

Patient & Stakeholder Engagement .. in health research

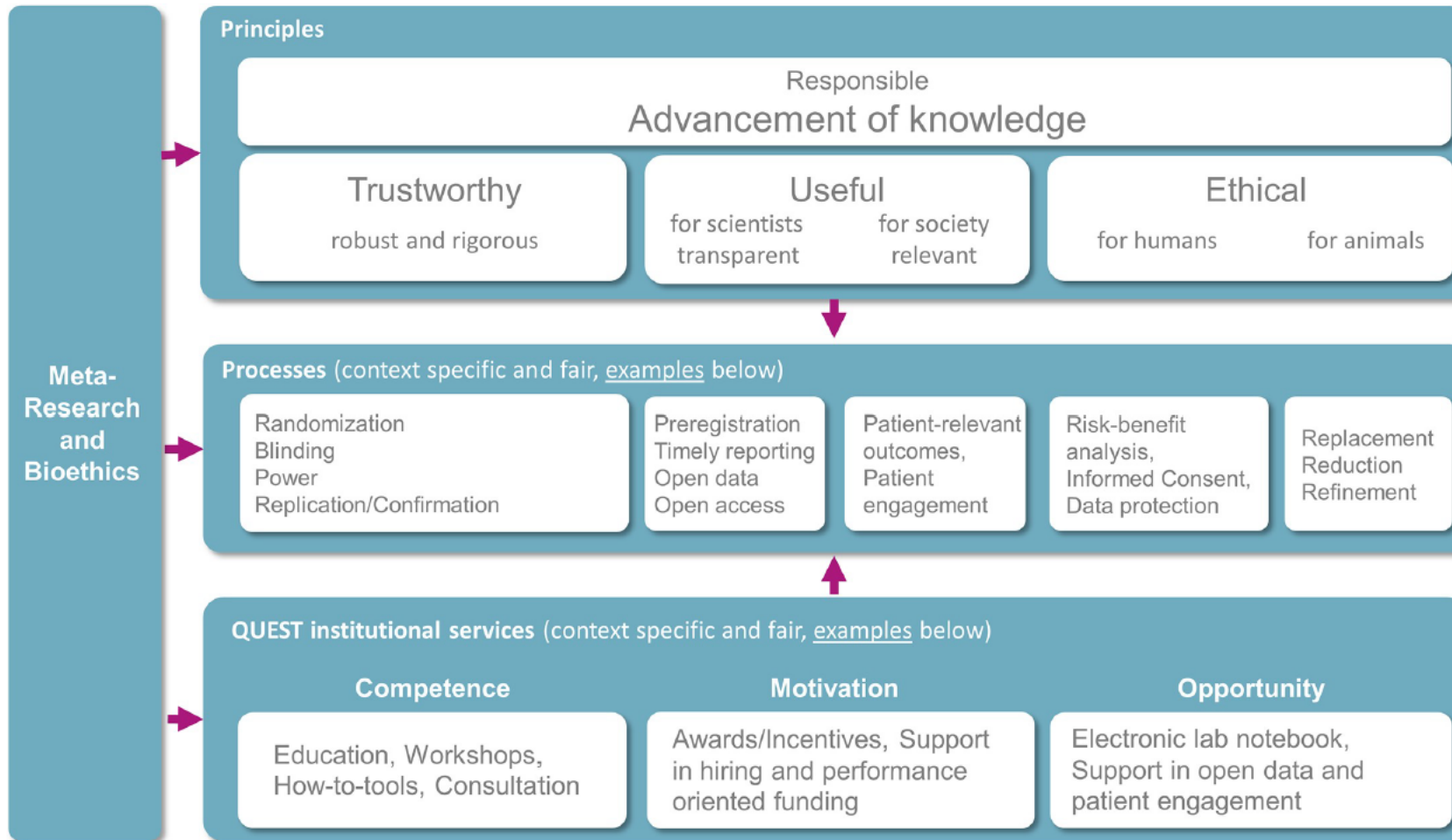
QUEST Seminar on Responsible Research
October 25, 2022

Sarah Weschke

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

Patient Engagement

Active Role

Engagement is bi-directional

Co-creation in the research process

Answers questions that matter to patients

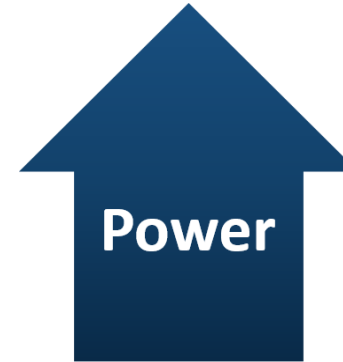
Research conducted 'with' or 'by' patients

