The Social Interventions Research and Evaluation Network (SIREN) and PAF Social Needs & Equity Learning Community

Background

Social care research, which is research on how healthcare organizations can assist patients with social needs like food insecurity or housing instability, hasn’t been taking patients’ lived experience enough into consideration when defining research questions, designing studies, or interpreting study results. Social care research may be asking the wrong questions and designing and promoting the wrong interventions. At best these interventions may not be as helpful as they could be; at worst, they could be harming patients.

What we did

In 2022, PAF and SIREN partnered to create the Social Needs & Equity Learning Community to elevate patient voices to impact social care research. The Community meets bi-monthly to discuss a range of projects related to social care research, such as studies, conferences, and scientific journal article abstracts. Approximately 15 Experts by Experience (ExEs) have advised on 8 social care research studies to date.

What has SIREN learned so far?

- ExE feedback and insights have had a range of impacts on these studies including changes to research questions, recruitment strategies and materials, interview guides and survey questions, and interpretation of study results.
- What this tells us is that this way of facilitating relationships between researchers and ExEs is both feasible and impactful.
- To make this process even better, SIREN needs to work more with researchers in preparation (e.g., lose the jargon, consider content, engage in active listening).
- We also need to stay in communication with researchers months or even years after their presentation to the Learning Community, so we can report impact back to ExEs.

TAKEAWAY MESSAGES

1. Experts by Experience (ExEs) are providing insights to social care researchers through a Social Needs & Health Equity Learning Community hosted by PAF and SIREN.
2. So far, ExEs have advised on 9 social care research studies. Their feedback has changed research questions, recruitment strategies and materials, interview guides and survey questions, and interpretation of study results.
3. SIREN is applying what we’ve learned from ExEs’ hard work these past 2 years to continue pushing a culture shift among social care researchers to incorporate lived experience in all parts of our work.

Our recommendations to researchers

To make ExE feedback more impactful, researchers should:
1. Build more buffer into their study timelines so that they can make changes ExEs advise.
2. Be transparent about expectations: what can be changed and what can’t?
3. Make the changes that are in their power to make.
ExEs are generous with their time because the potential for making positive change is meaningful to them, so researchers need to honor that generosity.

In conclusion...

Culture shift among researchers is a work in progress. The ExEs have been working hard the past two years to inform social care research and raise expectations for social care research that is more responsive to patient priorities. This is an active ongoing group with opportunities to join if you have lived experience relevant to social care and are interested in guiding research in this area.

Want to learn more? Email siren@ucsf.edu or visit www.patientinsightinstitute.org/equity-learning-community

An example of our impact

Take our 2-min survey to help us learn more about your experiences with patient-engaged research!

View our poster on your device