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A multi-method evaluation of how equity deserving communities were engaged in research

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Abstract

Background We aimed to understand and evaluate the types, experiences and levels of engagement of all groups engaged in the OPTimise research study. The OPTimise study used virtual community engagement to engage equity-deserving populations across three sites to help public health units tailor strategies to improve vaccine uptake during COVID-19. Our evaluation was uniquely conducted at arm's length from the OPTimise researchers who facilitated the virtual engagement with these groups.

Method The community members involved in research (community leaders and citizen partners) were invited to complete the 22-item Patient Engagement in Research Scale (PEIRS-22) survey to understand the nature of engagement. Twenty-three participants were invited to complete the survey and 19 (83%) completed the survey. We conducted individual and focus group interviews with members of all four groups (community leaders, citizen partners, public health unit knowledge user and connectors, and methods researchers) to learn about their engagement experiences with the OPTimise study and research team. Thirty-five participants were invited to join an interview or focus group interview with 22 (63%) completing an interview.

Results OPTimise study members reported "extremely meaningful" engagement which is the highest level on the PEIRS-22 scale. The interviews demonstrated that the OPTimise study was designed appropriately across the three sites. Interviews were analyzed based on four topics: relationship management, supporting processes, power sharing, and satisfaction with operations. Qualitative and quantitative data are compared to the Levels of Patient and Researcher Engagement in Health Research framework. Citizen partners and methods researchers reported being engaged at the level of "lead" on the framework. Community leaders reported their level of engagement as at the level of "involve" throughout the study while connectors and public health knowledge users reported their level of engagement was at the level of "involve episodically" throughout the study.

Conclusions This evaluation found that building authentic relationships between the OPTimise research team and participants was key in the early phases of the OPTimise study. Researchers on future projects could benefit from developing working relationships with organizations who can connect with the target audience to facilitate trust building between researchers and engagement participants, especially in virtual environments.

Keywords Community engagement, Engagement evaluation, COVID-19, Virtual engagement

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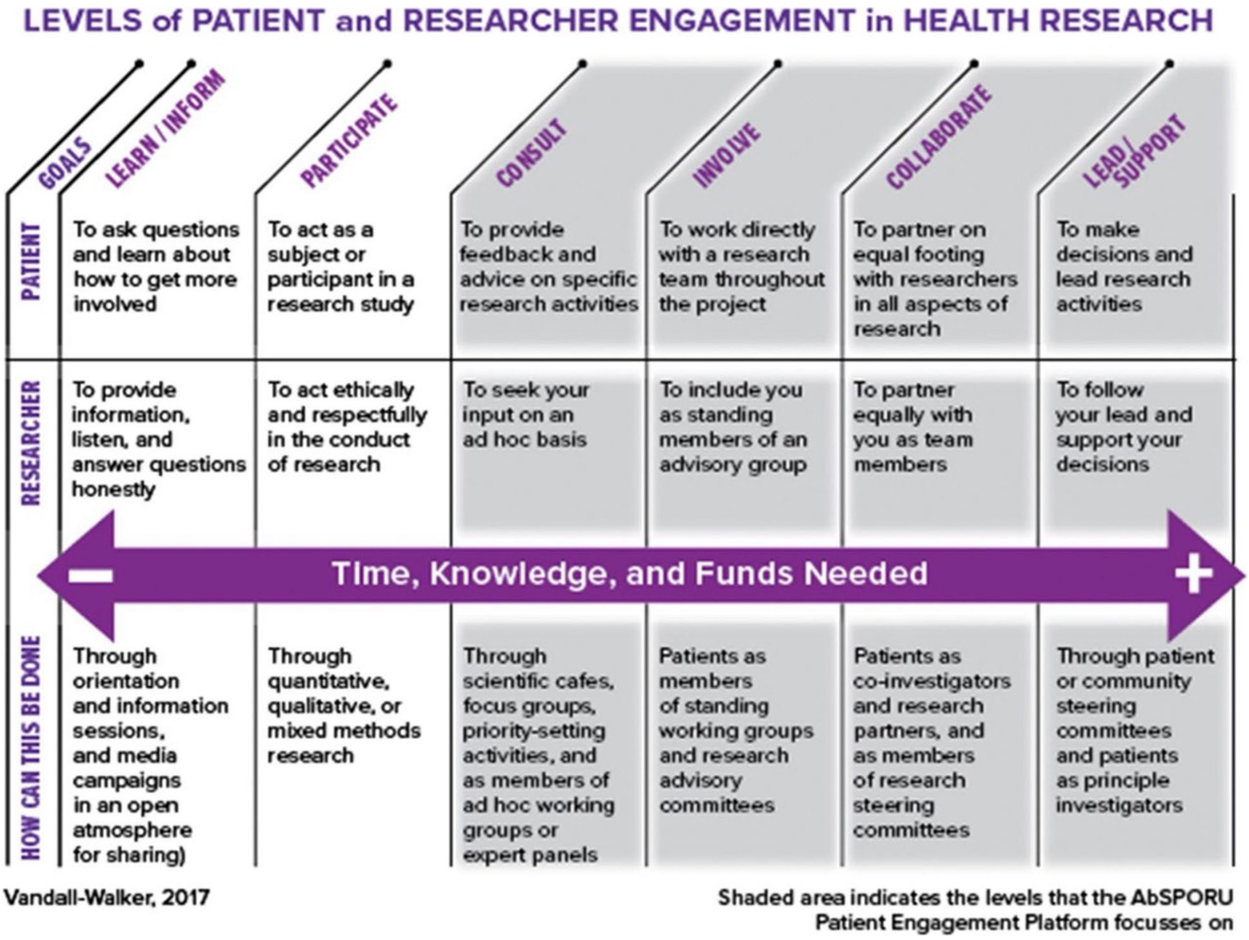
Background

