

Patient Involvement in a Nutshell

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Open Innovation in Science Center

The LBG Open Innovation in Science (OIS) Center was founded in 2016 and wants to foster open and collaborative practices in research.

Implementation



Priority
Setting

Support to **identify and prioritize** research questions together with stakeholders.



Patient & Public
Involvement

Support in the implementation **direct involvement** of patients or the public in the research process as co-researchers



Capability
Building

Capacity building for researchers and research institutions for the **application** of Open Innovation practices



Societal
Impact

Support to plan, analyze and increase the **social impact of research**



Research Ethics
& Integrity

Support for **ethical considerations** in participatory research projects

Research

- **How and under what conditions** do open practices influence **novelty, efficiency and impact** in research **processes and results**?
- **Necessary conditions and constraints (infrastructure, culture...)** for OIS at the individual, organisational, ecosystemic level

What is Patient Involvement or PPIE?

PPIE: Patient and Public Involvement and Engagement

Developing something not only for patients but
also with patients or affected groups.

*“User or public and patient involvement in research means doing research **‘with’** patients and the public so they are **not just participants** in the research. This requires users to **have a say** in the decisions made about research, so that the methods and outcomes are more appropriate to research participants and patients.”*

NIHR, UK

Why PPIE is important

For researchers:

- Identification of most socially relevant problems
- Wider impact, applicability and research effectiveness
- Better understanding of patients' needs and lived experience as well as gaps which are not addressed

For patients:

- Have a say in developments that will affect them
- Gaining research skills and scientific literacy
- Be recognized as experts of their own experiences

Modes of PPIE

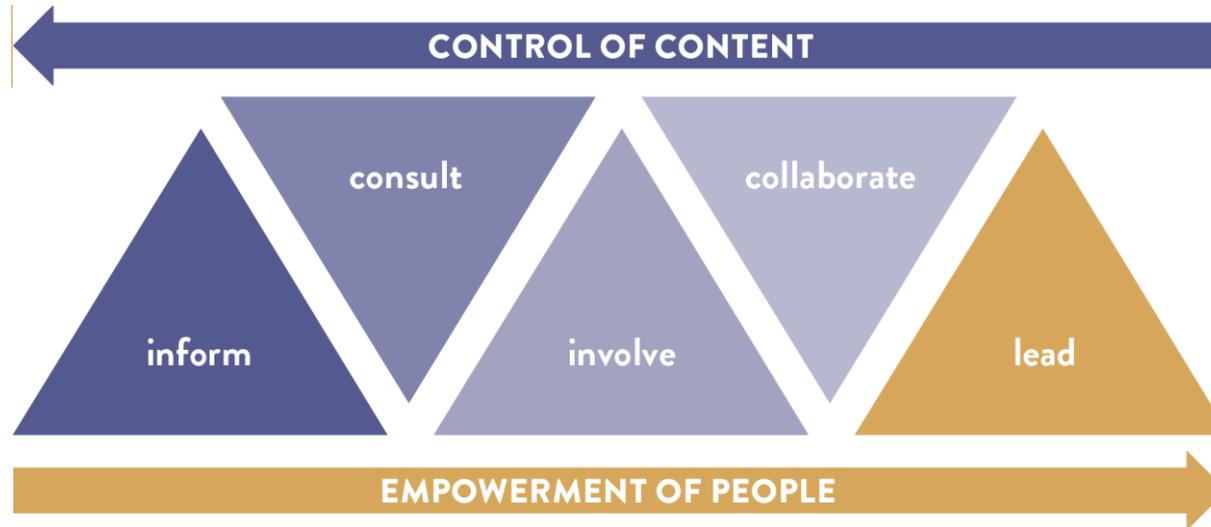
Based on the NIHR in the UK

- **Participation:** Citizens and patients take part in research studies. (being recruited for a clinical trial or filling out a questionnaire)
- **Engagement:** Information and knowledge about research is provided and disseminated. (science festivals, science cafés, ...)
- **Involvement:** Citizens and patients are actively involved in research. (writing grants, member of advisory board, co-researcher, ...)

