Patient & Stakeholder Engagement
.. in health research

QUEST Seminar on Responsible Research
October 25, 2022

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Agenda

- What is Patient & Stakeholder Engagement (not)?
- Why is Patient & Stakeholder Engagement (PSE) important?
- Fostering PSE at Charité and BIH: Services and activities of the QUEST Center
- Discussion & questions
Patient & Stakeholder Engagement (PSE) within the QUEST framework

(Strech et al. on behalf of QUEST group (2020), p. 3)
**Patient & Stakeholder Engagement (PSE)**

- **What is Patient & Stakeholder Engagement?**
  “The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision-making is guided by patients’ contributions as partners, recognizing their specific experiences, values, and expertise.” (Harrington et al., 2020, p. 682)

- **Our (minimal) definition:**
  PSE in health research means that patients or other stakeholders (e.g. relatives) have a say in at least one phase of a research project (e.g., planning, conduct, dissemination). The earlier patients are involved, the more influence they can have on the study/research project.

- **PSE is not:**
  Participation in clinical trials (= being a “participant”), providing data without further (active) involvement in the study.
Patient Participation

Passive Role

Outreach is uni-directional
Patients are being studied
Answers questions that matter to researchers

Research happens ‘for’ or ‘to’ patients

Active Role

Engagement is bi-directional
Co-creation in the research process
Answers questions that matter to patients

Research conducted ‘with’ or ‘by’ patients

Patient Engagement
Patient & Stakeholder Engagement (PSE)

Different terms to describe patient engagement activities:

- Patient & Public Involvement (esp. UK)
- Patient Engagement (esp. US, Canada)*
- (community-based) participatory (health) research
- Citizen Science/Patient Science

* UK: Patient/Public Engagement: science communication

- Patient-controlled
- Collaboration
- Consultation

See INVOLVE (2012) for description of levels/approaches
Patient & Stakeholder Engagement (PSE)

- Identification of research questions
- Planning and design
- Funding
- Study conduct
- Dissemination
- Analysis and interpretation
- Translation
- Evaluation
Why is PSE important?

Value-related, moral dimension, democratisation of research...

Societal change / empowerment

Quality, relevance, acceptance of research and its results

External motivators (funders, publishers...)

(Modified from Ball et al. 2019, Jilani et al., 2020)
Why is PSE important?

• “The reasons for involvement might not always be clearly defined and at times will overlap each other. However understanding why you want to involve members of the public in your research will help you think who you want to involve and how you want to involve people.” (INVOLVE, 2012)

➤ Who to involve/who are the stakeholders? (Warner et al., 2018)

• Individual patients
• Carers
• Patient advocates/patient organisation representatives
• Patient experts
Fostering PSE at Charité and BIH: Services and activities of the QUEST Center

• **Aim:**
  • Fostering high-quality Patient & Stakeholder Engagement at Charité (and beyond)

• **Approaches:**
  • **Service and support for researchers**
  • Networking and PR within and outside Charité/BIH
  • Incentives (and funding)
  • Research on PSE (and future directions)
Service and support for researchers

• Information on PSE on the QUEST webpage, including guidelines and tools, research policy, calls ([https://www.bihealth.org/en/quest/service/stakeholder-engagement](https://www.bihealth.org/en/quest/service/stakeholder-engagement))
• Consultation
• PSE network via Teams/Peer-to-peer learning
• Training courses for researchers together with IQIB and DLR-PT (currently only in German: [https://akademie.iqib.de/](https://akademie.iqib.de/))
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Networks

- Working group on quality and impact of patient engagement

- PartNet (network for participatory health research in German-speaking countries)
  (http://partnet-gesundheit.de/)

- Citizen Science Community: Working group on Citizen Science in health research
  (https://www.buergerschaffenwissen.de/netzwerk/ag-cs-medizin-gesundheitsforschung)

- Public Engagement Community: Network of Berlin School of Public Engagement and Open Science
  (https://www.publicengagement.berlin/)
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Incentives and funding

• QUEST 1,000 € Patient & Stakeholder Engagement Award (https://www.bihealth.org/en/translation/innovation-enabler/quest-center/calls-and-awards/patientstakeholder-engagement)


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Research on PSE and future directions

- Reporting of Patient Engagement: current practice in health research
  (https://www.medrxiv.org/content/10.1101/2022.04.20.22274033v1)

- Developing a model for Patient Engagement in stroke research (Juliet Roudini)

- Developing quality criteria for Patient Engagement

- PSE Community @ Charité? How can we (better) support you?
Contact us!

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Literature


• INVOLVE (2012). Briefing notes for researchers: public involvement in NHS, public health and social care research. Eastleigh: INVOLVE.


Thank you!

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