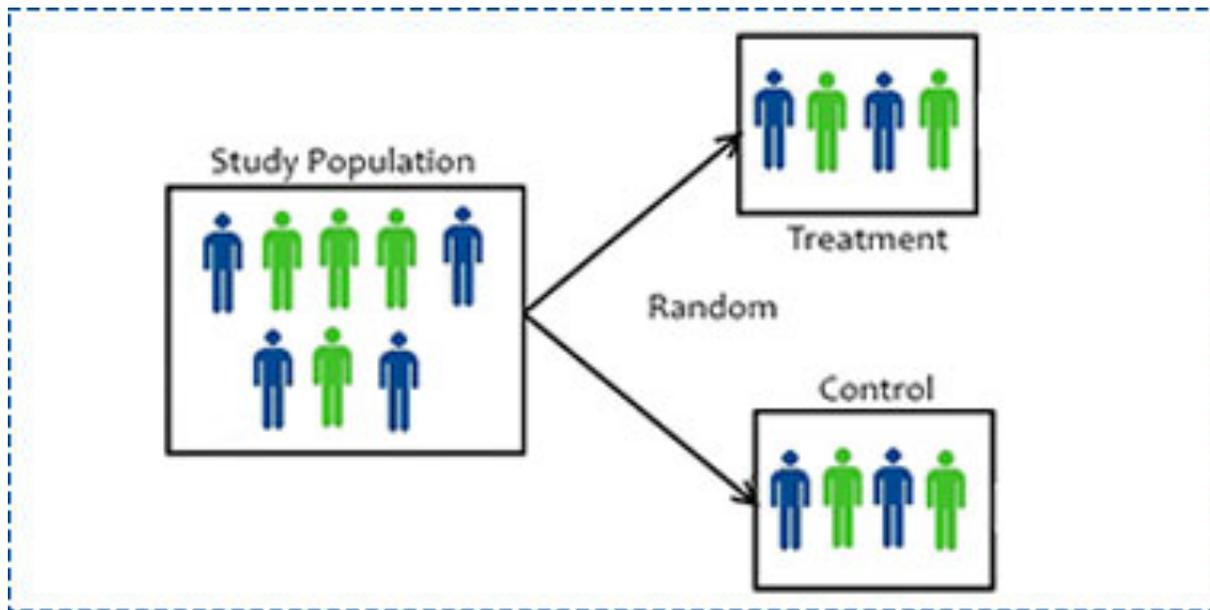
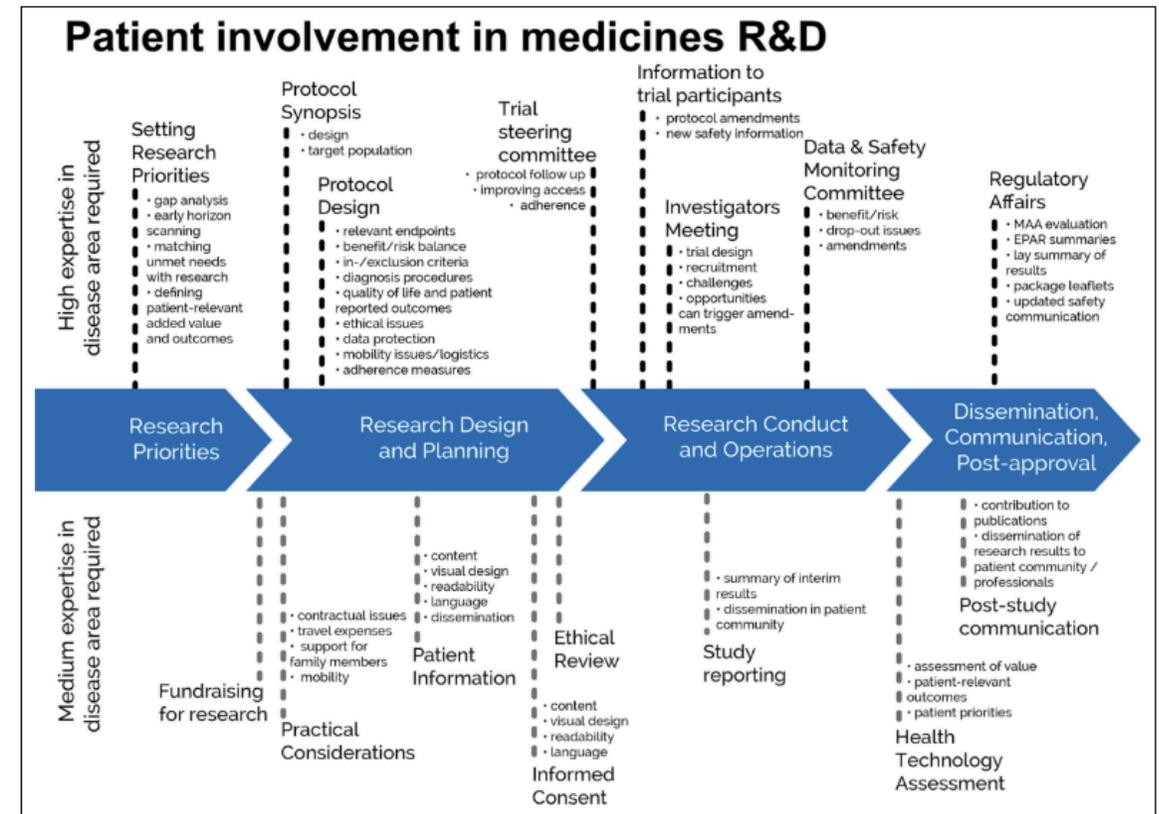


