RISING TIDE Foundation

Patvocates

Recommendations on Patient Involvement for Funding Institutions

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The importance and merits of patient involvement in research and development are commonly acknowledged and offer benefits for all involved parties. Patient involvement also makes sure that clinical and medical research work more effectively together and deliver what patients really need. The discovery, development, and evaluation of new treatments is also improved if patients provide input throughout the design, conduct, and evaluation of studies and projects. These improvements are based on the collaborative identification and understanding of patients' unmet needs, their research priorities, patient-centric clinical study design, and meaningful outcome measures and study endpoints. Therefore, we encourage engagement with patients, caregivers, patient advocates, patient experts and patient organizations. This engagement should be promoted throughout the funding framework, partnering concept, grant application, application review, project design, project conduct, and dissemination of results. Engagement also extends to other work such as the sharing of evidence and outcomes with other patients and patient groups. It is important for a funding organization to include patient involvement in the review process, and during the conduct of clinical research and studies.

This guidance document was developed for public and private health research funding institutions in national and international disease-specific or other settings. The document suggests standard approaches for the implementation of patient involvement from the earliest stages of health-related research. It contains guidance for funding institutions to involve the patient community and patients' perspective in clinical and other research programs they fund. It is structured into three sections:

Patient involvement in prioritization and generating topics for calls for proposals: How funders could engage with patient advocates when compiling calls for proposals (CFP) to ensure patient relevance is considered in the CFP text. Also, how to define the requirements that applicants would need to fulfil in terms of their patient involvement strategy when responding to a specific CFP. Patient involvement should also be ensured in the dissemination of published CFPs in the patient community. This will help raise interest within the patient community to collaborate with researchers in applications.

Bringing researchers and patient communities together: How funders could facilitate researchers to identify relevant patient partners for the application, and for implementing the project should the project be granted. **Providing pre-application funding for patient involvement**: How funders could support the input and efforts of patient organizations and patient advocates during the application phase before a project has been funded (e.g., with grants for time or tasks).

Patient engagement in assessment of applications: How funders could engage with patient experts as review panel members when assessing grant applications.

Contents

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.

2 Patient engagement in prioritization and generating topics for calls for proposals

Issues covered in this section include:

- **Patient engagement in the definition of research questions and calls for proposals (CFP)** to ensure calls for proposals address patient-focused[3] questions or areas.

- **Patient engagement in the dissemination of published CFPs in the patient community**, to raise sufficient interest to collaborate with researchers in applications.

- **Patient engagement in the definition of the expected roles for patients in the selected CFP**

There is a strong need for patient communities to be involved at the earliest stages while research priorities and objectives are being defined and set.

From a funding institution perspective, this means defining terms and conditions for a CFP which ensure patient involvement actually happens. Mechanisms and procedures are proposed that ensure patients' needs (unmet medical needs and first-hand experiences) are adequately reflected in the setting of research priorities and objectives.

Some patient organizations already participate in this type of work. However, their participation may be to a limited extent and their involvement is often informal. Good personal relationships may be maintained by key patient opinion leaders and patient experts with researchers and clinicians. This relationship may be the basis for becoming partners or even initiators of research ideas and projects. We propose targeted development and some formalization of such relationships**.**

2.1 Patient engagement in defining CFP topics

Patient engagement should be the goal when defining CFP topics for funding programs. This ensures the CFP addresses patient-relevant questions or areas. To achieve patient relevance, the patient community should be involved in the process the same as every other expert group like clinicians.

Typical patient input could be elicited through the following mechanisms:

- Input into the **scientific strategy** of the funding body (annual research priorities, topic development etc.).
- Definition of the **overarching goals, aims, scope and structure** of a specific CFP topic.
- Description of **the patient relevance of the expected** outcomes of funded projects, e.g., how the CFP's projects intend to address the unmet needs of patients**.**
- **Definition of patient roles in the research topic.**
- Review of CFP-related documents to ensure they are accessible and understandable to patient advocates. Also, in language or jargon that does not exclude patients **when it comes to patient engagement** at later stages.
- Definition of the **evaluation criteria** of grant applications, e.g., on patient relevance of the research, and the patient engagement plan of the applicant.

[3] https://www.fda.gov/media/131230/download

- After the decisions: criteria for evaluating patient engagement and evaluating research as part of the annual assessment of the research progress.

Specific questions can be collected from different reviewers. Establishing a small team of patient/public expert reviewers with experience of the specific indication could be a promising strategy. Another way to get involvement in the earliest stages is the organization of partnering meetings as described in a later section. It might also be achieved through fostering and promoting more open and better relationships between research and patient communities. The following sections provide further recommendations for this type of work.