<https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

Degree of Involvement

Model based on Arnstein

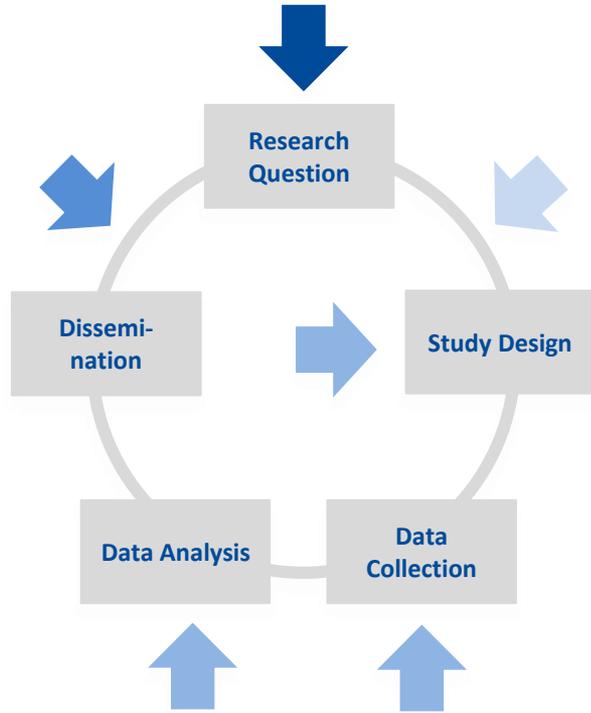


Modified from:

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35(4), 216-224

Timeline of Involvement

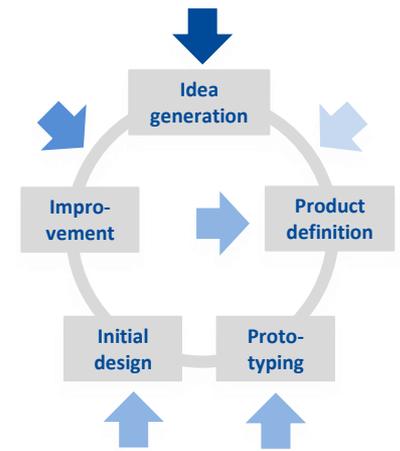
In research and in product development



➤ Involvement can happen **at any stage** of the research process.

➤ Involving from the start is important (co-developing research question → priority setting)

➤ Be aware at what stage you involve who and for what reason.



Some examples: CCCFS (Chronic Fatigue Syndrome)

- CFS as a little researched disease (Long-COVID)
- Only few specialized physicians are currently able to diagnose CSF
- 5-8 years until a correct diagnosis
- Patients and family members as active partners next to researchers and physicians
- Objectives:
 - To systematically collect detailed information on the disease
 - To create an extensive questionnaire to diagnose the disease
 - To help patients reach a diagnosis and appropriate therapies more quickly in the future



Some examples: YOUNGSTARS1 (Type 1 Diabetes)

- Type 1 diabetes as a complex disease especially for young adults
- Objectives:
 - To adapt diabetes care to the realities of young adults' lives
 - To identify novel research questions
 - To improve and develop new support services
- Young adults with T1D as active partners in the research process:
 - Visualize their everyday lives using photos and records
 - Discuss needs and resources
 - Structure and interpret data
 - Formulate an action plan
 - Communicate needs to decision makers



PPIE: Some advice for implementation

- Consult our **guide** and get inspired by other PPIE **projects** (see Ressources)
- Clarify each other's **needs, expectations and roles** from the start.
- Meet each other regularly (**pre-set dates**) to keep each other informed at every step.
- **Co-design** elements of the research/the idea (even if technical implementation of the idea will be up to the researchers).
- **Communication is key**. Don't be afraid to ask again if something is unclear.
- When preparing a presentation or similar, co-design and co-lead it. **You're a team!**
- **Everyone** has their expertise! Use it. 😊

Further Ressources

- **Guide:** OIS Center: PPIE Guide for researchers:
<https://doi.org/10.5281/zenodo.5017791>
- **Guide:** NIHR INVOLVE: Guidance on co-producing a research project:
https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
- **Database:** OIS Center: Project Database (project descriptions in German):
<https://ois.lbg.ac.at/projekte>
- **Database:** Patient-Centered Outcomes Research Institute: Literature Database:
<https://www.pcori.org/engagement/engagement-literature>
- **Review:** Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., & Chant, A. (2019). Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expectations*. DOI: [10.1111/hex.12888](https://doi.org/10.1111/hex.12888) (open access)

Thank you for your attention!

If you have any questions, message me!

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