Patient Involvement for Applicants

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Effective involvement of patients, caregivers and patient organizations based on co-design principles allows a better formulation of patient-relevant research questions and, more effective and relevant data generation. Involvement also enables increased credibility of knowledge and data, prevention potential challenges that patients may face during the conduct of a study, and more effective dissemination (notification to other parties) and use of research outcomes in clinical practice.

Engagement with patients, caregivers and patient organizations ensures that research questions and clinical research outcomes are implemented in a manner relevant to patients.

This document provides guidance to research teams to prepare and implement patient involvement during the grant application phase and implementation phase of projects.

The document covers the following areas:

Checklist for applicants when planning patient engagement during the application phase, during the implementation of the project, and beyond the project.

Examples for potential contributions of patients, caregivers, patient advocates and patient experts to a research project.

Organizational models of patient engagement in research projects, including roles of the patient community in coordination, contribution and advisory roles in a study.

Identification of the right patient organizations or patient advocates as research partners, as well as **resourcing the contributions of the patient community.**

Patient involvement plans, describing patient involvement processes during application and implementation of a research project.

Preparing the patient community for their contribution in the post-application, pre-launch phase.

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Contents

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1 Glossary

Term	Definition
Patient engagement	Patient (public) engagement covers the various ways in which the activity and benefits of higher education and research can be shared with the public in a two-way process. Engagement encourages researchers to listen and interact with the general public. Engagement also helps discussion with the public at a general level and to be able to talk about topics like research ethics. Public engagement can include opportunities for researchers to discuss their preliminary ideas for future studies. Researchers might also get people involved as contributors and in conducting part of a research project as ”citizen scientists”.[1]
Patient involvement	Patient and public involvement means that research is carried out ”with” or “by” members of the public, rather than “to”, “about” or “for” the public. The word “public” can refer to patients, potential patients, caregivers and people who use health and social care services. It can also refer to somebody from an organization who represents people that use services, and members of the public. Patient and public involvement focuses on a specific research project, program or process.[1]
“Involvement” as used in this document	Involvement in clinical trials/clinical research, and basic and translational research.
Patient	The term “patient” is often used generally. It does not reflect the input and experience that patients, patient advocates and patient organizations use when working (collaborating) with other groups. In this document, “patient” includes individual patients, caregivers, patient advocates, patient organization representatives and expert patients (discussed in section 2.1). When an individual patient is engaged, it is suggested that the relevant patient organization, if one exists, is informed and/or consulted to provide support and/or advice. The type of input and mandate (what they do) for the involved person should be agreed in any collaborative process prior to engagement.[2]
Patient community	Formal and informal networks of patient organizations and patients, patient advocates, experts etc.

[1] Adapted from https://www.spcr.nihr.ac.uk/PPI/what-is-patient-and-public-involvement-and-engagement
[2] Adapted from https://www.frontiersin.org/articles/10.3389/fmed.2018.00270/full#:~:text=EUPATI%20focuses%20on%20education%20and,friendly%20information%20for%20the%20public.

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2 Checklist when planning patient involvement

Early involvement of patients and caregivers based on co-design principles allows a better formulation of relevant research questions. This also increases credibility of the knowledge produced, helps to identify and solve potential challenges faced during the trial, and enables better application of outcomes to specific contexts.
Here is an activity checklist when planning patient involvement in the application phase, during the implementation of the project, and beyond the project.