2.2 Promotion of CFP and patient engagement in the patient community

The patient community should be made aware of CFPs so they are more likely to engage.

There is a general problem regarding the accessibility and availability of information about planned or ongoing research initiatives and calls for patient communities. This was highlighted in January and February 2021 by the funding body Rising Tide who conducted a series of interviews with a panel composed of expert patients, representatives of funders and academia. In these interviews, 12 respondents from all stakeholder groups expressed concerns that the earlier the stage of a research initiative then the less information was available. It was increasingly more difficult to learn about these initiatives as one moved to the earlier stages.

The ways in which academic institutions and funders disseminate information on the content of research initiatives tend to be erratic, informal, and unreliable. The processes described below use a multi-pronged strategy:

- **Building an inventory of ongoing research with researchers, academia and patient organizations:** Proactively contact academic communities and research groups (including patient organizations) to make an inventory of their research initiatives and to increase awareness of an upcoming CFP.

- **Systematic communication with patient communities:** Contact patient communities to inform them about engagement opportunities and deadlines in their areas of interest. They can assist in the compilation of lay language versions.

3 Bringing researchers and patient communities together

This section recommends how funders can facilitate researchers to identify relevant patient partners for the application, and for implementing the project should it be granted.

Different ways how this could be implemented are:

- **Setting up and using a patient partner database** which could be used to suggest patient partners for potential applicants of a CFP.

- **Partnering meetings, information days and matchmaking services** could be set up once a CFP has been published to give researchers and patient community members the opportunity to discuss a research collaboration.

- **Providing pre-application grants to patient contributors** could elminate one of the main barriers to the involvement of patient organizations in the pre-application phase: the lack of funding and the resulting risk of non-participation.

To support these approaches, a **platform** could be set up that registers information about calls, research initiatives, and potential partners in research and patient advocacy (i.e. a **"clearing house"**). This platform would support matchmaking between the different potential partners, thereby **linking the partner database with the clearing house** of research information.

3.1 Setting up and using a Patient Partner Database

It is possible to start by **setting up and using a Patient Partner Database** to interact with experienced patient advocates and patient organizations in research or funding institutions. This database could be used during the definition phase of a call topic to recommend patient partners to potential CFP applicants. It could also be used to involve funders as review panel members for working on proposals, and on ongoing and completed projects.

Similar Patient Pools and databases have previously been built by: the Innovative Medicines Initiative (IMI Pool of Patient Experts, https://www.imi.europa.eu/get-involved/patients/imi-pool-patient-experts), the European Medicines Agency (EMA Experts' Stakeholder Database, https://www.ema.europa.eu/en/partners-networks/patients-consumers/getting-involved) and the Swiss National Science Foundation's (SNF) Patient/Public Reviewer Pool. The IMI and SNF databases can be used as models but are not openly accessible. The EMA database is currently accessible to third parties.

A more sophisticated matchmaking service or partner database may become available in the future from the European Patients' Academy **(**EUPATI) or Patient Focused Medicines Development (PFMD). Alternatively, it has been proposed to discuss building a joint patient partner/expert pool with other funding institutions to perform these tasks.

Who would be in a Patient Partner Database?
Patients, caregivers, patient organizations, patient advocates or patient representatives could submit an Expression of Interest to be listed in the database for a call for applications. The database would be accessible to the funding body (e.g., Rising Tide) but only for the specific purpose of engagement in the funding program, and not publicly or for marketing purposes. The available information enables the funder's office to rapidly identify patient experts with the most suitable profile for a specific task.

To be eligible as a patient partner they should:

- Be a patient, a family member or taking care of a patient (caregiver), or a patient representative of a patient organization in a specific therapeutic area.
- Have a specific interest in one of the disease areas.

In their Expression of Interest, the patient experts may state:

- Their individual experience as patient and caregiver, if any.
- Their motivation for applying for membership in this patient partner database and participating in the funding activities.
- Their knowledge and/or experience of clinical research and innovation activities in general, the clinical development cycle, and research ethics.
- Their prior experience of working/interacting with different stakeholders in clinical development e.g., with academic researchers, industry Research and Development, clinical institutions, and regulatory bodies.
- Their prior experience of patient engagement in research projects or with funding institutions.

A check of all the Expressions of Interest may first be carried out to make sure all the minimum criteria listed above have been fulfilled. Applicants that meet the eligibility criteria can become part of the patient expert database. From this pool, the funding institution will draw individual experts for specific assignments and activities as and when needed.