Patient & 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

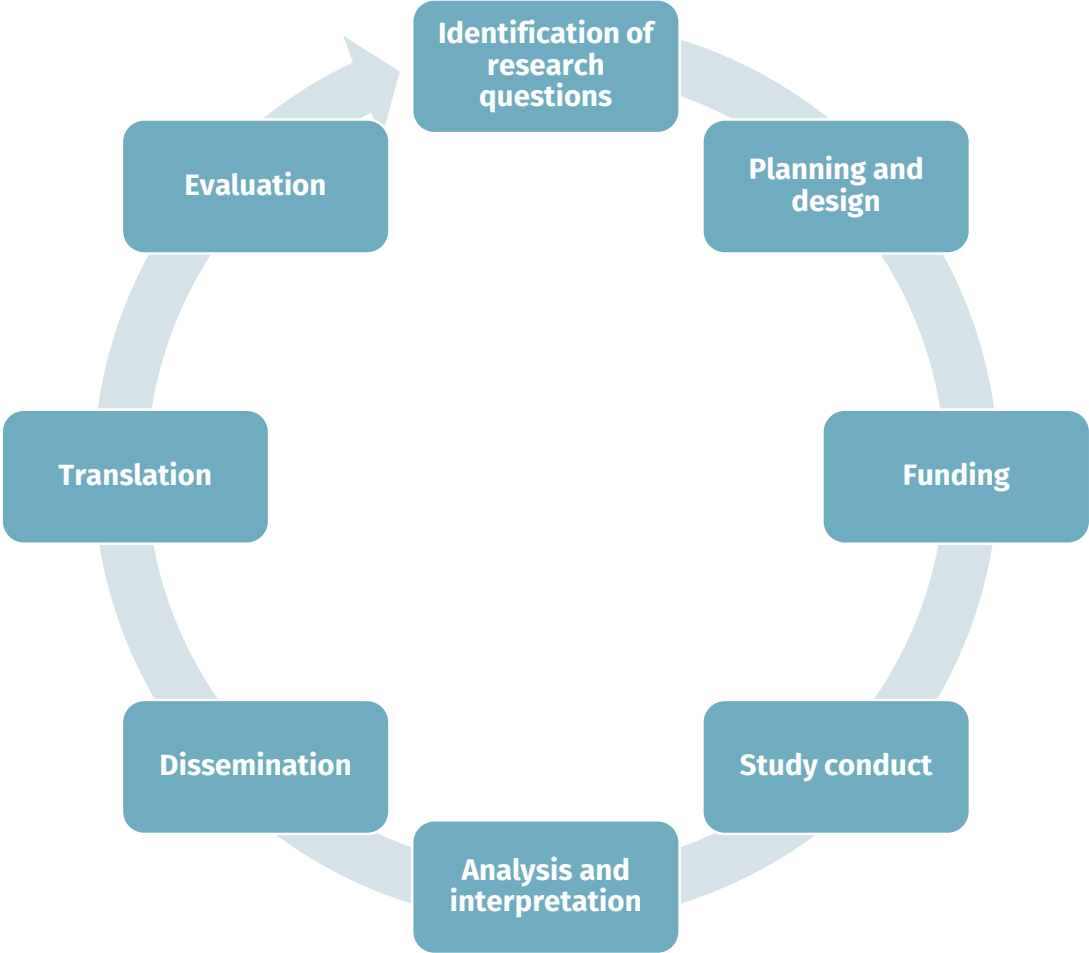
* UK: Patient/Public Engagement: science communication



- **Patient-controlled**
- **Collaboration**
- **Consultation**

Modified from Hickey, G. & Turner, K. (2019). Patient and public involvement in research: What, why and how? Webinar from the International PPI Network, Aug. 20, 2019
See INVOLVE (2012) for description of levels/ approaches

Patient & Stakeholder Engagement (PSE)



Why is PSE important?

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

Quality, relevance, acceptance of research and its results

Societal change / empowerment

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>)
- 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/>)



BIH QUEST
Center for Responsible Research

BIH Berlin Institute
of Health
@Charité

QUEST PSE projects and initiatives

Here you can find information on Patient & Stakeholder Engagement projects of the QUEST Center for Responsible Research.

[Further information](#)

Charité PSE projects

Here you can find information on recent and completed Patient & Stakeholder Engagement projects in the BIH research area.

[Further information](#)



Research policy and funding of PSE in health research

While the active engagement of patients and other stakeholders in health research is already standard practice in some other countries, there is some backlog demand in Germany.

[Further information](#)



More resources and links on Patient & Stakeholder Engagement

Numerous guidelines and other resources on patient and stakeholder engagement have been published internationally.

[Further information](#)

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Aus Forschung wird Gesundheit

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Networks

- Working group on quality and impact of patient engagement
(<https://www.bihealth.org/de/translation/innovationstreiber/quest-center/services/stakeholder-engagement/quest-projekte-und-initiativen-im-bereich-pse/ag-qualitaet-und-impact>)
- 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>)
- QUEST Fund for PSE (<https://www.bihealth.org/en/translation/innovation-enabler/quest-center/calls-and-awards/quest-fonds-fuer-patient-stakeholder-engagement>)
- NCRC Fund for PSE (<https://neurocure.de/clinical-center/funding/ncrc-brainlab-projekte-2022/psencrc-and-crdmncrc.html>)
- QUEST Grant for PSE (2021): four funded projects in 2021 (<https://www.bihealth.org/en/quest/service/stakeholder-engagement/quest-pse-projects-and-initiatives/quest-grant>)



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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

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Thank you!

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