2.1 Proposal preparation and application phase

- **Define the need for patient involvement in the proposal generation phase**
- Plan the role of patient involvement in the project proposal
- Choose the most appropriate patient involvement model and organizational structure
- Identify the right patient partners to work with
- Involve patients early in formulating the concept, the hypothesis, and while developing and reviewing the proposal
- Apply for funding to involve the patient organization/patients in development of the proposal or support the patient organization/patients in applying for a pre-application grant
- Reserve appropriate budget for patient involvement which will be reflected in the Patient Involvement Plan and the overall grant budget request
- Consider measuring the impact of patient involvement in your project

2.2 Project Plan

- Understand and assess the needs of trial participants
- Collaborate with patient partners to adapt the trial and procedures where necessary
- Collaborate with patient partners to design the assessment of the research outcomes and dissemination (notifying other parties) of the research findings
- Assess the impact of patient involvement in the project during mid-term and at the end of the project

2.3 Beyond the project

- Consider communication and dissemination activities involving patient/public partners after project end
- Consider ongoing collaboration with patient community on trial outcomes
- Consider the involvement of patients in future research projects

For further reading on tools and case studies, please refer to Chapter 7 on “Additional references and further reading”.

3 Potential contributions of patients to research projects

The table below lists some examples that patients, caregivers, patient advocates and patient experts could contribute to a clinical or other research project. The list is adapted from the DIA recommendations on the different roles and functions of the patient:

Patient role	Examples	Engagement level
Partnership role	● Patients provide consultation before and during a study on outcomes of importance, study design, etc. ● Patients are paid investigators or consultants ● Patients have a governance role – "a seat at the table" ● Patients are project partners and responsible for part of the project work	High
Advisor role	● Patients serve as advisory committee members or provide consultation prior to a study on outcomes of importance and study design, but have no leadership role or governance authority	Moderate
Reactor role	● Patient input is collected through surveys, focus groups or interviews rather than consulting patients directly or before a study, on study design and important outcomes ● Patients are asked to react to what has been put before them rather than being the source of the idea	Low
Trial or study participant	● Patients are recruited or enrolled as study participants, but are not asked for input, consultation or reaction	None

Adapted from: http://synapse.pfmd.org/resources/considerations-guide-to-implementing-patient-centric-initiatives-in-health-care-product-development/download

Note that the patient roles listed above may have to be changed according to current practice of patient involvement with stakeholders in collaborative research projects, or with the pharmaceutical industry and regulators.

3.1 Roles of patients, caregivers and patient advocates

The term "patient" is often used generally. It does not reflect the input and experience that patients, patient advocates and patient organizations use when working with other groups. The European Patients' Academy (EUPATI) has defined the following categories of patients:

- **"Individual Patients"** are persons with personal experience of living with a disease. They may or may not have knowledge in research or drug regulatory processes. Their main role is to provide experience on their disease and treatment.

- **"Caregivers"** are persons supporting individual patients such as family members as well as paid or volunteer helpers.

- **"Patient Advocates**" are persons who have the insight and experience in supporting a larger population of patients living with a specific disease. They may or may not be affiliated with an organization.

- **"Patient Organization Representatives"** are persons given responsibility to express the collective views of a patient organization on a specific issue or disease area.

- **"Patient Experts"** have both disease-specific expertise and knowledge in research and/or drug regulatory affairs through training or experience. For example, EUPATI provide training for patient experts in the research and development of medicines.

Adapted from: https://www.frontiersin.org/articles/10.3389/fmed.2018.00270/full

It is important to understand that "lay patients" without previous research experience can contribute important insights at any stage of a research project. This "lay engagement" can happen in various ways – public community interviews, focus groups, or qualitative (descriptive) input are useful methods.[3]

However, useful involvement in the design or conduct of a clinical research project often requires more than just personal experience. Wider community insights and/or technical training may be additionally needed. The engagement described in this guide requires a significant level of know-how and expertise from the patient contributors. The level of insight of each patient contributor varies in their understanding of the concerned patient community. This is why expectations of individual knowledge, experience and community insight to fulfil the role of a patient contributor need to be clarified before engagement is initiated.

Some possible partnership roles are listed below. Although these roles may not apply in all situations, examples of all of them occur in various projects within and outside the EU.

3.1 Partnership roles

3.1.1 Coordination and supervision

Patients can provide useful input to research projects in leadership roles within research teams and consortia (associations). These roles are infrequent but are increasingly accepted by research consortium members and endorsed by funders, e.g., the Innovative Medicines Initiative (IMI).

