

VIRTUAL PATIENT (VIP) ENGAGEMENT STUDIO

Using technology to engage hard-to-reach patients

Nabil Natafqi & Kenneth Baxter



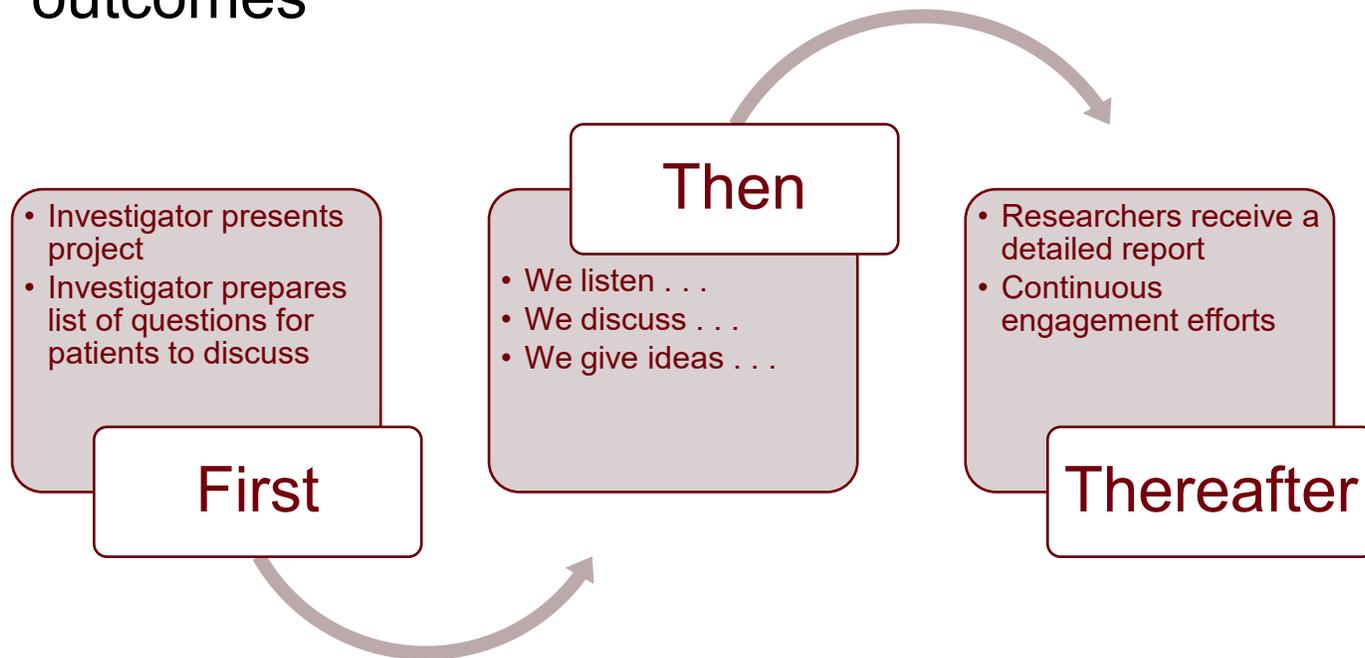
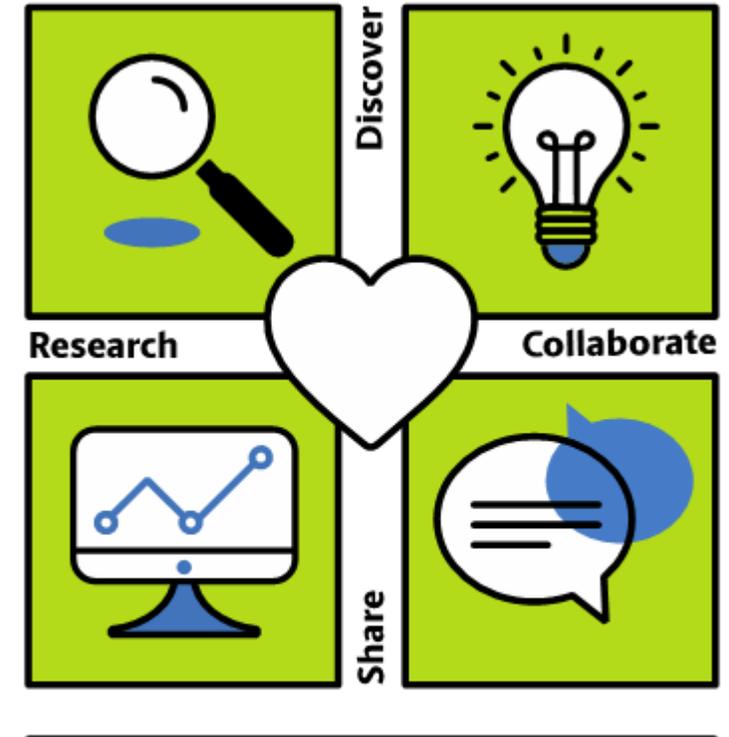
FUNDING

