# Case study: Patient-directed study design – virtual reality to mitigate chronic cancer pain

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## Executive summary

**Objectives**
In order to design a study that was highly relevant to the patients we serve, our research team sought to incorporate the expertise, experiences, and input of cancer patients living with chronic pain when developing our research protocol and when determining outcomes of importance. We leveraged our partnership with a local nonprofit that offers a cancer survivor support group.
**Activities**
Patient Partners provided consultation via regular in-person and virtual meetings over a 4 months.
**Outcomes**
Patient Partners spoke to the subtlety and subjectivity of chronic cancer pain, provided insight with respect to research questions that had the most relevance to their experiences, and helped craft a study design that speaks to the lived cancer pain experience.

## Challenge

Increasing access to VR for patient stakeholders:
- Funding from Rising Tide allowed patients to explore non-medication therapies and mind-body/behavioral modalities for pain management and opioid reduction. VR is a technology which none of the Patient Partners had used before and it is something they would not otherwise be able to utilize.

Improving the trial design through patient feedback:
- Funding from Rising Tide ensured that patients would be fairly compensated for their time and insight throughout the process, and that transportation would not be a barrier to patient participation.

# Moving the needle from theory to practice

## Direct involvement of patient experts

**MedStar Health Research Institute**
- Largest clinical research center in Washington, DC
- Expertise in symptom science clinical trials in serious illness care, including cancer

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- Largest not-for-profit cancer survivorship support organization in Washington, DC
- Experience collaborating with MHRI investigators

**3 Clinician Investigators + 10 Cancer Survivor Partners**

## Incorporating feedback

**Patient Partner education on VR for pain management**
- *Learn about evolving research*
- *Test VR equipment*
- *Collect feedback on VR applications relevant to study*
- *One 2-hour session*

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**Development of relevant research questions**
- *Long term project goal development*
- *Discuss and test specific aims*
- *Four 1-hour sessions*

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**Collaborative study design**
- *Introduce different quant, qual methodologies*
- *Discuss patient-reported outcome measures of interest*
- *Four 1-hour sessions*

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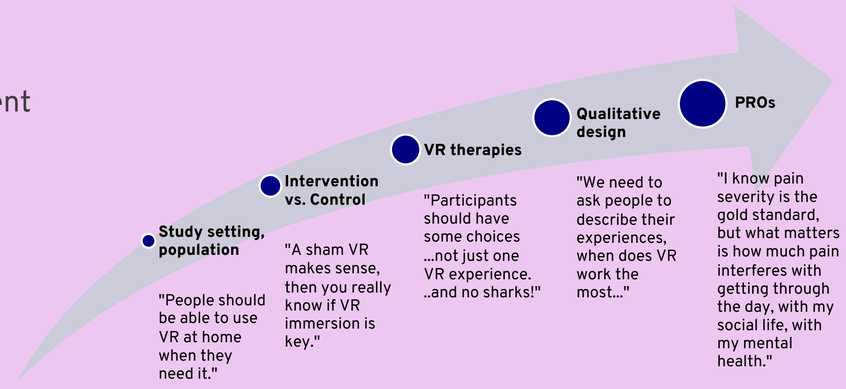
**Study advisory board formation**
- *Ongoing . . .*

## Impact on study design

Throughout the project, the Research team introduced key content relevant to prospective randomized controlled trial design and solicited specific input from Patient Partners. As a result, the developing study proposal reflects the needs and concerns of patients living with chronic cancer pain and is significantly more likely to appeal to eligible participants and provide results that influence non-pharmacologic pain management strategies. Examples of Patient Partner input are shared here:




# Influencing the field of clinical cancer research

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**Cancer Survivor Partner Perspective**
"I am beyond grateful to be part of this group…Thank you so much for all you have done to allow this work to develop into a trial. It makes my heart so full" – DM, Stakeholder

**Investigator Experience**
"As a clinician investigator studying symptom management in serious illness, this collaborative process was critical to hear [the patient experts'] experiences. Having patients involved in the research design in this way brought the subtlety of the cancer pain experience to the forefront of the project." – Dr. Hunter Groninger, Primary Investigator

1 **Applying for the pre-application grant**

2 **Activities proposed**

3 **Outcomes & incorporating them back into endpoint and trial design**

### Providing pre-application funding for patient involvement

A new grant mechanism called "pre-application grants" has been launched. These small grants are to close the funding gap for patient experts to provide input to the development of a grant application/protocol.

We are aiming at supporting patient organizations during this early phase with a budget. The budget should be planned to cover travel costs to preparatory meetings and the work time invested by staff or patient experts. This work should be carried out as a preparation step prior to the submission of a clinical research grant application to RTFCCR

4 **Conclusion**