- **Chair, Co-Chair or Member of a Governance Board** – patients and patient organizations may not only participate in governance boards, they can take a leadership position.
- **Leader or Co-leader of a Work Package** – many projects, especially supported in the EU, are structured around work packages. A "work package" is a group of related tasks within a research project often organized as sub-projects within a larger project. Patient organizations can play a key role by becoming full project members and lead or co-lead some work packages.
- **Chair, Co-Chair or Member of an Advisory Board** – although advisory boards may be organized by the research project or the sponsor of a trial, patients can also take a leadership and coordination role on these boards.

[3] https://www.fda.gov/drugs/development-approval-process-drugs/fda-patient-focused-drug-development-guidance-series-enhancing-incorporation-patients-voice-medical

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3.2 Advisor roles

The following examples describe advisory roles of patients or patient organizations in the design and implementation of a research project. Involvement may be at different time points, time limited or cover the entire project duration.

3.2.1 Design phase

- Pre-activity research
- Pre-involvement planning
- Selection of outcome measures and how and when to measure them during the research phase
- Co-creation (joint development) of research design and related documents
- Pilot testing of research elements like surveys, focus groups etc.
- Assessing the inclusion and exclusion criteria for prospective participants in research

3.3 Reactor roles

- Reviewer of research design – patients can review and propose modifications to the research design. This role is different from co-creation because patients review concepts and/or study documents that have been developed by others.

3.3.1 Data generation

- Facilitator or participant of focus groups
- Collect additional registry data
- Conduct a membership survey
- Support recruitment into a study, trial, or other engagements

3.3.2 Data analytics

- Contribute to data analysis and/or interpretation of data/preliminary findings
- Conduct analyses of survey or registry data
- Community review – review of data analyses, articles and presentations from the patient community's perspective

3.3.3 Communication and outcome dissemination of research results and recommendations

- Presentation/speaker at international conferences, meetings, symposia
- Author/co-author of scientific publications
- Communications/awareness campaign collaboration

3.4 Trial or study participant

The enrolment of patients as trial participants into a clinical study is not considered as patient involvement or involvement.

Care is required if a patient is engaged in a double role as both a study participant and as a contributor to the design and implementation of a research project. There may be a conflict of interests and possible bias in the study results if the patient works as an expert and is also enrolled in the study. We do not advise this double role, but are aware that by example in rare diseases it can be difficult to avoid.

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4 Choice of models of patient involvement in research projects

This section will help the applicant team and the patient community to agree on a meaningful model on patient involvement for a specific research project. It is based on the classification of patient roles and contributions above. Examples are also added from previous research projects which include relevant patient involvement and input.

4.1 Choosing suitable models of patient involvement in research projects

Applicant teams should think carefully about the activities across the whole project lifecycle that the patient community could undertake. Short term activities are easy to define upfront, but it is more challenging to think about sustained involvement across the entire project. Therefore, it is important to think about the most applicable **model of patient involvement** in a clinical or other research project. The choice may depend on the particular research project and the specific tasks required.

The table below gives examples for the different roles described in Section 3. Patient involvement is organized in a systematic way by placing patients into different leadership or advisory roles for a given research project. The table also provides information on the level of impact and resource required. The more complex the role and the greater the degree of responsibility then the higher the workload and more intensive effort required. Some benefits and limitations of particular models are also outlined. Choosing the right model will depend on the nature of the project, the intended outcomes, the available resources, and the time when patient involvement becomes an active part of the project. Here, the basic rule of “the earlier the better” always applies, especially when basic research is considered.