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- The views, statements, and opinions presented in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.



ABOUT US: The **PATIENT ENGAGEMENT STUDIO**

Our mission: to meaningfully integrate the patient voice in all stages of research by promoting collaboration with scientists and clinicians to optimize health and research outcomes



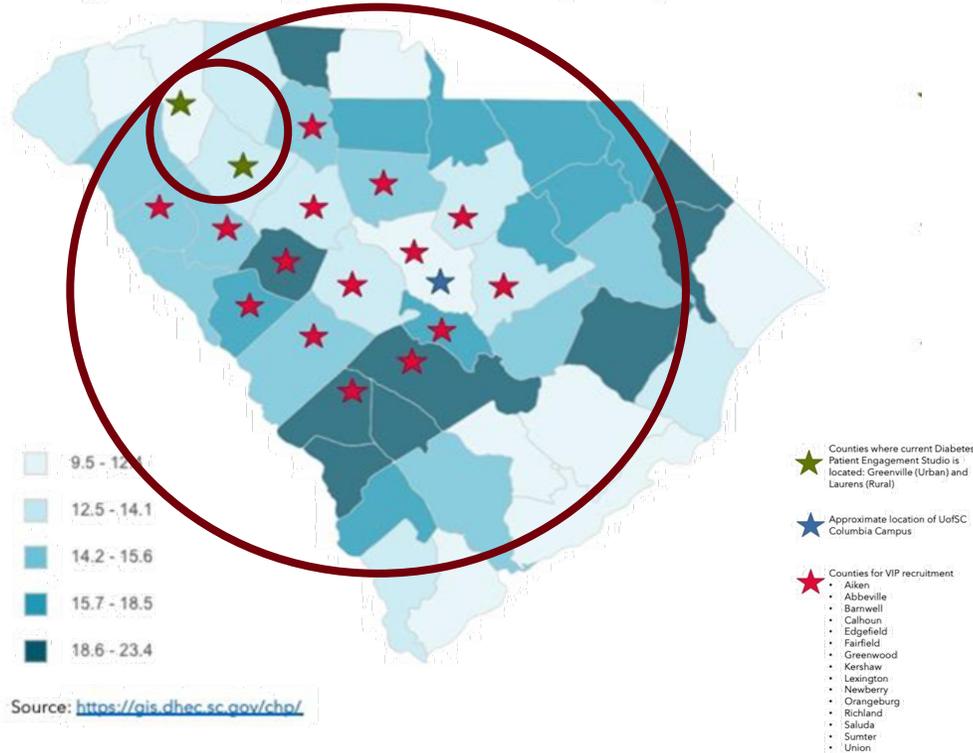
WHAT DID WE DO?

Background, Solution, and Specific Aims

BACKGROUND

Traditionally, most patient engagement activities were facilitated in-person. Little is known about methods and effectiveness of virtual engagement.

Percentage of Adults diagnosed with diabetes by county between 2015-2016



1 in 8 African-Americans have type 2
16th highest rate in the nation



7th leading cause of death in the state



5th in the nation for type 2 diabetes
Also **6th in the nation** for obesity



Diabetes

Source: Diabetes in Impact in South Carolina. (February 2019) Diabetes Initiative of South Carolina. S.C. Department of Health and Environmental Control.

SPECIFIC AIMS

- **Goal 1:** Build a diverse network of geographically dispersed patients and stakeholders (VIPs) who can serve as experts with lived experiences of diabetes and can be meaningfully involved in the VIP Studio
- **Goal 2:** Train recruited VIP Studio experts (VIPs) and implement the VIP Studio activities by engaging patient experts in ongoing and new PCOR/CER research opportunities
- **Goal 3:** Evaluate the virtual experience and disseminate the capacity-building plan to expand and replicate the VIP Studio among other PCOR partners

HOW DID WE DO IT?

