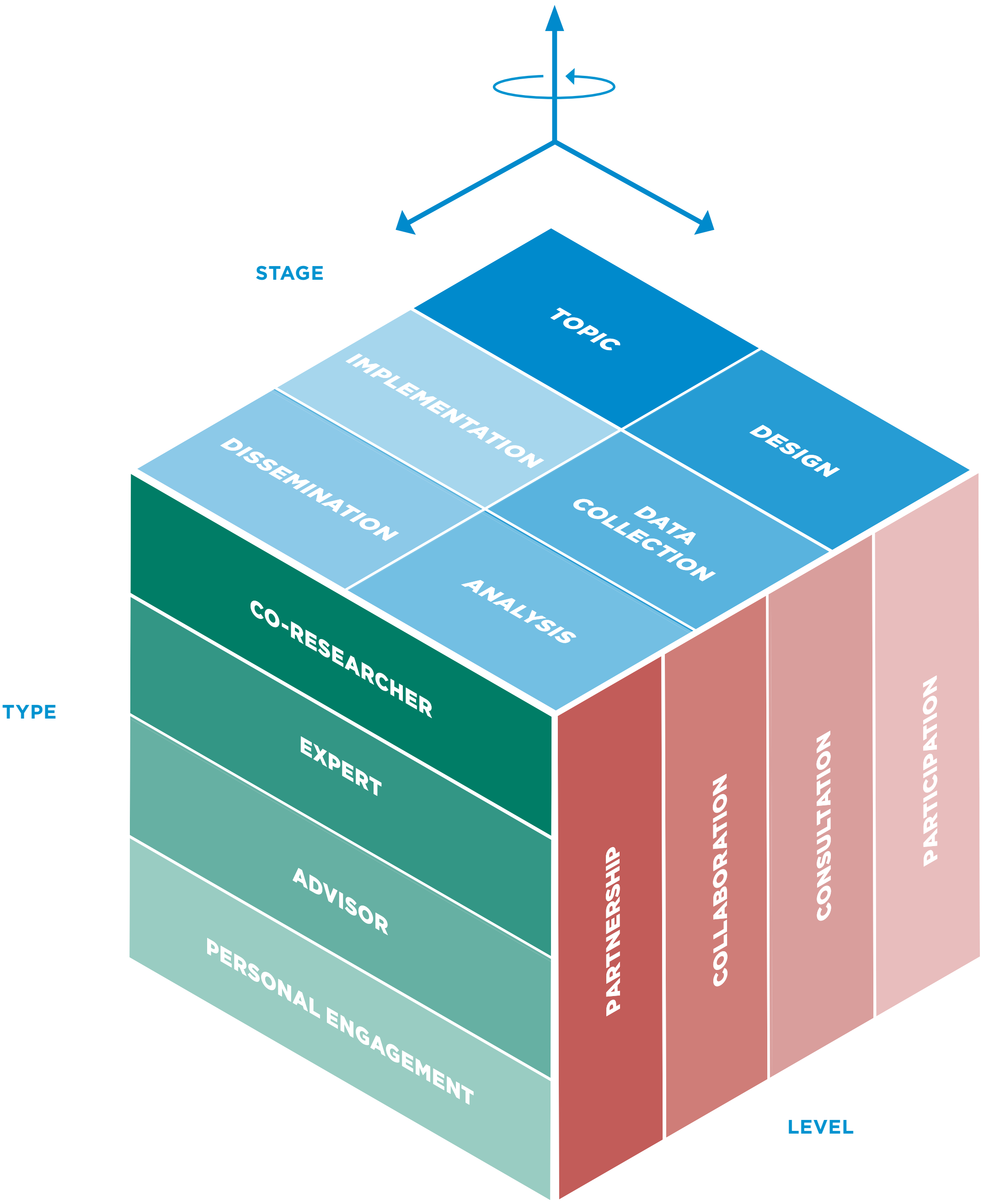
[2] Approach that entails using processes and frameworks where a set of ideas and actions are intended to address or solve a problem by developing alternative solutions



+ CAPABILITIES OF THE PATIENT
+ CAPACITY OF THE RESEARCH ORGANIZATION

REPORTING AND EVALUATING PPI*

Reporting and evaluating the impact of PPI in research should allow to:

- improve the quality of PPI, and hence the quality of research
- evidence the impact of PPI and encourage stakeholders to commit to having PPI in research
- justify funding and other resources for PPI, especially in times of financial constraint
- inform members of the public of the difference that they have made
- facilitate planning for future projects, e.g. taking steps to avoid harm or limitations(Kok, 2018)

THE GRIPP2 CHECKLIST

GRIPP2 represents the first international evidence based, consensus informed guidance, for reporting patient and public involvement in research. Both versions of the GRIPP2 (long and short) aim to improve the quality, transparency, and consistency of PPI, to ensure PPI practice is based on the best evidence (Staniszewska et al., 2017).