The different examples in the table confirm that it is possible to devise a theoretical framework for patient involvement as described in Section 3 above. However, many actual solutions are implemented as hybrids or mix of more than one model. The ideal model may be determined by the purpose and conditions of the project. The recommended models should be treated with a degree of flexibility depending on some key factors:

- Objectives of the research project
- Capacities and level of expertise of the patient organization and/or the patients involved
- Clear definition of work processes and workflows
- System readiness of the applicant to be able to work with patients

4.2 Involvement models in research projects: roles, impact, effort, pros and cons

The following table provides a list of formal project roles. Each project role has perceived benefits and drawbacks. These benefits and drawbacks have been reported and observed in actual patient involvement efforts. The list is not exhaustive. There may be other modalities of patient involvement that are more informal or more creative or innovative. This may increase the diversity and the extent to what and who is included. Regardless of the actual method used, a formal agreement with clear timelines and description of responsibilities should be defined to support the patient involvement activity.

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Role	Description	Impact, Effort, Pros, Cons
Project coordinator	Patient organization leads and coordinates the whole project	Impact: very high Effort level: very high + Most influential role, e.g., patient-led research project – Highest workload, skills, experience and commitment required Example: European Patients' Forum in EUPATI, https://www.imi.europa.eu/projects-results/project-factsheets/eupati
Steering committee member	Patient organization / advocate is member of the governing committee of the project - and is funded for the work delivered	Impact: very high Effort level: very high + Patients are part of all relevant strategic decisions – High workload, skills, experience and commitment required – Not always funded for the work delivered. Example: ART CC, HIV cohort collaborations, http://www.bristol.ac.uk/art-cc/
Work package leader	Patient organization / patient advocate coordinates a specific work package in the project	Impact: high Effort level: high + Patients with responsibility to coordinate and deliver defined elements of the project e.g., a work package on patient involvement, needs assessment, external communication + Patients organizations (sometimes) funded for the work delivered – High workload, skills, experience and commitment required Example: LeukaNET in the IMI HARMONY Big Data project, https://www.harmony-alliance.eu/patient-cluster , or Myeloma Patients Europe in SISAQOL-IMI, https://event.eortc.org/sisaqol/
Research project member	Patient organization/patient expert is a full member of the research project	Impact: medium Effort, skills, experience level: medium + Full participant of the overall project team + Patient organizations (sometimes) funded for the work delivered – Limited influence on decisions, usually only through project meetings of work packages and annual assembly Example: Association Française du Gougerot Sjögren – AFGS in H2020 NECESSITY, https://www.necessity-h2020.eu/patient-involvement/

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Role	Description	Impact, Effort, Pros, Cons
Patient involvement hub	Patient organization/patient expert is a full research project member, coordinating contribution from other patient organizations outside of the project team, e.g., indication specific	Impact: high Effort, skills, experience level: high + Full participant of the overall project team + Patient organizations funded for the work delivered +/– Does the administration and coordination workload for the wider patient community Example: LeukaNET in the IMI HARMONY Big Data project, https://www.harmony-alliance.eu/patient-cluster, or Myeloma Patients Europe in SISAQOL-IMI, https://event.eortc.org/sisaqol/
Associated project partner	Patient organization has a partnership agreement with the research project	Impact: low Effort, skills, experience level: medium + Patients may prefer as it may take less time + Easier to combine with other activities – Patient organization usually not funded for the contributions and work – Usually not much influence on decisions of the project – Usually no compensation for time, so little time investment possible Example: Patient Advisory Group of four patient organizations in IMI PREFER, coordinated by ECPC, https://www.imi-prefer.eu/stakeholders/patients/
Advisor / advisory board member	Membership of ethics committee, scientific advisory board, project advisory board, data safety monitoring board.	Impact: low Effort, skills, experience level: low + Patients' expertise provided into specific committees, but no participation in active work – Usually no compensation for time, so little time investment possible – Advice only – usually little influence on decisions and no accountability whether advice is actually used and implemented by project Example: Patient Advisory Group of four patient organizations in IMI PREFER, coordinated by ECPC, https://www.imi-prefer.eu/stakeholders/patients/

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4.3 Providing an organizational structure and terms of reference

The composition and process of patient involvement differs based on the nature of the project and the engagement model chosen. However, the expectations from all involved parties always need to be clear and realistic. Patient involvement should be recognized by all partners as an integral and equal part of the project.