Engaging communities in research

Researchers are actively striving to bridge the gap between health research and implementation by engaging with those directly impacted by research findings [1]. This push is increasingly coming from funding agencies, among other groups, which look for meaningful engagement practices [2–5]. Engagement with equity deserving communities [3] can help to reduce inequities when done appropriately [1]. There is an ethical imperative to engage the public and communities in research which is highlighted by the global movement "nothing about us without us" that originated in disability studies and has spread to health services research [6, 7]. Public engagement in science and healthcare leads to democratizing science and challenging traditional academic methods [5, 8]. Further, public engagement in health research leads to more equitable research outcomes and improved science through increased relevance, improved the trust of stakeholders, mutual learning, improved uptake, transparency, updated research methods and goals, improved measurement tools, and improved analysis of findings [9–11].

Research engagement can take different forms, reflecting several levels of engagement as per health and health services research frameworks. Supple et al. [3] note the importance of engaging early, widely, and deeply, and allowing those engaged to share their own stories. But there are different ways to do this. The IAP2 spectrum of public participation highlights how to support effective engagement of stakeholders [12]. The IAP2 spectrum was adapted to become the Levels of Patient and Researcher Engagement in Health Research as shown in Fig. 1. The levels include learn/inform- provide with information on activities, participate- act as a participant in research, consult- draft plans and provide feedback with influence on decision-making, involve- work directly with a research team throughout the research process, collaborate- work together on all aspects of a decision and lead/support- patient leading the work [13]. Throughout this paper, the term engagement is used to refer to all of the



LEVELS of PATIENT and RESEARCHER ENGAGEMENT in HEALTH RESEARCH

GOALS	LEARN / INFORM	PARTICIPATE	CONSULT	INVOLVE	COLLABORATE	LEAD/ SUPPORT
PATIENT	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researchers in all aspects of research	To make decisions and lead research activities
RESEARCHER	To provide information, listen, and answer questions honestly	To act ethically and respectfully in the conduct of research	To seek your input on an ad hoc basis	To include you as standing members of an advisory group	To partner equally with you as team members	To follow your lead and support your decisions
HOW CAN THIS BE DONE	Through orientation and information sessions, and media campaigns in an open atmosphere for sharing)	Through quantitative, qualitative, or mixed methods research	Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels	Patients as members of standing working groups and research advisory committees	Patients as co-investigators and research partners, and as members of research steering committees	Through patient or community steering committees and patients as principle investigators

Vandall-Walker, 2017

Shaded area indicates the levels that the AbSPORU Patient Engagement Platform focusses on

Fig. 1 Levels of patient and researcher engagement in health research. Adapted from Amirav et al., 2017 with permission. Amirav et al., 2017 adapted the figure from Dr. Vandall-Walker based on the International Association for Public Participation Spectrum [12, 14] levels of engagement as demonstrated in Fig. 1. The commitment level and resources required for engagement must increase when moving across either spectrum.

More considerations are needed when engaging with the public and equity deserving populations. First, there is a need for sensitivity and trust building. To effectively reach communities, cultural sensitivity is required [15], with inclusive, accessible, and supportive processes for those engaged. Expectations during the research process and about the research relationship should be made upfront, especially when the relationship is time-limited [16]. Clear expectation-setting can promote trust which is a slow process as a relationship is formed. Adding a social space at the start of a study also helps develop that relationship which can turn into trust if those clear expectations are honored such as, creating a WhatsApp group with participants or doing an informal check-in at the start of meetings [16]. Second, power needs to be handled carefully and distributing power can be challenging, especially when working with equity deserving communities [17]. Power should be distributed among those engaged in research to promote justice such as, sharing the co-host role of virtual meetings with all participants or allowing people outside of the research team to facilitate conversations. If the engagement is fair, representative, and if there is recognition for the work that is done, while moving further right on the spectrum to collaborate and lead, it creates justice by distributing research benefits and burdens among those who participate in research [18].