Activities and Key Milestones

93 individuals **signed up** to attend one of the

23 informational sessions held over the course of **3 months**

A total of **51** individuals **attended** one of these meetings

25 VIPs participated in **7** training modules

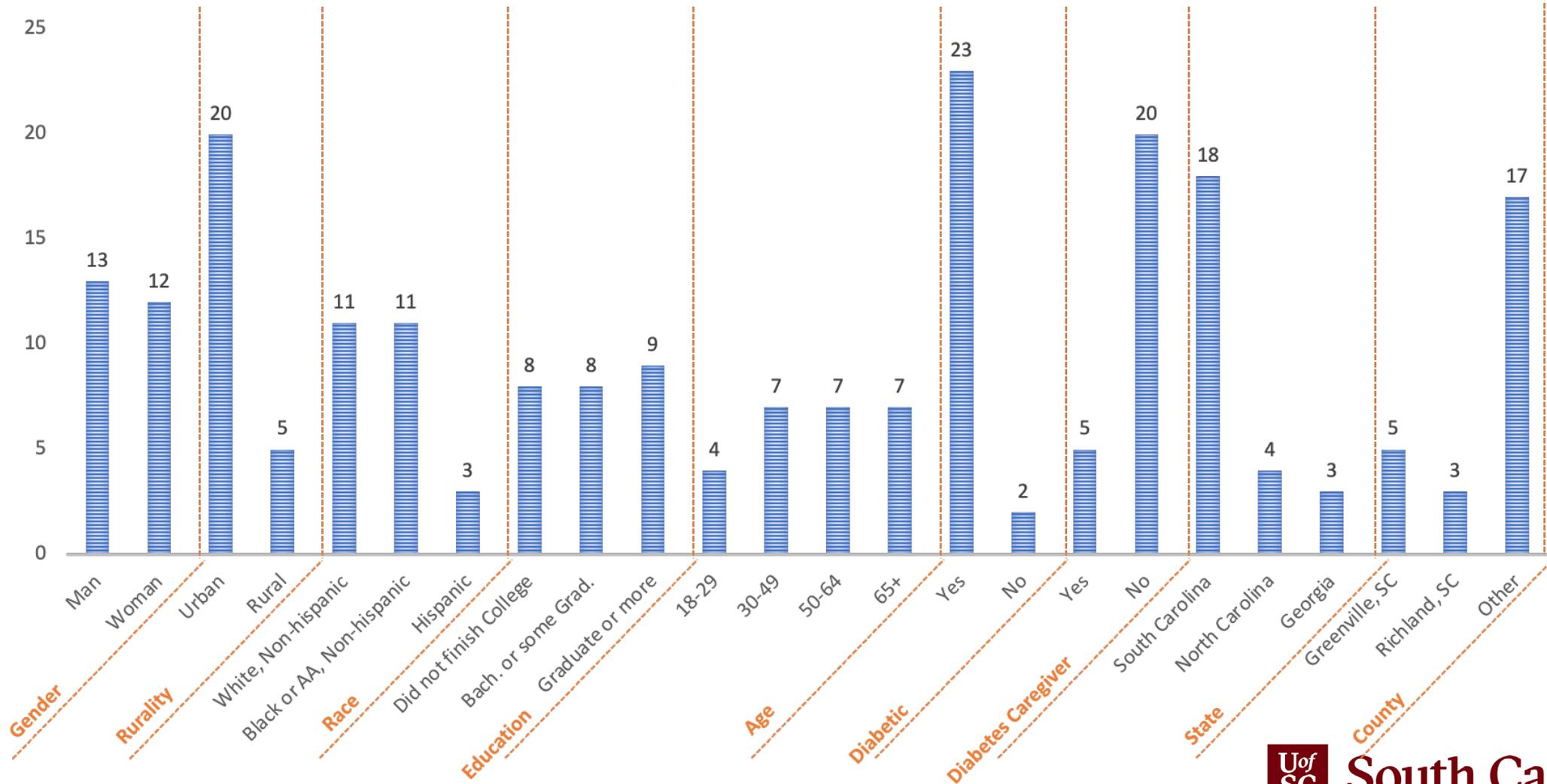
6 of which were held **twice** for a total of **13 sessions**

