

THE DON'TS AND DOS

Top 10 Recommendations for Researchers Working with Lived Experience Partners

- More and more, patients and caregivers are being involved in health research. Why? Because research is more relevant when it includes the views of people with lived experience of what is being studied.
- Still, there is limited guidance on how to partner with patients in research and, most importantly, how to do it well.

Our [Hatching Ideas](#) team held a research forum that brought together people with lived experience of suicide and suicide prevention researchers, trainees, and policy makers with the goal of improving the skills of all participants to help them partner meaningfully on suicide prevention research projects.

Through sharing experiences, good and bad, our partners with lived experience crafted a set of recommendations for researchers. Together, we have presented these reflections visually and creatively, through a comic. By highlighting some of the DON'Ts and DOs experienced by patient partners in research, we hope to encourage genuine and respectful partnerships between researchers and lived experience experts.



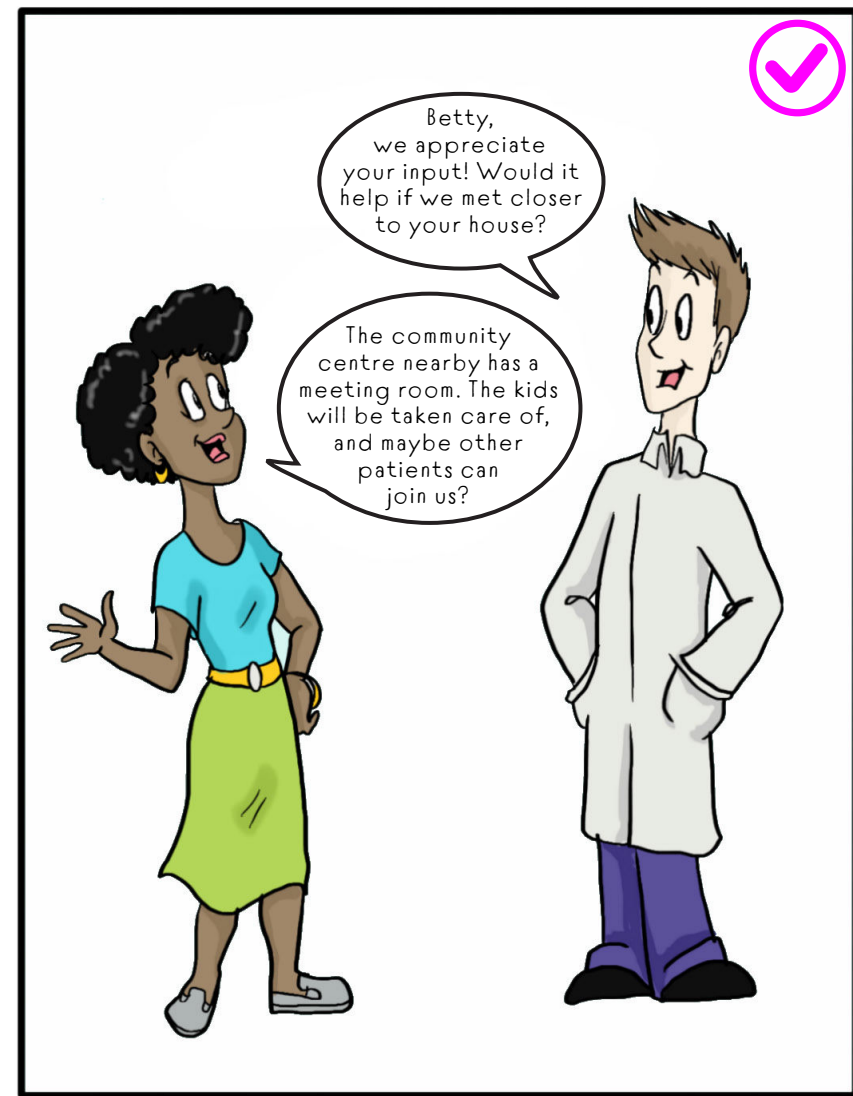
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1. USE COMMON AND CLEAR LANGUAGE.