To make sure meaningful patient involvement actually happens, it is recommended to provide a **clear organizational structure and terms of reference for patient involvement** from the start of the project. This is important because individual patient partners may not be connected through a structured, professional organization.

Therefore, a patient organization or other project partner should be assigned as **patient involvement coordinator** of the project. Their responsibilities are to define who should coordinate meetings, to develop terms of reference and to ensure that the project infrastructure is accessible to the patient partners. The patient involvement coordinator will also ensure regular communication with the overall project management and the patient partners. They should also ensure that involved patient partners do not become detached from the situation, especially when patient partners are not directly connected to the research being conducted.

5 Identification of patient partners – and resourcing their contribution

This section will help the applicant team to identify patient organizations or patient advocates who are the best candidates to achieve the objectives of a patient-relevant clinical research project. The section also describes limitations of patient organizations and patient partners in terms of resourcing.

The members of a project team should define the most important aspects of a project to consider. They should also determine the necessary level of diversity and representation that is possible.

5.1 Characteristics of patient partners

There are some guiding questions that the project team should ask themselves when considering which patients, caregivers, patient advocates, or patient perspectives should be involved in the research project:

- Do the patient partners need to have **experience** in a specific disease area?
- Which **roles** would the patient partners have in the project?
- Which **contributions** should they provide?
- Which **competencies**, skills and experience do they need (e.g., basic medical expertise, indication-specific expertise, regulatory expertise, communication skills, political interaction, deep community insight)?
- Which **region** should they come from and how can a balanced region representation be achieved (e.g., avoid focusing on English-speaking countries)?
- Are there specific **mobility and accessibility** requirements (physical, economic, psychological, linguistic)?
- What about **diversity** (gender, age, ethnicity, cultural, educational, socio-economic) and **representation** (regional, disease-specific)?

It is also important to consider that the research team may be in a single country but the clinical application of the outcomes may be pan-European or transcontinental. Patients' needs and

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expectations as well as healthcare systems may differ between regions. Therefore, an international representation of the patient community is most important.

The project team should consider if the attributes of the project can be delivered collectively or individually. If it is collectively then the process might be better served by an established patient organization. Alternatively, a team of advocates and/or experts could be set up to work together collectively. The appropriate choice of partners should be carefully carried out to ensure all possible partners are included in the project.

5.2 Identifying partners

It may be challenging to find patients, caregivers, patient advocates or patient organizations who can contribute well to a project. In practice, many organizations are run by volunteers, organizations may have very limited resources, and may have limited experience in working with researchers. An important challenge for applicants is that applications are very often submitted under time pressure. In such situations, creative solutions to involve patients in a timely manner can be helpful.

Some possible mechanisms to identify patients, caregivers, patient advocates or patient organizations are listed below:

- For questions related to the implementation on site, it might be beneficial to contact **local patient groups, hospital and community organizations** or persons within those institutions who have some responsibility for public involvement.
- **National or pan-European patient organizations** may help to address overarching research questions or may help to identify local organizations in their membership.
- **Exploration of informal contacts and networks** can also be a useful tool to identify potential partners. Many patient experts and patient organizations keep in contact with colleagues working in other therapeutic areas. These contacts may be informal and based on friendships and acquaintances. Care should be exercised in these informal network situations to ensure privacy issues, compliance and other legal requirements are upheld

5.3 Appropriate funding of patient involvement

A common problem with patient involvement is lack of funding and human resources. People living with a chronic condition often have to stop paid work. Sometimes patients have a lot of volunteer commitments in addition to their normal job. They may also have increased costs due to additional medical care, childcare or other support needs. If only travel costs and some other expenses are reimbursed for patient involvement, this is usually insufficient and will lead to a very limited availability of patients who may be able to contribute.

Therefore, it is good practice to remunerate (reward) patient representatives for the contributions they make to projects just as it would be for any other professional person. The valued contribution that patient representatives make should be part of the project budget. An appropriate financial system should be in place to make sure that patient involvement is budgeted for and funded. Examples of these models are inclusion of patients as consortium partners, third party consultants, or as consultants to one of the consortium partners.