over the course of **5 months**

& reviewed a total of **10 projects**

over the course of **2 months**

VIP EXPERTS BY KEY ATTRIBUTES



Nabil N... (Cohost, me) | ANNA NOURSE (Host) | ANN KENN... (Cohost) | Call-in User_3
 Kenneth Ba... (Cohost) | Call-in User_4 | Call-in User_5 | Call-in User_6
 Call-in User_7 | Call-in User_8 | Call-in User_9 | Call-in User_10
 Call-in User_11 | Call-in User_12 | Call-in User_13 | Call-in User_14
 Call-in User_15 | Call-in User_16 | Call-in User_17 | Call-in User_18
 Call-in User_19 | Call-in User_20 | Call-in User_21 | Call-in User_22
 Call-in User_23 | Call-in User_24 | Call-in User_25 | Call-in User_26
 Call-in User_27 | Call-in User_28 | Call-in User_29 | Call-in User_30

Participants (30)

Search

- JB
- JI
- KD
- KB
- KJ
- LJ
- MT

Mute All | Unmute All

Chat

Wanda, the invite should have come from Microsoft Teams to indicate that you were added to the Teams Channel

Send to: Everyone

Enter chat message here

COMPLETED TRAINING SESSIONS

Session	Date	Team Building	Learning*
Session 1	October 2020	<ul style="list-style-type: none"> • 30 second introductions • Finding your word 	Intro to VIP/Ground rules Technology Training
Session 2	November 2020	Sharing my diabetes story	Conversation about diabetes with Michelle Stancil
Session 3	November 2020	The Big Picture	Introduction to research and the 10-step framework
Session 4	December 2020	<ul style="list-style-type: none"> • What is your favorite sound? • Photovoice 	PCORI approach to Patient-Centered Research
Session 5	January 2021	Think-pair-share – Magic Wand exercise	Wonderings to research questions
Session 6	January 2021	Think-pair-share – Trusting your healthcare team and COVID-19	<ul style="list-style-type: none"> • Communicating with researchers • Research group presentation framework and explanation
Session 7	February 2021	<ul style="list-style-type: none"> • Research question creation • Exploring emerging themes 	Practice research study review

* Homework: PCORI online training

TOPICS OF 10 PROJECTS PRESENTED



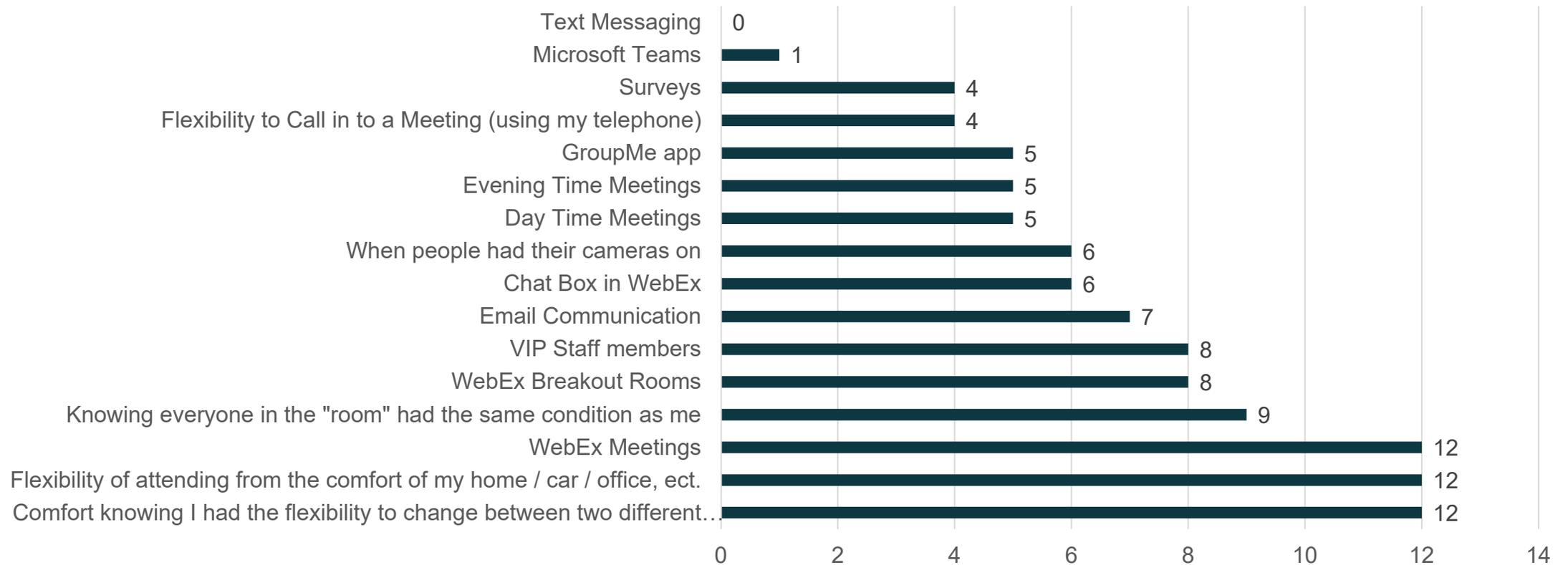
WHAT DID WE FIND?

