

A Patient's Perspective on Research Participation

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Legal Proofreader and **Kidney Warrior**



My extremely condensed CKD journey

Diagnosed with ESKD (end stage kidney disease) in October 2009; started in-center hemodialysis in November 2009

Not exactly a model patient. My second care plan meeting in April 2010 completely changed my outlook

Six years of dialysis, including three different modalities; living with a deceased donor kidney transplant since June 2015

Advocating for better care for people living with serious illnesses since 2012

I was recruited to participate in four clinical trials as a dialysis patient

- Mindfulness / body scans to reduce pain in in-center hemodialysis
- Telehealth (vitals reporting) in peritoneal dialysis
- Spironolactone (Spin-D) to treat cardiovascular events in dialysis patients
- ***Unknown – lost opportunity***

Challenges / barriers to partnering in research

- Investigators may not have received any training / know how to partner with patients in research
- Patients may not have the experience, confidence, or capacity (infrastructure) to partner with investigators and research teams
- Sponsors may not require patient engagement / partnering with patients in study proposals
- **only 20% of CKD clinical research addresses the top 10 patient priorities**

Frank L, Basch E, Selby JV, For the Patient-Centered Outcomes Research Institute. The PCORI Perspective on Patient-Centered Outcomes Research. JAMA. 2014;312(15):1513–1514. doi:10.1001/jama.2014.11100

Jamal, Z., Perkins, A., Allen, C. et al. Patient and public involvement prior to trial initiation: lessons learnt for rapid partnership in the COVID-19 era. Res Involv Engagem 7, 13 (2021). <https://doi.org/10.1186/s40900-021-00250-9>

Gutman T, Kelly A, Scholes-Robertson N, Craig JC, Jesudason S, Tong A. Patient and Caregiver Experiences and Attitudes about Their Involvement in Research in Chronic Kidney Disease. Clin J Am Soc Nephrol. 2022;17(2):215-227. doi:10.2215/CJN.05960521

Best practices – PCORI's Foundational Expectations for Partnerships in Research



Patients at the Table:


HOPE Consortium Trial to Reduce Pain and Opioid Use in Hemodialysis (HOPE) Study

Patients at the Table: The HOPE Study

- Objective: Evaluate the effectiveness of pain coping skills training (PCST) on pain interference in people receiving in-center hemodialysis
- Design: Randomized controlled trial; nonrandomized evaluation of buprenorphine as an alternative to opioid medications
- Funding: NIH HEAL Initiative[®] (Helping to End Addiction Long-term)
Sponsor: National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- Study start: January 2021; Study end: May 2024
- **Results**: While the effect on the overall cohort was of modest magnitude, the intervention resulted in a *clinically meaningful improvement in pain interference* for a substantial proportion of participants.

The HOPE Study Patient Advisors were recruited *before the study was funded*



► Clin J Am Soc Nephrol. 2018 Apr 19;13(5):675–676. doi: [10.2215/CJN.03540318](https://doi.org/10.2215/CJN.03540318) 

Appropriate Use of Opioids in Patients with Kidney Diseases

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HOPE Trial Patient Advisors



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Jamaica, NY

The Rogosin
Institute

Purposefully setting expectations

- Paul Kimmel, M.D. set the expectation of “Patients as Partners” at the HOPE Consortium’s first Steering Committee meeting
- Result: a study culture of *respectful co-creation*

The Patient Advisors made the recruiting poster...

A

Patients actively involved in logo and tagline development

HOPE Helping People on Dialysis Manage Pain

HOPE: Hemodialysis Pain-Reduction Effort

HOPE actually stands for **Hemodialysis Opioid Prescription Effort**

- Do you suffer from chronic pain that interferes with your usual activities?
- Have you felt that your pain was ignored by others?
- Have you had bad experiences with pain medication?

HOPE is a research study that is testing ways to improve pain management in patients on dialysis with pain for more than 3 months.

Pain Coping Skills Training involves 12 one-on-one video sessions with a trained coach who will help you learn skills to manage pain.

Later, you might be offered a medication called **buprenorphine** that may treat your pain with fewer side effects than traditional opioid medications. It is possible that you may be assigned to one, both, or none of these groups. You do not need to be on pain medication in order to participate, and you will not be required to change your pain medication.

Participants enrolled in the study will be compensated for their time.

If you are interested in learning more about the HOPE study, go to WEBSITE or text HOPE to xxxxx.

Patients liked implication that pain can strike anyone, anywhere

Patients liked the idea of beating pain or getting control over it


The HOPE study is funded by the National Institute of Diabetes and Digestive and Kidney Diseases

... more person-centered

B

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HOPE
HEMODIALYSIS PAIN-REDUCTION EFFORT



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If you are interested in learning more about the HOPE study, go to www.hopetrialstudy.com or text HOPE to 215-898-HOPE.

HOPE
Helping People on Dialysis Manage Pain

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HOPE **HEMODIALYSIS PAIN REDUCTION EFFORT**



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To see if the HOPE study might be a good fit for you, complete our survey by going to www.XXXX.org or use your smartphone camera to scan the QR code.

The HOPE study is funded by the National Institute of Diabetes and Digestive and Kidney Diseases.

HOPE
Helping People on Dialysis Manage Pain

White, David M.; Kimmel, Paul L.; Dember, Laura M; Wilkie, Caroline; Edwards, Dawn P.; Williams, Joel; Bernardo, Leah; Quintana, Nina; Cheatle, Martin D; Lash, James P.; Fischer, Michael J.; Schmidt, Rebecca; Doorenbos, Ardith; Schrauben, Sarah; Johansen, Kirsten; for the HOPE Consortium, a member of the HEAL Initiative. Patient Engagement in the Design and Conduct of the HOPE Trial: Addressing Chronic Pain in Hemodialysis Patients. *Clinical Journal of the American Society of Nephrology* 20(10):p 1461-1469, October 2025. | DOI: 10.2215/CJN.0000000866

Patient Advisors participated in almost all of the HOPE Study's committees and working groups

- Data Safety Monitoring Board
- Demographic Characteristics Analyses
- Executive Committee
- Quality Control
- Patient Advisors Committee
- Publications
- Recruitment and Retention
- Return of Results
- Steering Committee

Selected quotes from patient engagement manuscript

“I had grown up with a negative feeling about science, medical trials and studies. I was always told that people of color were used as Guinea pigs, and that scientists just wanted to experiment with us. It just didn't sound right to me. How could we receive safe and equitable care if we weren't represented in trials and studies? So, I decided to see for myself how things were done”

“This study is not just about me and what it can do for me. It's about what it can do for everybody in changing how we do studies and making sure that the studies we're doing are important to patients”

“Everybody wanted us to be involved. I always felt very welcomed, and like my opinion mattered, and you don't always get that. I've been on projects where it's just lip service, [but in] this project, it wasn't just lip service. People actually took our opinions seriously and took them to heart”.



Thank you!