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.

Top 10 Recommendations for Researchers Working with Lived Experience Partners
We are carrying out an RCT to evaluate long-term outcomes of PE on PTSD.

I think I need a translator for this guy!

I know, was that even English?

The study we design together will help improve patient care. Given your experiences, does anyone have ideas as to what might work best?
I'd like to help, but with two kids and my job, I just can't make the 2 o'clock meetings.

Hmm, well I'm sorry you can't participate.

Betty, we appreciate your input! Would it help if we met closer to your house?

The community centre nearby has a meeting room. The kids will be taken care of, and maybe other patients can join us?

We appreciate your input!
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.

...but, I would like to contribute to the project?...

Oh, we’re professionals. We’ve done this for ages. We’ll let you know when we need you.

What can I do to contribute to the project?

How would you like to be involved? You mentioned you might want to help with recruiting participants?
I'm the keynote speaker and will be chairing this event... and you?

Uh...

[Diagram showing a character named Michael marked N/A and another named John marked Speaker]
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.

Last time I came, I paid for transportation and parking. I’m sorry, but I can’t afford to be involved.

That’s too bad. We just don’t have room in the budget for those things.

We’re happy to reimburse any expenses you have as a result of partnering with us.

Wonderful! That makes it easier for me to participate.
8. BUILD RELATIONSHIPS THROUGH HONESTY AND TRUST.

At our last meeting, I suggested making a change to the protocol, but I don't see that change here.

Oh, sorry, you weren't here. We decided to leave it in.

At our last meeting, I suggested making a change to the protocol, but I don't see that change here.

Oh! Must have been an oversight. Let's have a look together.
I was invited to sit on a research panel, but it never met.

The reason I continued to participate was because I began seeing my suggestions appear in the results.

10. ESTABLISH AND ENCOURAGE CONTINUOUS COMMUNICATION AND FEEDBACK.

I had a few ideas about the research. Is there an email where I can reach you?

Sorry, no. You will have the opportunity to provide feedback at the next meeting.

But by then it will be too late!

Of course! Also, if you want to meet in person, feel free to send me an e-vite!

I had a few ideas about the research. Is there an email where I can reach you?