Expenses should be agreed and paid in advance before a patient partner has to pay any costs. No patient partner should ever be "out of pocket" for their contribution. Remuneration or "reward and recognition" payments or honoraria should be regulated separately.

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It is important to talk to the individual patient partner and assess their options for remuneration. Everybody's situation is different. The policy for remuneration should be flexible enough to take this into account.

6 Patient Involvement Plan

A call may require you to submit a "Patient Involvement Plan" as part of the application. The plan should describe patient involvement strategies and processes during the implementation of your project. It describes involvement e.g., how you engaged or identified useful perspectives with the patient community when the research question was defined, while the proposal was being written, when it was being submitted and resubmitted, and which patient involvement model and processes were chosen for the implementation of the project.

It is recommended to include patient involvement in the general ethical considerations of the research plan.

When developing the Patient Involvement Plan, there are some guiding questions to ask yourselves:

- How did you assess your research question regarding the relevance to patients?
- How were patient advocates involved in the design of the clinical trial?
- How will patients, caregivers and patient advocates be consulted and have an active role during the conduct of the clinical trial?
- How will involvement be supported, resourced and funded?
- How will the patient community be involved in the dissemination of your clinical trial results?
- How will patient involvement efforts be monitored and evaluated? And how, will patient involvement be adapted in the future and the lessons learned be shared?

When developing the project budget, please ensure that adequate and realistic resources for patient involvement are reflected in the Patient Involvement Plan and the overall grant budget request. This should include an appropriate budget e.g., for work time (staff or contractors in patient organizations) and project-related pass-through costs (e.g., IT, travel expenses and meeting venue costs).

7 Pre-launch project preparation

Consider how you can involve the patient community in preparing the launch of your project before official project funding starts. Given that the funding is not available before the official launch, resourcing from patient partners for preparatory work will be very limited.

However, in order to prepare the patient community for their contribution to your research project, you may consider providing the following in the pre-launch phase:

- Finally submitted grant application documents including all annexes
- Invitation to preparatory meetings and teleconferences
- Inclusion in your preparatory mailings and pre-launch communication
- Detailed information about the upcoming launch
- Training provided to your patient partners