Data protection and withdrawal
All data captured must be obtained and stored according to the EU's General Data Protection Regulation (GDPR) rules. Any individual may request to be removed from the database at any time. A contact address must be given.

Third party databases
Building and maintaining a patient partner database requires considerable effort. The most effective way might be to rely on locally available resources. Partnering with the EUPATI Foundation could be an option in Europe and contacting the National Health Council in the US is worth considering.

3.2 Partnering meetings and information days

Partnering days of the funding institution
Once CFP topics have been published, **information days, partnering/matchmaking meetings and webinars** provide different ways to ensure potential applicants understand the CFP content. Potential applicants should understand the CFP topics, the funder's rules and procedures, and the expectations and requirements of applications. The partnering events also give researchers and patient community members the opportunity to meet and discuss research collaboration.

The funding institution should invite the patient community to the meetings to ensure that funded projects are relevant. It should be emphasized at the meeting that the patient community are able to contribute value in terms of their unique insights, knowledge and resources. Researchers are often unaware that early and systematic patient engagement increases the likelihood of a successful application and clinical research project.

In addition, **the funding institution should identify and make relevant patient organizations aware** of published calls and partnering days that may cover specific research in their area of interest. Patient organizations do not usually follow scientific funding institutions and may be unaware that a call topic in their area of interest has been published and they may be unaware about a funding program's specific deadlines.

The organization of regular online and face-to-face events on specific topics will gradually create a lively and vibrant "marketplace" for the exchange of ideas, initiatives and needs. Although results may not always be immediately measurable, longer term benefits will become apparent. Benefits will include research projects that are more relevant to patients (hence the end users) and an easier, more welcoming interaction across different communities. Communities such as researchers and patients may have otherwise been confined to silos.

Academic project leaders should understand the different roles patients can play in the project life cycle. Depending on that role, there will be specific criteria for finding the most suitable patient partners. Lay patients can play an important role in focus groups and are informative at the project planning and implementation stages. Research-experienced patients may be active as implementation partners and can contribute to work packages. Very advanced patient experts may also be suitable for advisory roles from the application and planning phase to publications and dissemination. **Training of clinical researchers in efficient patient engagement processes could be provided** in close collaboration with research institutions active in the field of training or by funding institutions themselves.

Identifying patient partners on patient engagement platforms and at events using **existing platforms, partnering meetings and services** may also provide the opportunity to bring together researchers and patient organizations. These approaches may also make good platforms to create awareness about the CFP topic. For example:

- **PFMD SYNaPsE patient engagement hub:** The global multi-stakeholder initiative on patient engagement, Patient Focused Medicines Development (PFMD), provides SYNaPsE, PFMD's Global Mapping and Networking Tool. The user-populated platform categorizes and maps over 500 patient engagement initiatives, over 900 organizations active in patient engagement, and more than 2400 individuals active in patient engagement. SYNaPsE may allow identification of individuals or organizations that may be interested in a specific call topic. https://synapse.pfmd.org/

- **Patient Engagement Open Forum (PEOF):** The PEOF is an annual event held by PFMD, EUPATI and European Patients' Forum (EPF), that brings together all stakeholders across the patient engagement ecosystem. The event covers frameworks, tools, recommendations and good practices. The PEOF may be a good opportunity for researchers to identify patient organizations. https://patientengagementopenforum.org/

- **Pan-European patient advocacy organizations:** Many pan-European patient advocacy organizations run annual conferences, workshops or open forums focused on patient engagement. These events present a good opportunity to identify patient organizations interested in a specific research program. Contacting the EPF (www.eu-patient.eu) or the Workgroup of European Cancer Patient Advocacy Networks (WECAN, www.wecanadvocate.eu) or EURORDIS (www.eurordis.org) may help.

- **EUPATI matchmaking service:** EUPATI is preparing a "Matchmaking service". It facilitates collaboration between the graduates of the EUPATI Patient Expert Training Course and researchers in regulatory agencies, academia and industry. EUPATI can assist in connecting with the right person for the task. https://collaborate.eupati.eu/home/matchmaking/

In the future, the funders' database of suitable and available patients and patient experts could be linked to a clearing house that registers information about calls and research initiatives. The semi-automated and non-commercial databases could build on automatic

matchmaking processes and informal deliberations on the proposed matches. However, such a solution is not yet available.

3.3 Providing pre-application grants to patient contributors

Patient organizations struggle to cover the costs arising during the application phase of a new project. This is because funding is not yet available and members of the applicant team are usually investing time and resources into the application.