Patient involvement in research

Traditional (=old-fashioned) view



Present-day view



Original Article

Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap

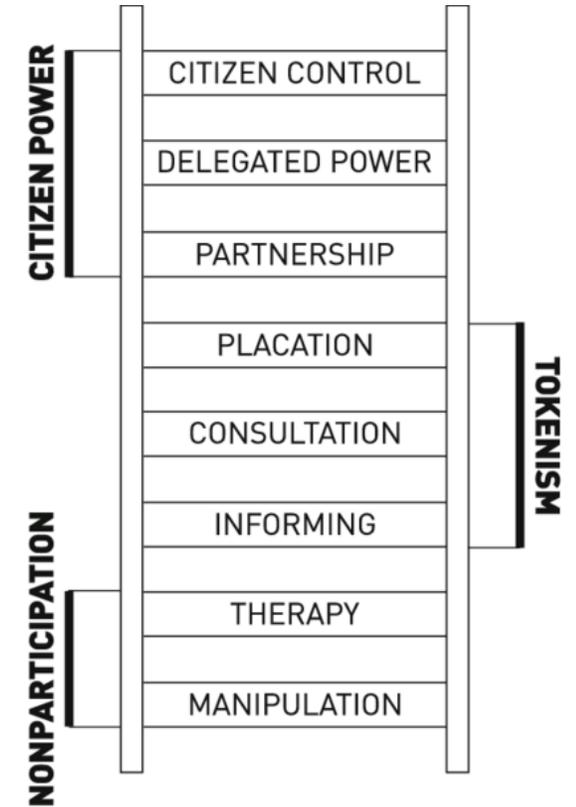
Jan Geissler, Dipl.-Kfm.¹, Bettina Ryll, PhD, MD^{2,3}, Susanna Leto di Priolo, PharmD⁴, and Mary Uhlenhopp, RN, MS, MPH^{5,*}

DIA DEVELOP INNOVATE ADVANCE

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Figure 3. Practical roadmap for patient involvement in medicines R&D.

Some examples of involving patients in research



Arnstein, Sherry R. "A Ladder of Citizen Participation," JAIP, Vol. 35, No. 4, July 1969, pp. 216-224

Why involve patients in research?

"Patients aren't interested in research planning"

"Patients don't know anything about research methodology"

"Why would patients want to do research on themselves anyway? Isn't it better if you all just give your data to a proper researcher?"

"Women don't know anything about politics"
Senator James Reed from Missouri to suffragists in the early 1900s

For whose sake is research done?

Why involve patients in research?



Staley K, Minogue V. User involvement leads to more ethically sound research. Clin Ethics. 2006;1:95-100.12.

B. Levitan et al., "Assessing the Financial Value of Patient Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project," Ther. Innov. Regul. Sci., 2017.

Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N. Patient engagement in research: a systematic review. BMC Health Serv Res. 2014;14.

Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2014;17

British Medical Journal examples



- Since 2014: Patient and Public Partnership Strategy and Patient Advisory Panel
- "Authors submitting research papers are required to complete a statement documenting if and how they involved patients and the public in their work. Papers are also sent for review by patients and public reviewers, as well as to peer reviewers."

What happens when patients can read scientific publications?



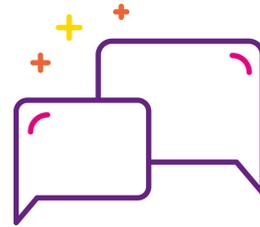
- PubMed publicly available online since 1997
- Open access since 2002
- Patients can
 - Access new research
 - Discuss and compare with fellow patients
 - Come prepared to the next doctor's appointment
- How does this change the patient – doctor relationship?



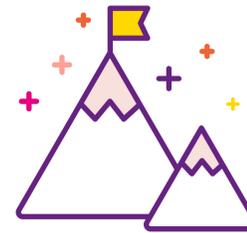
Selfcare expert



Activist



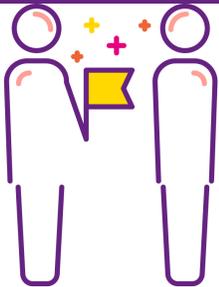
Communicator



Entrepreneur



Innovator



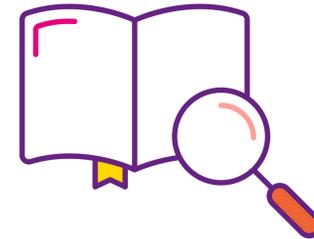
Mentor



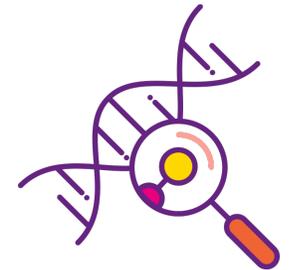
Tracker



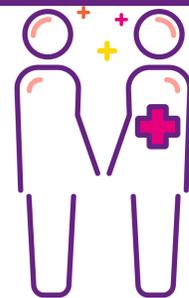
Hacker



Knowledge seeker



Patient researcher



Healthcare partner



Healthcare coordinator