Engagement with equity deserving groups during COVID-19

The World Health Organization guidelines stated that equity deserving communities need to be engaged, involved, informed and enabled to utilize public health and safety measures [19]. Specific populations must be engaged and listened to so that safety measures can be targeted to them [19]. This captures the voices of equity deserving groups, who are often excluded, to address their health disparities [20]. To prevent leaving equity deserving groups behind during COVID-19, their voices need to be prioritized but more evidence is required on how to conduct meaningful engagement [16, 18]. During COVID-19 where inequalities stemming from race, access to technology, socioeconomic status, location, and age were magnified, engagement with equity deserving communities was necessary.

COVID-19 turned many in-person activities into virtual activities, including community engagement in research, making trust even harder to build [21]. COVID-19 planning, and prevention could support meaningful relationship building through mutual experience if a relationship has already formed [21]. However social distancing impacts the close bonds required for initially engaging equity deserving groups in research [22]. General recommendations for developing trust virtually include providing accurate communication and creating capacity when working with equity deserving groups [19]. Although recommendations have been made for engaging equity deserving communities in research virtually, there is not one singular 'best' approach to engagement [21]. Researchers continue to investigate best practices for developing trust virtually when engaging the community while recognizing the importance of context.

Many studies conducted during COVID-19 engaged patients and communities. Some of the benefits of engagement research in a virtual format are that many study participants feel comfortable in their own space, reduced travel, private chat ability, more opportunities for reflection, and alternative roles and responsibilities for both researchers and individuals engaged in research [22]. A number of challenges have also been highlighted. Typically, rapport is built through face-to-face interactions. It is challenging and time-consuming to build the relationship, especially at the beginning, using virtual methods [15, 16, 18, 22]. It is difficult to create an atmosphere for open discussion using check-ins and online meetings [16, 22]. Some individuals can be isolated from participating due to a lack of internet connection, technology access and skills [22, 23]. Some researchers have asked whether it is ethical to conduct research during a global pandemic and it is hard to gauge what resources are needed [15]. Virtual interaction clearly works differently than in-person interaction methods.

Virtual methods for engaging the community in research have not disappeared post-pandemic. A better understanding of how to engage communities in research virtually, what works, and what does not for different communities is needed. König et al. (2022) suggested that more research be done on how to adjust virtual methods to meet the needs of diverse groups and how to build trust online in a virtual format. Hall et al. [22] also reiterated the need to learn more about virtual engagement methods, especially when creating relationships initially in a virtual setting. Many of the current engagement studies had relationships that had already formed before COVID-19 and pivoted online. We need more research to understand how to create relationships and build trust virtually.

Evaluation of engagement

To better understand engagement processes in research there are different ways to evaluate the process and outcomes. Tools such as the Levels of Patient and Researcher Engagement in Health Research showcase empowerment outcomes, enrollment retention and impact [14, 24]. There are validated surveys on patient engagement such as the Patient Engagement in Research Scale with 22 questions (PEIRS-22) used in this study [25]. This validated scale with slightly modified terminology was used to evaluate patient engagement during COVID-19 in a study relating to a community advisory group [24]. Barn et al. [24] found meaningful engagement with additional qualitative questions. Conducting an evaluation of engagement is often challenging due to a lack of documentation of the engagement processes [15].

Even when there is an appropriate framework and documentation available there are other factors to consider when evaluating the continuum of engagement. Often evaluations are led by the researchers who conduct the engaged research [26]. Some evaluations are co-led by patient or community leaders but there is rarely an external review process [5, 26, 27]. Moving forward, this paper contributes to the engagement literature by reporting on an external evaluation of virtual engagement processes with equity deserving groups in the OPTimise study.

Research aim

The aim of this study was to conduct an arm's length evaluation of a multi-site research study (OPTimise) from October 2022 to November 2023; the study commenced in December 2021. This multi-site study engaged equity deserving community leaders, citizen partners, knowledge users and connectors, and methods researchers, primarily using virtual methods. The OPTimise study engaged with public health units to identify priority populations for COVID-19 vaccination and build rapport with community leaders and residents to identify enablers of vaccination uptake in specific communities [28]. This paper aims to describe the types, experiences, and levels of engagement of all of the groups, as defined in Table 1, engaged in the OPTimise research study.

Methods

The evaluation used a multiple-methods approach. Quantitative and qualitative data were collected concurrently and independently of each other and integrated at the stage where inferences were made [29, 30].

Setting

This evaluation was performed at arm's length from the OPTimise study. The OPTimise core research team planned to have an evaluation of their engagement processes from the beginning of their study, conducted by us (EP, IG, AK), a separate research team. In carrying out our evaluation of the OPTimise study, we consulted with the OPTimise core research team about methods, recruitment and the verification of accuracy during manuscript preparation. The OPTimise study included the core research team, methods researchers and citizen partners who worked with three communities to optimize how to address their priority public health and safety measures (PHSM) during COVID-19. By way of context the OPTimise core research team is white-appearing and presents as one male and three female researchers.

The OPTimise study took place in three large socially and ethnoculturally diverse urban communities in Ontario, Canada (sites O, T and P) and used a variety of engagement strategies and targeted different PHSM and populations as shown in Table 2. Clinical trial number: not applicable.