The use of **pre-application grants** could support patient organizations during this early phase with a budget. The budget could cover travel costs to preparatory meetings and the work time invested by staff, patients or consultants. A working contribution from these groups is required while the application is being prepared and/or submitted. Examples include: the authoring or iteratively reviewing (giving regular feedback) sections of the applications, generating, and providing required documentation, and attending coordination calls and sub-workgroups of the applicants. Such an approach could also improve the relevance of the application to the patients concerned.

A pre-application grant may not be an incentive for an organization to participate in an application. However, their participation helps to ensure the applicant is able to plan a meaningful patient engagement during funding and implementation of the project.

Potential mechanism for pre-funding
A possible scenario which describes a fair pre-funding mechanism by funders is described below:
A patient organization applies for a pre-application grant of 1,000 EUR for travel funding and 3,000 EUR to cover the work carried out in the pre-submission phase of a proposal. To make the application, the patient organization could submit a pre-application grant request form. Accompanying information should include a description of the organization, their interest and their contribution to this specific call. The coordinator of the proposal (usually a researcher) is required to sign the application form.

4 Patient engagement in assessment of applications

This section describes how funders might best engage with patient experts as review panel members when assessing grant applications.

Three steps are described:

- Metrics to be used for assessing the level and quality of patient engagement of applications.
- How to identify and train patient reviewers.
- Fair compensation and acknowledgement of patient reviewers.

4.1 Metrics to assess patient engagement

The following potential assessment questions could be used to score applications for the level and quality of patient engagement. These questions should be listed in the application guide to help applicants in developing their patient engagement plan for their grant application.

Patient-centric design:

- To what extent have applicants assessed patients' needs, goals, concerns or preferences when generating the application?
- How were patient advocates involved in formulating the research question?
- How were patient advocates involved in the design and development of the application and of the project?

Patient engagement during the project:

- How are patients engaged? Is the model chosen likely to be adequate, meaningful, feasible and effective in the proposed project? (Refer to chapter 3 of the Applicants' Guide)
- How will engagement of patients be supported and resourced?
- **How much training does the project provide for patient partners?** Involve the patient partners in determining which training is required and how it should be offered to the patient partners.
- How will the patient community be involved in the dissemination (notification to other parties) of the project's results?
- Is there a proactive dissemination plan that includes scientific journals, conferences, the patient community and the public?

Evaluation of patient engagement:

- How will the applicant evaluate the impact and outcomes of patient engagement in the research project (e.g., surveys, interviews)?

4.2 Identifying and training patient reviewers

Qualified and knowledgeable expert patients could act as reviewers when reviewing research applications to funding institutions. For example, they could assess patient-related relevance of the research questions and intended outcomes or evaluate the patient engagement strategy of the applicant. These patient reviewers should be fully integrated into the multidisciplinary review panels and have equal weight and rights.

To ensure that reviews are consistent, all applications should be assessed based on the same criteria for patient engagement, patient relevance, and the use of metrics.

Some criteria that may help to choose a suitable patient expert for a given task are[4]:

- **Being a patient expert, patient advocate and/or representative of a patient organization** and having a deep insight into the patient community in a relevant therapeutic area. Insights into the unmet needs of the wider community is more important than having personal disease experience.
- **Having expertise in the processes of clinical research and innovation**, the clinical development cycle, and ethics.
- **Having prior experience of working/interacting with different stakeholders** in clinical development e.g., with academic researchers, industry research and development, clinical institutions, regulatory bodies.
- **Having prior experience of patient engagement in research projects or with funding institutions.**

[4] https://imi-paradigm.eu/PEtoolbox/identification-of-patient-representatives.pdf

It is also helpful if patient reviewers are prepared and trained in these assessment criteria. They should also receive training about the system of assessment and how to collaborate with other reviewers on a review panel. The funding body should implement a training program and an onboarding process to acquire knowledge and skills for patient reviewers.

4.3 Compensation of patient expert reviewers

An organization needs to have a clear policy on reimbursement and compensation of patient experts.

Unless they decide otherwise, invited **patient experts should be entitled to a time-based honorarium, plus reimbursement of expenses** when invited to carry out reviews (e.g., for travel, accommodation and subsistence expenses). Allowances may be increased for experts with disabilities.

Compensation for patient reviewers should be in line with compensation for any other professional. However, exceptions may include healthcare professionals expected to act as scientific reviewers. For example, clinical experts and other members of the scientific community may review the applications in the context of their paid job. Patient expert reviewers may also qualify for compensation for their time.

Patients and patient advocates 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. It is sometimes forgotten that patients and patient advocates do not usually receive a salary to cover the time they spend on advocacy work or research. 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. Even patients and patient experts who are still working cannot do this work within the context of their paid job because they work in very different environments and in very different roles.