GRIPP2-LF (long form) includes 34 items on aims, definitions, concepts and theory, methods, stages and nature of involvement, context, capture or measurement of impact, outcomes, economic assessment, and reflections and is suitable for studies where the main focus is PPI. GRIPP2-SF (short form) includes five items on aims, methods, results, outcomes, and critical perspective and is suitable for studies where PPI is a secondary focus.

Researchers are highly encouraged to think about using the reporting and evaluation tool for PPI as some scientific journals might require to provide it during the revision process.

***PPI = Patient and Public Involvement**

TASK DESCRIPTIONS, NEEDS AND REMUNERATION

Lived experience of a disease or condition creates an understanding and knowledge which is unattainable to those without such experience. Medical research cannot fully comprehend the issues that it addresses, unless the traditional clinical or scientific knowledge on which medical research is built is complemented by including the patient perspective acquired by experience of the disease, and the care and treatment associated with it.

In this sense, lived experience has a high value, which healthcare professionals and researchers endeavor to access, understand and integrate into their work by involving patients.

This is a challenge for many organizations, particularly to achieve the diversity of patient informers and advisors that are needed to reflect all segments of the community and to access the information that will broaden the relevance and quality of the research.

The areas where patients can best contribute to a research project must be defined, as well as the appropriate level of involvement and in exactly what roles can patients contribute. A balance must be found between formalization and flexibility. Formalization is needed to meet the defined values and guiding principles. A flexible approach is needed towards the specific characteristics and needs for each individual project and the requirements, resources and abilities of every patient partner.

To meet these needs a task description should be drafted for each structural element of a research project, e.g. a committee, steering, focus or working group, and also for each participant, or individual patient role. These contain the standardized elements but allow the necessary flexibility.

TASK DESCRIPTION FOR BODIES

A body can be a committee, steering, focus or working group, or ad hoc group.

- Title
- Purpose / aims
- Constitution and Dissolution
- Number of members and composition of skills
- Responsibilities and Rights of members (e.g. meeting attendance, representation, workload, confidentiality, conflicts of interest, additional individual contracts)
- Duration and meetings (how many, how long, when and where)
- Reporting (how and to whom)
- Payment and expenses.

TASK DESCRIPTION FOR PATIENT OR RESEARCH PARTNERS

Task descriptions should be defined for every new role profile for each involvement activity. This enables the partner to have a clear understanding of expectations, and also allows for the advertising of the role and potentially to enable a selection process.

Patient specific knowledge

The task may require different levels of understanding of the disease or condition, the ability to conceptualise outcomes and/or assess the reported outcomes.

Standardised attributes

The experience, knowledge, skills and personal qualities needed for the tasks can be categorised in the standard formats, e.g. as essentials and desirable attributes.

Levels of engagement

The levels listed above are a useful point of reference, but it should be remembered that one partner will generally have multiple involvement activities.
The contribution may vary over the research cycle.
For instance involvement may be co-creative in one area, and consultative in another.

Training needs

To fulfil requirements and importantly to support communication between often heterogenous participants, both groups (patients and researchers), as a whole or individual patient, may need training to support their activities and improve their ability to contribute. This training may be separated from the partnership activity itself or “on the job”. It may be formal or have informal character in the sense of peer support.

Special needs

Finally it should be remembered that patients may have special needs relating to their conditions. These must be considered both within the context of the structures that they are working in, e.g. length of meetings or travel requirements, but also related to personal needs (e.g. dietary constraints, childcare facilities, translation and interpretation).

Acknowledgement

Patients’ contributions must be acknowledge. In the case of publications, patients can either be included as co-authors or mentioned in the acknowledgement section, depending on the level of involvement in the research process.

Remuneration and Expenses

Patients add value to a research initiative, and be remunerated for their work accordingly, unless they specifically decide to donate their time. They should never be out of pocket and expenses should be covered in a timely fashion (e.g. travel and refreshments).

Depending on their roles patients are using their market skills in their work, which should be recognised and honoured independently of their patient status, e.g. they may have scientific training, marketing, statistical analysis, public speaking or other leadership skills, which should be acknowledge as resources allow.

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