Table 1 Definitions of terms describing the groups evaluated in this study and their activities

Term	Definition [28]	Activities in the OPTimise study
Community leaders	Individuals from the communities of interest in the OPTimise Studies who are advisors to the researchers	Planning the execution of the research methods, relationship building, data collection and reviewing results
Citizen partners	"Patient with extensive experience in COVID-19 citizen engagement recruited during the development of the grant application to provide high-level input and support throughout the study, including reviewing all materials and co-leading community engagement." (28 p4)	Grant writing, methods development, engagement work, analysis, and manuscript drafting
Connectors/Connector organizations	Individuals working at community organizations who are connected to community leaders. (e.g., Community Resource Centers and Community Health Centers). Through their work they have pre-existing relationships with community leaders	Identified community leaders
Knowledge users	Public health units who define the problem in their city and receive information from the OPTimise study to use in their work. Also acted as a connector	Grant writing, relationship building and receiving study results
Methods researchers	Researchers leading the novel methodological approach of the OPTimise study	Grant writing, methods development and analysis, manuscript preparation

Table 2 Characteristics of each OPTimise study sites population, behavior of interest and community leader recruitment process

Site	Equity Deserving Group of interest [28]:	Behavior of interest [28]:	Key Processes used by the OPTimise Team to recruit Community Leaders:
Site O	Individuals aged 18 and older from fifth-quintile socio-economic status neighborhoods	Third COVID-19 vaccine dose	The research team contacted the Public Health Unit (PHU) who connected the research team with eight individuals at four connector organizations. The connectors make connections to seven community leaders. Six joined the study.
Site T	Individuals aged 18 and older who are members of African, Black and Caribbean (ABC) communities in the five neighborhoods with the lowest rates of vaccination	Initially targeted first COVID-19 vaccine dose and later prioritized the 3rd dose as well	The research team contacted the PHU but the PHU were unable to connect them with connector organizations. The research team searched for potential connector organizations and built relationships with those organizations to get connected to potential community leaders. Also, leveraged pre-existing research relationships for further community leader connections.
Site P	Initially, individuals aged 30–49 who are members of the Eastern European community (ex. Polish, Ukrainian or Russian) communities. Later broadened the age range to 18 and older	Initially targeted first COVID-19 vaccine dose and later prioritized the 3rd dose as well	The research team contacted the PHU. Eventually got connected to connector organizations after many attempts of reaching out to them directly. This led to the recruitment of 9 community leaders, 7 of which were engaged until the end of the study

The evaluation participants

The evaluation participants were all part of the OPTimise study and were composed of four groups: community leaders, citizen partners, knowledge users and connectors from connector organizations, and methods researchers based on recommendations from the core research team of the OPTimise study (see Fig. 2); these four groups helped mobilize the OPTimise study. The knowledge users and connectors from connector organizations were merged into one group due to small recruitment size, performing a similar function for our evaluation and recommendation from the core research team of the OPTimise study. The evaluation participants do not include the OPTimise study participants. Recruitment results for each of the four groups are described in Table 3.

Recruitment

The OPTimise core research team made a recommendation about which groups from their study might participate in the evaluation and all members of each group were invited to the evaluation. During recruitment the groups were told that the evaluation is conducted by a separate research team and that the OPTimise research team would not see any individual responses attributed to any individuals.

PEIRS-22 survey

The community leader and citizen partner groups were recruited through email to complete the PEIRS-22 survey. Participants received two email reminders to complete the survey.

Individual and focus group interviews

Members of all groups were invited to interviews or FGs with members only from their group and site through email. Two email reminders were sent to participate.

Data collection

PEIRS-22 survey

The community leader and citizen partner groups were asked to complete an adapted 22-item PEIRS survey administered online through Qualtrics about their experiences as community members engaged in the OPTimise study. The validated survey uses a 5-point Likert scale questionnaire to determine a score for overall meaningful engagement. PEIRS-22 was developed with patient partners with the intent to evaluate patient and family engagement in research and was validated through web and paper surveys across Canada and the United States with patients or family caregivers over the age of 17 who communicated in English and engaged in research projects [25]. An example PEIRS-22 item is “PR1. I was interested in the issue(s) being researched in the project “ with a scale including Strongly Agree (4), Agree (3), Neutral (2), Disagree (1) and Strongly Disagree (0) [25]. The score is based on seven domains: procedure, convenience, contributions, team environment and interactions, support, feel valued and benefits [25]. The PEIRS-22 was designed to measure meaningful patient engagement. We adapted the scale for use in community engagement, where not all participants identify as patients. We replaced the term

