

## **Project BRIDGE: Building Research Initiatives by Developing Group Effort**

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### **Webinar #2R: How to involve patient partners in research: General models and approaches**

#### **References and Resources**

Aleligay, A., Worrall, L. E., & Rose, T. A. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*, 22, 383-407.

Battaglia, T. A., (2016). The Value of Patient Advisory Groups. Available at: <https://www.pcori.org/blog/value-patient-advisory-boards>

Brennan, A., Worrall, L. & McKenna, K. (2005). The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: An exploratory study. *Aphasiology*, 19, 693-711.

Domecq JP, Prutsky G, Elraiyah T, et al. (2014). Patient engagement in research: a systematic review. *BMC Health Serv Res*. 14, 89.

Forsythe, L., Heckert, A., Margolis, M. K., Schrandt, S. & Frank, L. (2018). Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute. *Quality of Life Research*, 27, 17-31.

Frank, L., Forsythe, L., Ellis, L., Schrandt, S., Sheridan, S., Gerson, J., Konopka, K., & Daugherty, S. (2015). Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. *Quality of Life Research*, 5, 1033-1041.

Goberman-Hill, R., Burston, A., Clark, E. Nolan, S. Wells, V. Betts, L., & PER-R. (2013). Involving patients in research: Considering good practice. *Musculoskeletal Care*, 11, 187-190.

Hamilton, C. B., Hoens, A. M., Backman, C. L., McKinnon, A. M., McQuitty, S., English, K., Y& Li, L. D. (2018). An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expectations*, 21, 396-406.

Kirwan, J. R., deWit, M., Frank, L., Haywood, K. L., Salek, S., Brace-McDonnell, S., Lyddiatt, A., Barbic, S. P., Alonso J., Guillemin, F., & Bartlett, S. J. (2017). Emerging guidelines for patient engagement in research. *Value In Health*, 20: 481-486.

Palmer, R. & Paterson, G. (2013). To what extent can people with communication difficulties contribute to health research? *Nursing Research*, 20, 12-16.

Rose, T., Worrall, L. & McKenna, K. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology*, 17, 947-963.

Sims, S., Brearly, S., Hewitt, G., Greenwood, H., Jones, F., Ross, F., & Harris, R. (2013). How to develop a patient and carer advisory group in stroke care research. *Nurse Researcher*, 20, 6-11.

Singler, L., McAdams, P. Uhlenbrauck, G., Jernigan, K., & Schulman, J. (2018). Models for engagement: Patients as partners in clinical research. *Applied Clinical Trials*. Downloaded from <http://www.appliedclinicaltrials.com/models-engagement-patients-partners-clinical-research?pageID=3>

Vat, L. E., Ryan, D., & Etchegary, H. (2017). Recruiting patients as partners in health research: A qualitative descriptive study. *Research Involvement and Engagement*, 3, 15.

### **Online Resources**

Engaging With People Who Have Aphasia: A Set of Resources for Stroke Researchers. Available at: <https://www.nihr.ac.uk/nihr-in-your-area/stroke/documents/Aphasia%20researcher%20resource.pdf>

NIH Plain Language: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language/plain-language-getting-started-or-brushing>

NIH Clear Communication: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication>

Patient Involvement in Research – A Way to Success. Available at: [https://www.eular.org/myUploadData/files/Reference\\_cards\\_explained\\_Booklet\\_pages\\_23-08-13\\_1.pdf](https://www.eular.org/myUploadData/files/Reference_cards_explained_Booklet_pages_23-08-13_1.pdf)

Toolkit on Patient Partner Engagement in Research (TOPPER). Available at: <https://www.hipxchange.org/TOPPER>