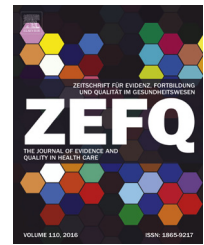




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DIE NEUEN ZEFQ-SEKTIONEN / THE NEW ZEFQ SECTIONS

Patient participation – What is it?



There are many different meanings of patients and participation. Patients, especially in the Anglo-Saxon area, is often referred to as users, sometimes as consumers. Also, patient regularly encompasses the participation of family members, carers or proxies. Others use the term patient and public. The public can be public patient groups, local patient networks, patient advocate groups, self-help groups, European patient organisations etc. The same for participation, which is frequently used synonymously with involvement, engagement or empowerment. Internationally, patient and public involvement (PPI) is a widely used term.

We would like to use the definition of the European Patient's Forum as starting point for this section. They write that patients take an active role in activities or decisions that will have *meaningful* consequences for the patient and patient community, because of their specific knowledge and relevant experience as patients [1]. However, the European Patient's Forum acknowledges that this is not a ready-made definition because meaningful differs across patient(groups), countries and cultures. Most importantly, the definition brings to the fore the contribution of *experience-based* knowledge. It is based on the premise that patients have a specific expertise derived from simply being patients. Patients' experience-based knowledge is derived from living with a health condition day-to-day and from being in frequent contact with the healthcare system. This makes it different from lay people and healthy consumers.

In a recent paper the Europeans Patient's Forum [1] distinguishes individual and collective patient participation: They state that individual participation is the extent to which patients and their families or informal caregivers, whenever appropriate, participate in decisions related to their condition (e.g. through shared decision-making, patient preferences, selfmanagement) and contribute to organisational learning through their specific experience as patients. Collective participation they describe as the extent to which patients, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation, design and delivery, as well as guideline development.

Levels of meaningful involvement are often illustrated by the ladder-model developed by Sherry Arnstein [2]. The

ladder-model describes eight rungs from non-participation to citizen control. Arnstein considers only partnership, delegated power and citizen control as 'real' participation (Fig. 1).

However, we also consider rungs at the level of tokenism as participation, as long as it is meaningful to bring in the experience-based knowledge of patients. What is meaningful should be clarified in a *shared dialogue with* patients and not be decided by researchers.

What is the arena of patient participation in health care?

The arena of patient participation is individual and collective participation in fields with direct impact on health care such as measuring and improving care processes, building health literacy, selecting treatment, strengthening self-care, ensuring safer care. But also more indirect or policy-related studies aimed at setting research agendas, effective methods for patients participating in research, training professionals, shaping services, guideline development, and health technology assessment. We are open to contributions in all these areas.

Some examples as inspiration: Patient participation in quality improvement [3] and priority setting for health-care improvements [4]; guideline development [5]; national health policy development [6]; health technology assessment [7]; setting the research agenda [8], as co-researchers [9] or participants in an action study [10] or as local research group [11]; systematic reviews [12] and clinical trials [13].

Research should be *with* patients and not *about* them. This means, that we would like to read information about patient participation in clinical epidemiological research or in quality improvement studies, preferably in a separate paragraph within the method section. We would like to read about the level of participation, what exactly was the patients contribution in the different phases of research (preparation, execution and translational) and the impact of this participation on the research project itself. For example, Shippee et al [14] described how they involved patients in a user advisory board and Schaefer et al [15] in guideline development.