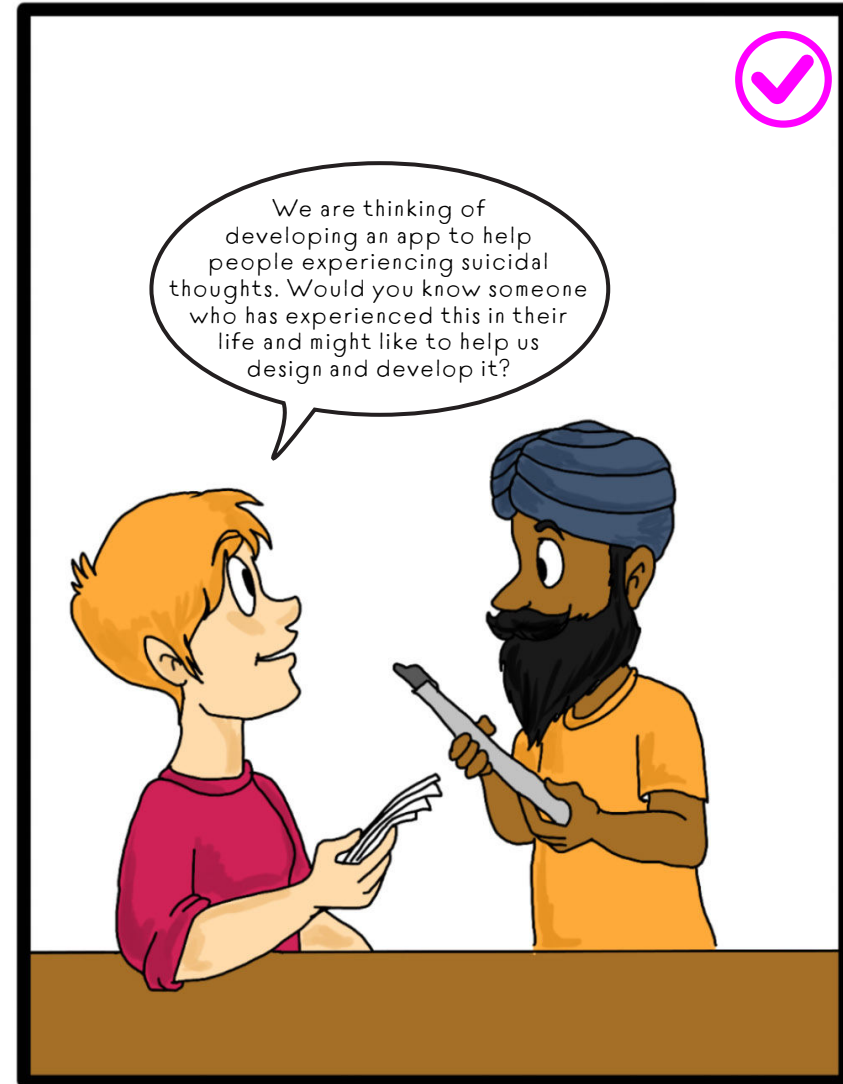


Avoid acronyms and unfamiliar jargon.