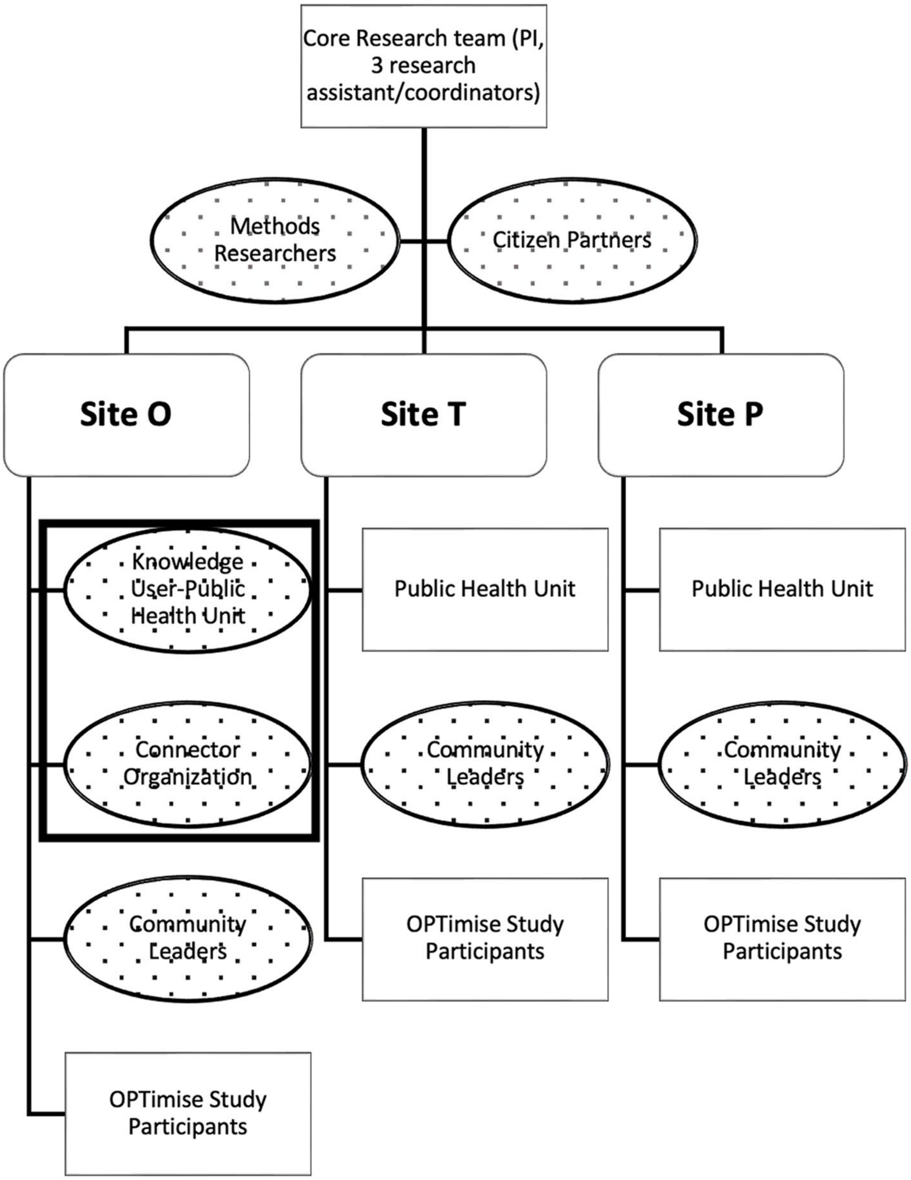


Fig. 2 A diagram demonstrating the overall structure of evaluation participation from the OPTimise study participants. The core research team composed of the Principal Investigator and three research assistants/coordinators, methods researchers and citizen partners were engaged across three sites. The dotted background indicates the groups that the OPTimise core research team advised us to approach for this evaluation. The circles represent the groups we approached and were able to recruit members from for the evaluation study. The knowledge user and connectors at connector organizations were merged into one group for our evaluation indicated by the black rectangle. The study participants in this figure refer to the OPTimise study participants who were interviewed regarding vaccine uptake, barriers and facilitators

"patient" with "community" in the PEIRS-22 survey. No formal validation was conducted but the PEIRS-22 has previously been adapted in a similar manner with review by survey developers [24].

Individual and focus group interviews (FGs)

Interviews were conducted by evaluation team members and lasted 30–60 min with participants as shown in Table 3; translators were available to help some participants fully express their thoughts. Participants selected interview timeslots from a list, which meant that some timeslots only had one participant and were conducted as interviews to facilitate schedules. The interview guide is available as a supplemental file. We shared the interview and focus group questions with OPTimise project staff to ensure clarity and that the use of terms would be familiar

Table 3 Description of the evaluation participant groups and enrollment numbers

Name of Group	Groups	Total Number of Participants	Number of Participants Recruited to Interviews	Invited to
Community leaders	3 A group for each site	6 for site O 8 for site T 7 for site P	5 Site O 6 Site T 4 Site P	Interview, Survey
Citizen partners	1	2	2	Interview, Survey
Knowledge Users and Connectors	1 Only Site O due to the nature of the engagement process	10 for Site O	3 Site O	Interview
Methods researchers	1	2	2	Interview

to our study participants. Interviews were facilitated by a researcher, audio-recorded, and transcribed verbatim. The interviews focused on relationship management, supporting processes, power sharing, satisfaction with operations, impact and long-term commitment.