Mid-Project Evaluation

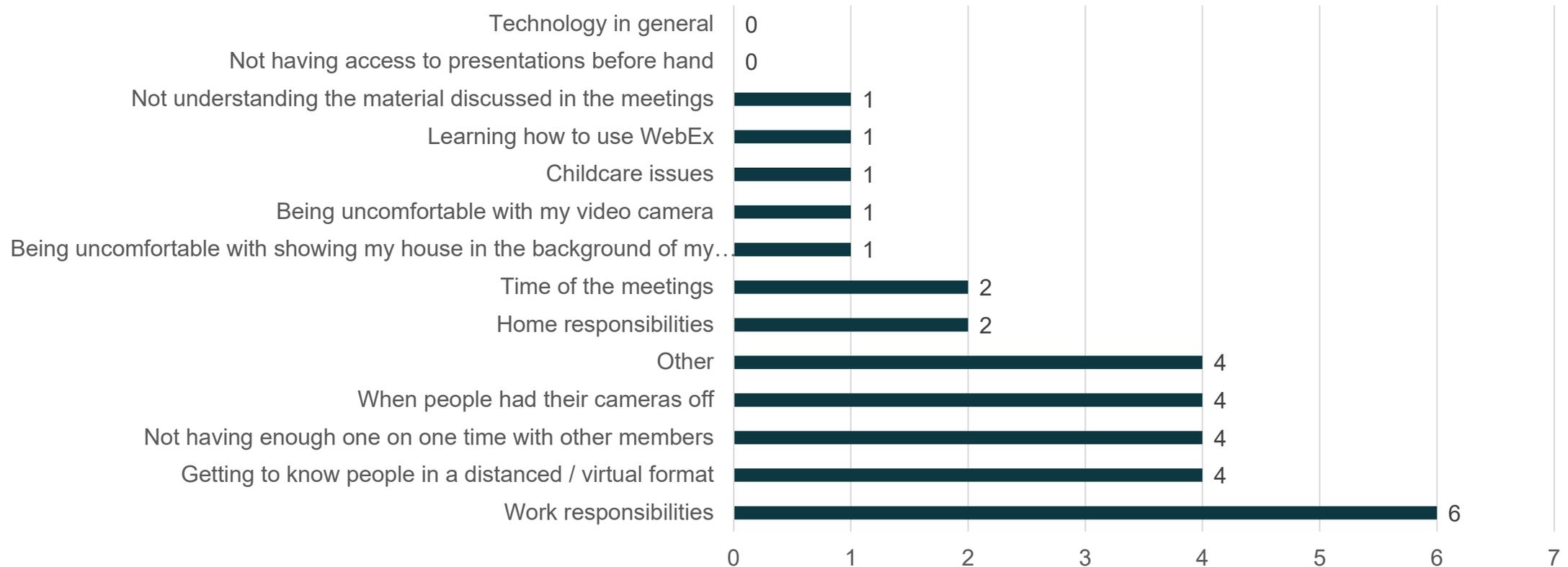
WHICH OF THE FOLLOWING STATEMENTS REFLECT YOUR REASONS FOR JOINING THE VIP STUDIO?