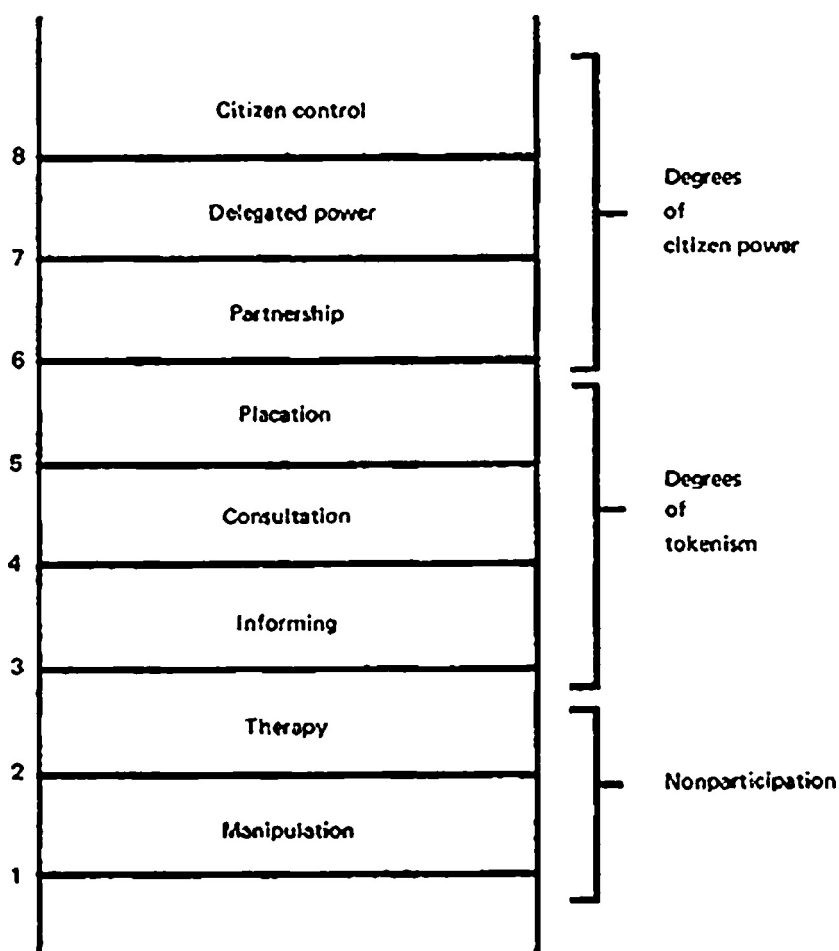


Figure 1 Ladder of participation from Arnstein [2].

What kind of studies?

Our starting point is that the study design should fit the research question and goal. We are interested in systematic reviews and meta-synthesis. We welcome quantitative, qualitative and mixed method designs. In quantitative studies we are interested in experimental as well as observational designs such as process evaluation, case and cohort studies, and cross-sectional designs etc. In qualitative studies we are interested in a broad range of designs such as ethnographic, grounded theory, phenomenological, narrative and case studies, participatory action research and sound content analysis studies. We also welcome research protocols, preliminary outcomes of pilot studies, but also studies with negative results since we can learn a lot from these studies. Finally, we welcome studies from different disciplines such as medicine, nursing, occupational therapy, physical therapy, speech and language pathology, social work, arts therapies, as well as from health sciences, medical anthropology, sociology, communication sciences etc, in German and English language. We expect that manuscript submissions comply with internationally acknowledged reporting guidelines such as CONSORT, STROBE, SRQR etc (see <http://www.equator-network.org/reporting-guidelines/srqr/>)

Internet resources for patient participation in research

www.invo.org.uk - Involve is a UK based platform for researchers. It is funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research. It is an open access site for researchers to support the involvement of patients in research. It also has an extensive library, for example on patient participation in research, but also case reports and best practices.

www.jrf.org.uk - The Joseph Rowntree Foundation is an independent organisation working to inspire social change through research, policy and practice. They provide rich resources on the involvement of people in social care and research, for example, a report about training older people as researchers: <https://www.jrf.org.uk/report/how-older-people-became-researchers-training-guidance-and-practice-action>

<http://www.jla.nihr.ac.uk/> - The James Lind Alliance (JLA) is a non-profit organisation. It brings patients, carers and clinicians together in Priority Setting Partnerships to identify and prioritise research (top 10 shortlist) about the effects of treatments. These priorities are promoted to key groups such as research funders, researchers,

patients and carers and the wider research and policy community.

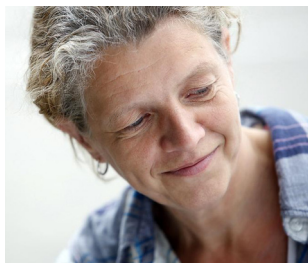
<http://www.g-i-n.net/working-groups/gin-public> - The Guidelines International Network has set up the G-I-N public working group. They support effective patient and public involvement in the development and implementation of clinical practice guidelines. G-I-N PUBLIC offers a forum for exchange between patient and public organisations, clinical practice guideline developers, and researchers.

We hope that this section will encourage the publication of reviews and empirical studies on patient participation and enhance our scientific knowledge of this topic.

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