Data analysis

Quantitative data from the PEIRS-22 survey were analyzed through a percent-based scoring metric according to the PEIRS-22 scoring system [25]. Data were exported from the Qualtrics survey tool to Microsoft Excel. Collective mean scores, standard deviations and quantitative analysis was done using Microsoft Excel. As a result, three levels were characterized by the mean scores and standard deviations. Subscale means and standard deviations were calculated. Overall engagement levels were demonstrated by frequency distributions.

Qualitative data from the interviews and FGs were extracted, transcribed verbatim, de-identified and uploaded into an Excel matrix and coded using inductive and deductive framework analysis [31, 32]. Interview themes and outcomes were based on our extensive experience doing partnered research and drawing on reviews of the literature [33, 34]. EP and AK reviewed a sub-set of transcripts together and decided on sub-themes based on the data and research aim. We then discussed the findings with IDG for confirmability. Deductive themes were based on the questions asked during the interviews and FGs (relationship management, supporting processes, power sharing, satisfaction with operations, impact and long-term commitment), with subthemes arising inductively.

Results

Quantitative

Twenty-three participants were invited to respond to complete the PIERS-22 survey. Twenty-two (96%) responded, of which one declined to participate and two did not fully complete the survey. Therefore, a total of 19 (83%) complete responses were captured.

The mean PEIRS-22 score was 92.46 (SD =9.24). This value is above the "Extremely Meaningful" cutoff point and falls within its standard deviation (SD) suggesting that the level of engagement was extremely meaningful, as shown in Fig. 3. The PEIRS-22 developers recommend that survey users direct their attention to individual scores rather than the group mean score. All individuals provided neutral or positive responses.

For each of the seven PEIRS framework domains we calculated the mean scores [25] shown in Fig. 4. The highest score was found on the Feel Valued domain, followed by the Team Environment and Interaction, Support, Contributions and Benefits domains. The lowest scores were found on the Convenience and Procedural domains.

Qualitative

Individuals from all four groups were invited to participate in interviews as shown in Table 3. A total of 35 participants were invited to join an interview or FG with 22 participants (63%) completing an interview or FG. The community leader group was split into three distinct groups based on site, for a total of six interviews as demonstrated in Table 3. Five of the six (83.3%) invited Site O community leaders, six of the eight (75%) Site T community leaders, and four of the seven (57%) Site P community leaders participated in interviews or FGs. Two of two (100%) citizen partners participated in FGs. Three of the 10 (30%) Site O knowledge users and connectors participated with one representing the PHU and the other two from connector organizations. Two of two (100%) of the methods researchers participated in interviews.

In the following sections are the themes from each of the four groups in the study. First, are all of the themes from the community leader interviews followed by citizen partners, then knowledge user and connectors, and methods researchers. Our intention was to analyze the data for the three sites separately due to anticipated differences in processes and experiences of engagement at the different sites. During data analysis the findings