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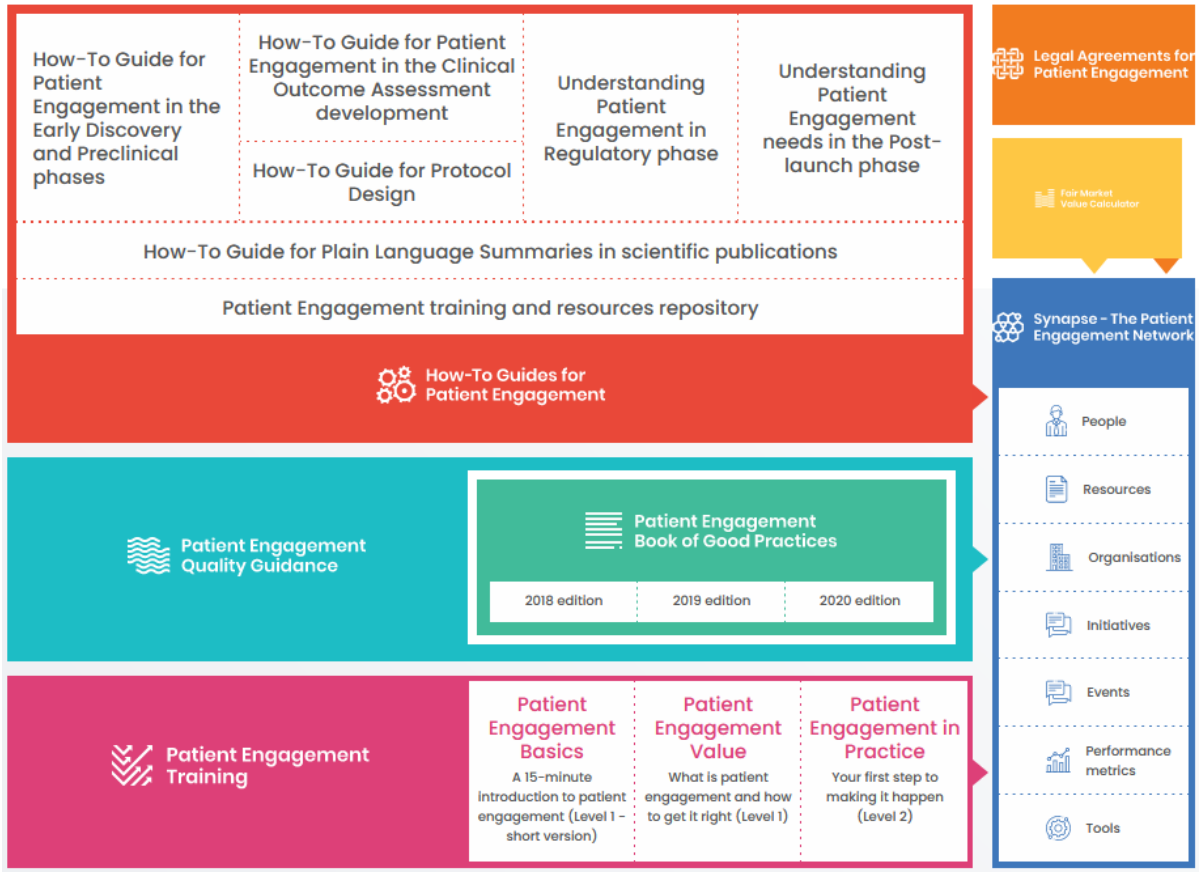
8 Additional references and further reading

Here are some additional external resources where you can find examples, templates or other reference materials on patient involvement in clinical research projects.

8.1 Patient Focused Medicine Development (PFMD)

Patient Focused Medicines Development (PFMD) is a global multi-stakeholder initiative on patient engagement in research and development, established in 2015. PFMD provides a Patient Engagement Management Suite (PEM Suite), featuring practical tools to plan, assess and execute patient engagement initiatives. It includes “How-to Guides” on early discovery and preclinical phases, protocol design, clinical outcome assessment development, regulatory and post-launch phases, and a "Patient Engagement Quality Guidance" and various e-Learning modules on patient engagement.
See https://patientfocusedmedicine.org/pemsuite/



8.2 European Patients' Academy (EUPATI)

The European Patients’ Academy (EUPATI) is a patient-led, multi-stakeholder partnership focused on education and training on patient engagement in medicines research and development. It runs an annual "EUPATI Patient Expert Training Course" and an open-access multilingual "EUPATI Toolbox on Patient Engagement in R&D" that has served more than 4 million users around the world to date.
The EUPATI Toolbox is available in multiple languages at https://toolbox.eupati.eu/
Specifically, relevant articles and case studies in the EUPATI Toolbox include:

- **EUPATI Guidance Documents on Patient Involvement in R&D, Ethics Review, Regulatory and HTA:**
- https://www.frontiersin.org/research-topics/7005/the-european-patients-academy-on-therapeutic-innovation-eupatiguidelineson-patient-involvement-in-re#articles
- **Patient experts on Bioethics Advisory Panels:** https://toolbox.eupati.eu/resources/patients-involved-patient-expert-on-external-bioethics-advisory-panel/
- **HIV case study: Between sponsors and participants:** https://toolbox.eupati.eu/resources/patients-involved-between-sponsors-and-participants/
- **Patient engagement in Patient-reported outcomes (PRO) assessment:** https://toolbox.eupati.eu/resources/patient-reported-outcomes-pros-assessment/
- **Patient engagement in a rare disease registry:** https://toolbox.eupati.eu/resources/patients-involved-patient-organisations-input-on-a-rare-disease-registry/
- **EUPATI Patient Engagement Roadmap in medicines R&D:** https://eupati.eu/patient-engagement-roadmap/?lang=de
- **Being developed: Patient engagement in medical device development** (should be available beginning 2022)