A common **"fair market value rate"** for the work of patient experts has not yet been established. However, an hourly non-governmental organization (NGO) rate in the range of 55-100 EUR has been observed as compensation for the work of patient experts on review panels or clinical research projects. Bigger funding institutions such as the Swiss National Fund use daily rates. Typical rates for patient experts' contributions to industry-sponsored research are up to three times higher. Fair market value rates usually take into account individual expertise, level of training and education, total amount of time invested, complexity of tasks, country of origin, and other contributing factors. Review and research work is usually rated at the upper rate limit in terms of expertise.

An important consideration in compensation for patient experts is that the individual situation of the patient expert can be very different. It is important that the individual situation of each patient expert is assessed and this assessment forms the basis of if and how they receive compensation.

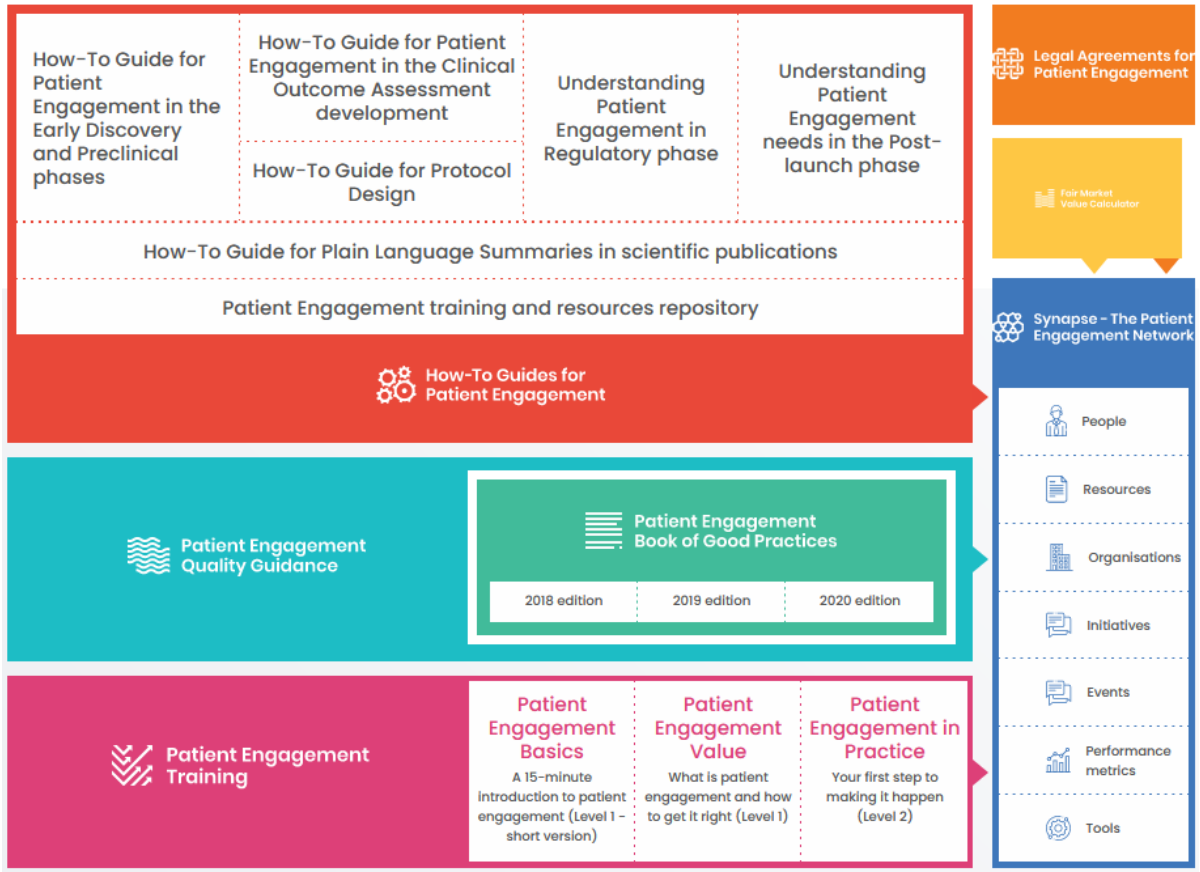
(see e.g., https://nationalhealthcouncil.org/fair-market-value-calculator/)

5 Additional references and further reading

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

5.1 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/



5.2 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)

5.3 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/

5.4 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

5.5 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

5.6 Journal of Research Engagement and Involvement

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/

5.7 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

5.8 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=

6 Authoring and acknowledgements

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