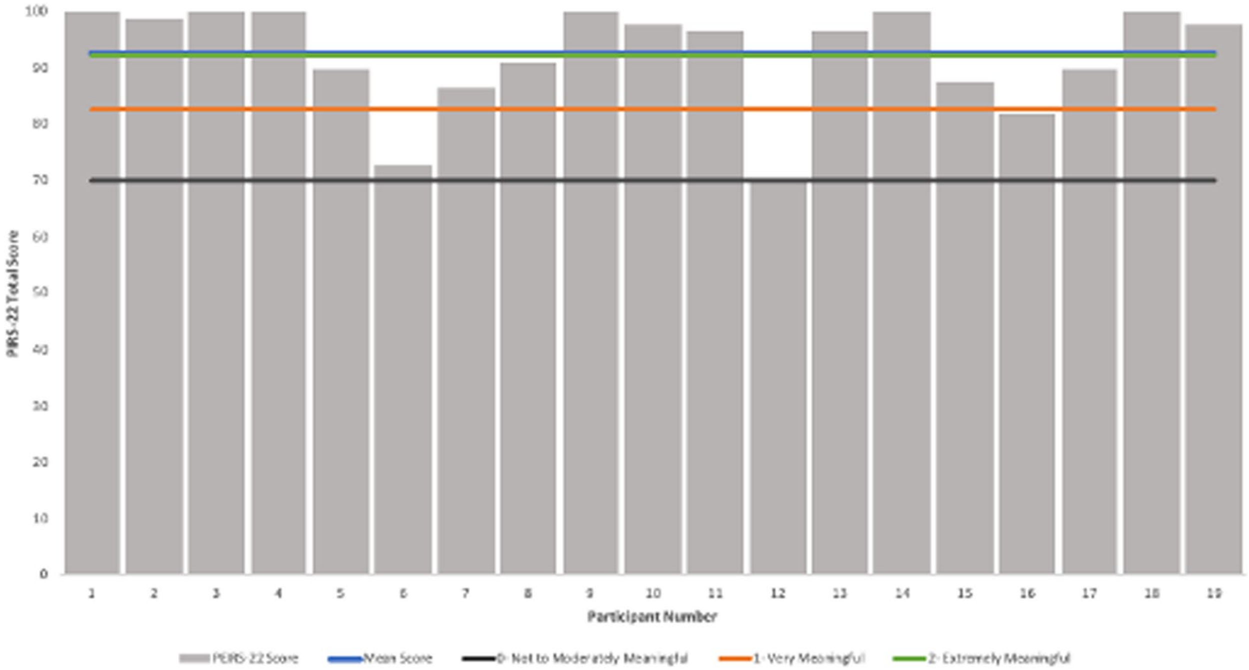


Fig. 3 Citizen leader and community partner scores for global meaningful engagement, using the modified PEIRS-22

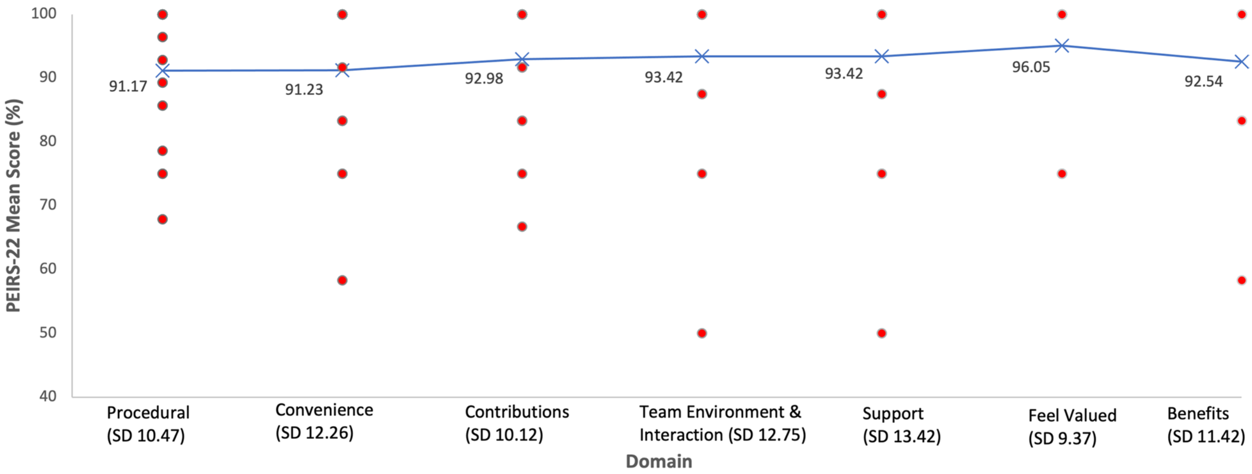


Fig. 4 Scatter plot of citizen partner and community leader scores by modified PEIRS-22 domains

demonstrated overwhelming convergence. Therefore, analysis of the three sites is done together with differences between sites noted. Table 4 provides an overview of the qualitative themes and sub-themes, if applicable, for each group. The interview questions asked about impact and long-term commitment however no themes were identified. Representative quotes for the themes are available from the corresponding author upon request.

Our interpretation of the themes in Table 4 follow. Relationship management is the way that the OPTimise project team interacted with, communicated and shared information. Supporting Processes refer to the facilitators of engagement. Power sharing includes the ways that the OPTimise project team established equitable environments and relationships with participants. Satisfaction with operations refers to how participants felt about technical logistics of OPTimise study participation. The themes were derived from piloting. Sub themes are aspects of the themes.

Table 4 Overview of qualitative themes and sub-themes

Group	Themes	Sub-themes
Community Leader	Relationship management	Trust, demeanor, overall positive interactions
	Supporting Processes	Compensation, language, in-person relationship building
	Power Sharing	Joining the study, listening, power sharing, value and respect
	Satisfaction with Operations	Clarity and detail, time, meetings, communication, overall satisfaction
Citizen Partners	Relationship Management	Trust, demeanor, overall positive interactions
	Supporting Processes	None identified
	Power Sharing	Joining the study, power sharing, value
	Satisfaction with Operations	Meetings, time, overall satisfaction with operations
Knowledge Users and Connectors	Relationship Management	None Identified
	Supporting Processes	None Identified
	Power Sharing	
	Satisfaction with Operations	Meetings, Time, Clarity, Communication
Methods Researchers	None Identified	None Identified

Community leader themes

Relationship management

Trust Community leaders reported that having an initial connection from a connector organization, knowledge user, or another community leader helped spark their interest in the study. Community leaders identified that trust building required connection and building relationships organically. Some examples include having conversations not directly related to the research study and showing genuine interest in each other. Another method used for trust building was through one-on-one phone calls and emails between community leaders and OPTimise research team members prior to the group meetings. Throughout the process, there was agreement that the group meeting space was safe and even if a community leader had divergent views, did not feel judged. This safe space helped to build trust especially on a topic like COVID-19 vaccination which already had mistrust associated with it.