8.3 PARADIGM Patient Engagement Toolbox

This toolbox centralizes all PARADIGM's co-created recommendations, tools and relevant background information to make patient engagement in medicines development easier for all. Browse from the sections below for the tools you might need, hover over to see a quick preview and click on the tool to access all related resources. Let us know how you've used these tools; we'd love to know how they've helped you in your patient engagement activities!
https://imi-paradigm.eu/petoolbox/

8.4 INVOLVE (UK)

INVOLVE is a key public participation charity in the UK, with a mission to put people at the heart of decision-making in healthcare and research. INVOLVE UK has developed a knowledge-based resource with guidance on how to plan participatory processes end-to-end, e.g., planning participation, preparing scope, purpose, outputs and outcomes, and whom to involve:
https://www.involve.org.uk/resources/knowledge-base
https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437

8.5 Macmillan "Building Research Partnerships" (UK)

The UK charity Macmillan Cancer Support runs a free course called 'Building Research Partnerships' which outlines the different types of research methods and terminology. It also explains how the public can get involved as well as exploring the issues related to becoming and being a consumer involved in cancer research.

https://learnzone.org.uk/downloads/Building%20Research%20Partnerships%20-%202013%20Report%20-%20Macmillan%20NIHR%20CRN.pdf

8.6 Journal of Research Involvement and Engagement

Research Involvement and Engagement co-produces a journal, involving academics, policy makers, patients and service-users, with a unique governance structure. They welcome articles from anyone involved in or engaged with research in supporting, encouraging or delivering the patient/public voice in research processes or structures. This certified Patients Included journal publishes articles on and with patient engagement and involvement in an open access format.
https://researchinvolvement.biomedcentral.com/

8.7 Guy Yeoman and Mitchell Silva: Patient Engagement for the Life Sciences

Patient Engagement for the Life Sciences is a practical handbook for anyone striving to incorporate patient value in the delivery of medicines from Research and Development into a practical healthcare setting. This book provides a tangible framework of how this can be achieved with and for patients.

Any profits generated from book sales will be donated to International Health Partners UK, Europe's largest coordinator of donated medicines, to support patients around the world.

https://www.amazon.com/Patient-Engagement-Life-Sciences-Yeoman-ebook/dp/B07GTQLRFJ

8.8 Julia Cartwright, Sally Crow, Carl Heneghan, Rafael Perera, Douglas Badenoch: Patient and Public Engagement Toolkit

Now that patient and public involvement is in the mainstream of healthcare, professionals at all levels from postgraduate trainee to consultant need to understand the issues and be able to collaborate with patients on joint initiatives. This Toolkit answers all your questions about setting up your project and seeing it through successfully. In the concise, easy to follow format so popular in the Toolkit series, it guides you through the process step-by-step. A seemingly complex project will become straightforward once the principles outlined here are grasped.

https://www.amazon.com/Patient-Public-Involvement-Toolkit-EBMT-EBM-ebook-dp-B005D7EHAY/dp/B005D7EHAY/ref=mt_other?_encoding=UTF8&me=&qid=

9 Authoring and acknowledgements

This document was authored between January and June 2021 for Rising Tide Foundation by Patvocates, a think tank and consultancy in the area of patient advocacy and patient engagement. Patvocates is run by an experienced team of leading patient advocates with in-depth knowledge on healthcare systems, institutions, stakeholders, cultures and the global patient community across different disease areas. The Patvocates team members Jan Geissler, Tamás Bereczky and David Haerry who co-authored this paper have been involved as patient advocates in research projects and grant review panels for many years. The project was coordinated by Alexandre Alencar, Senior Scientific Program Manager at the Rising Tide Foundation, and Alba Ubide, Project Manager at Patvocates.

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