2. ALLOW FOR CUSTOMIZATION TO PATIENT PARTNER'S NEEDS. BE FLEXIBLE.

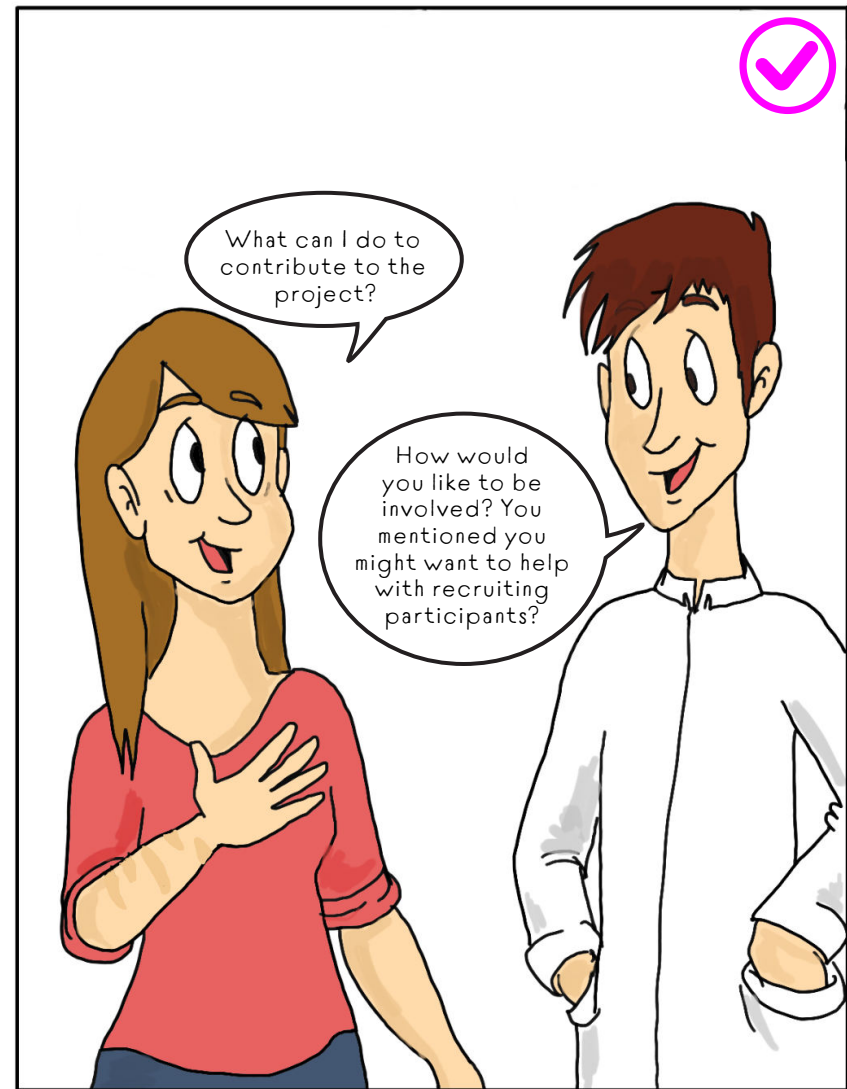


3. BE AUTHENTIC IN THE APPROACH TO PATIENT-ORIENTED RESEARCH. AVOID TOKENISM.

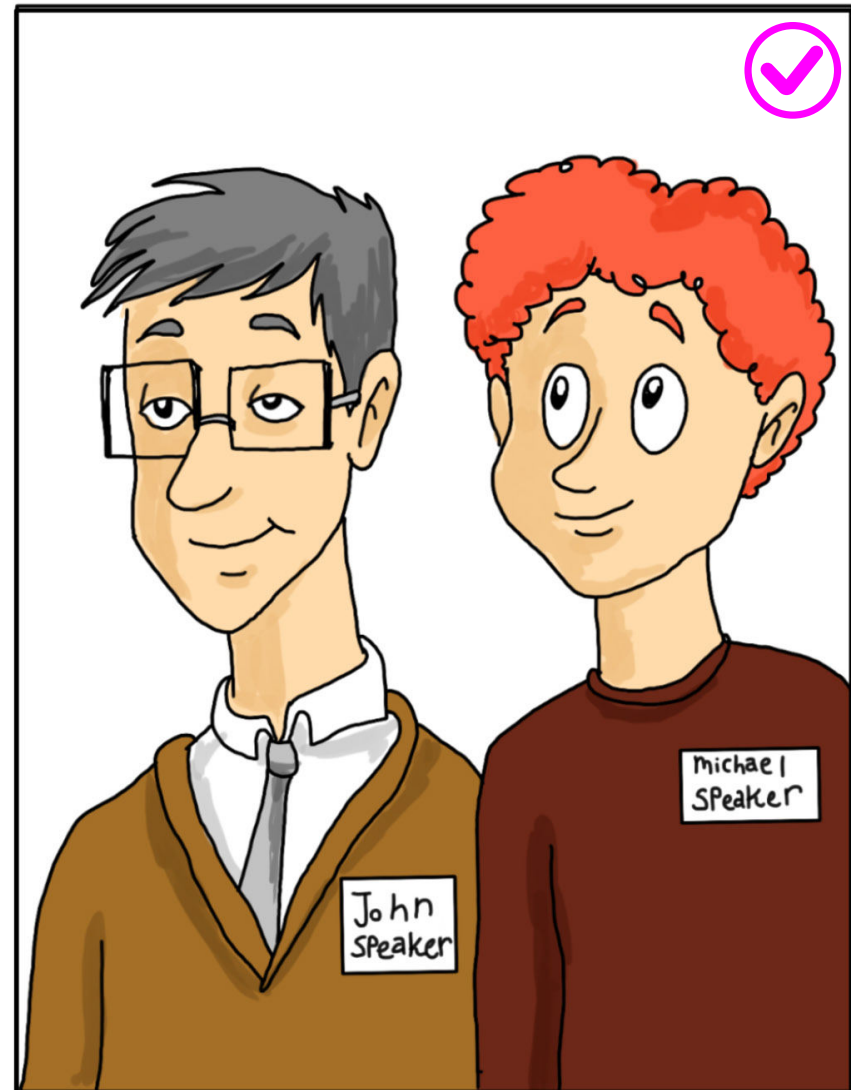


Tokenism: The policy or practice of making only a symbolic effort to include patients in patient-oriented research.

4. DEFINE ROLES. INVITE AND ACKNOWLEDGE EVERYONE'S CONTRIBUTION.



5. BALANCE POWER DYNAMICS.



6. INVITE PATIENT PARTNERS TO DO MORE THAN WHAT THEY ARE RECRUITED FOR.



Patients are people with plenty of expertise and experience to contribute.

7. COMPENSATE FAIRLY AND AS A MATTER OF COURSE. REIMBURSE EXPENSES.



Clearly outline and communicate terms with patient partners during recruitment.

8. BUILD RELATIONSHIPS THROUGH HONESTY AND TRUST.



9. ENSURE GOVERNANCE THROUGH INTEGRITY AND ACCOUNTABILITY.



10. ESTABLISH AND ENCOURAGE CONTINUOUS COMMUNICATION AND FEEDBACK.



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