WHAT HELPED YOU THE MOST IN INTERACTING AND ENGAGING WITH OTHERS IN THE VIP STUDIO?

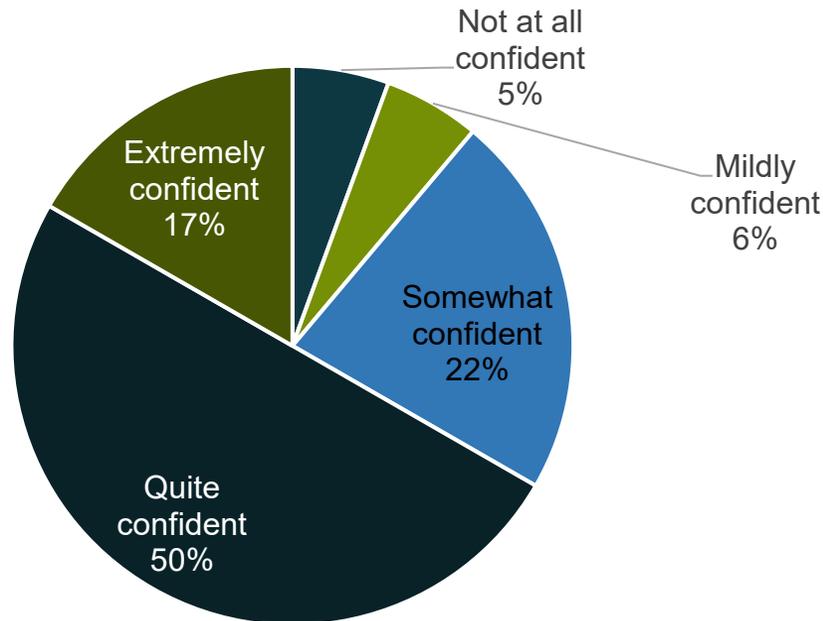


WHAT HAVE BEEN SOME OF THE CHALLENGES THAT HAVE MADE IT HARDER FOR YOU TO ENGAGE WITH OTHERS?

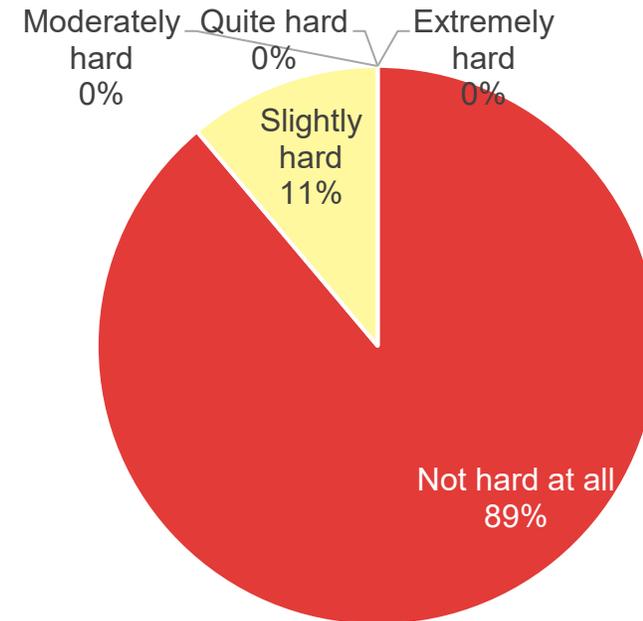


CONFIDENCE AND EXPRESSION

How confident are you that you have enough information to carry out your role in the VIP Studio?



How hard has it been to **express** your views freely during the VIP meetings?



WHAT ELSE WOULD YOU LIKE US TO KNOW ABOUT YOUR EXPERIENCE WITH THE VIP STUDIO?

- Engagement activities
 - more opportunities to get to know one another; meet in person (if not for COVID)
 - challenging to get to know those who participated only via phone (i.e., no video)
 - liked the one-on-one break out rooms; slightly more time in the breakout sessions
- Learning
 - benefited from hearing colleagues' diabetes stories + learning about the research process
 - sharing info between members and/or providing internet sources for info regarding their problem
 - PCORI Training module: clearer instructions + Assign one module a time / spreading them out
- Logistics
 - the group itself is a bit too large; with a group about half this size → more individual feedback in the time allotted
 - providing time boundaries for introductions/sharing

THANKS!

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