Community leaders at Site T shared that in diverse communities building trusting relationships can be more challenging due to historical traumas. Some suggested that the research team could have learned more about the community prior to starting any activities on the engagement continuum to overcome historical trauma and build trust faster. This was emphasized at Site T, where the focus was on Black communities, and it took more time for trust to develop.

Demeanor The team created an atmosphere described as open, friendly and honest. Several community leaders said that working with the OPTimise research team felt like talking with a friend or neighbor. During meetings there was space for introductions and sharing how everyone was doing personally. Throughout the study, respectful safe environments were created by leading by example. Even when different personalities or perspectives were shared the team would keep the peace by not arguing or debating among themselves. The setting was described as informal but professional.

Overall positive interactions Overall, trust was built through a series of actions and interactions. Team members made themselves very available to answer questions by phone or email. Meetings were carefully moderated to include everyone. This created relationships where some community leaders said they would miss the team when the study was over.

Community leaders at Site T highlighted that the research team demonstrated learning by ending the study with some slides celebrating Black History Month. This was an unnecessary but positive act that stood out to them and felt authentic.

Supporting processes

Compensation At site T, community leaders felt that monetary compensation was not the only factor influencing their decision to join the study, but it was appreciated and demonstrated the value of their time and expertise. Similarly, at Site P, monetary compensation was one factor influencing community leaders to join the study by valuing their ideas, opinions and time. But at site P another compensation method was also valued, reference letters to apply for permanent residency status. Two participants at site P also noted that they would not have participated, or reduced their involvement had there been no monetary compensation. The topic of compensation did not come up with site O.

Language At Site O community leaders identified that research team members who spoke both English and French, as well as a translator, supported their interactions since the community leaders spoke multiple languages. The community leaders also supported the research process at Sites O and P by ensuring communications were culturally appropriate when translated professionally and by speaking the languages of the communities they were engaging. A community leader at Site P acted as an interpreter for interviews, if needed, which they noted was a good learning experience. Language did not come up at Site T.

In-person relationship building Most of the core research team were based in the same city as site O. This allowed for some one-on-one in-person interactions with community leaders when needed. For example, researchers delivered flyers to some community leaders' homes for them to distribute into the community. This activity helped build relationships between the research team and some community leaders. At Site T, some community leaders understood that due to COVID-19 in-person activities were limited but believed that the relationship-building would have been stronger had the team visited their community and became immersed in their spaces. This was not directly discussed with community leaders at Site P.

Power sharing

Joining the study Across the three sites community leaders joined the study primarily through another connection. Several community leaders found out about the study through organizations they work or volunteer for. This connecting organization often provided flyers and discussed the opportunity with the community leader. Many also learned about the study from individuals known to them who were previously part of the study, for example, through a community leader already in the OPTimise study or through connections with the OPTimise research team members. This connection was crucial for some as they initially did not see the value in discussing COVID-19 at that time.

Listening There was an overwhelming consensus among the community leaders across the sites that they were listened to by the research team. The OPTimise research team asked for feedback, elicited diverse responses, and acted on the feedback they received. Some community leaders indicated that members of the research team were listening to them even when discussing more personal or non-research related ideas.

Power sharing Across the three sites there was a consensus that all input mattered and was important to the OPTimise research team. At Site O, a community leader highlighted that the team did not act as an all-knowing entity but created a comfortable space for working together. At Site T, the community leaders really felt like they were more than just information sources. There was a need to work together and be leaders since they know their community best. The research team also emphasized the voluntary nature of the work and that community leaders were not forced to be there or continue with the work.

Value and respect Across all sites community leaders reported feeling valued for their contributions to the study and respected. One participant mentioned being able to see the contributions of the community leaders in the final research recommendations which they interpreted as their contributions having been valued.

Satisfaction with operations

Clarity and detail Community leaders agreed that they were well informed about the scope and processes of the OPTimise study. They had opportunities for one-on-one discussions to understand the study processes, and had information provided by email as well. The first meeting of the study covered the scope and process of the study as well as the team's backgrounds. The community leaders reported having minimal understanding of the OPTimise research methodology.

Time There was a sense that the timing of the study was well-managed. The research team contacted community leaders by email and/or phone to select the meeting time for each monthly meeting. This promoted the flexibility and inclusion of as many community leaders as possible. Community leaders noted that the research team always ended meetings on time. At Sites O and P participants noted that the use of meeting time could have been more efficient and extending the meeting time by 15–30 min could have helped ensure that all the material was fully covered in the meetings. At Site T, one participant noted that they knew people who did not join the study because monthly research meetings were too much of a time commitment, especially for those who were leaders in their communities.

Meetings OPTimise study meetings for all three sites occurred virtually using Zoom. Community leaders found virtual meetings highly convenient especially around work, transportation and parenting schedules. During the meetings, community leaders liked being able to turn their cameras off. Community leaders appreciated having time to interact and get to know each other especially at the first meeting. Meetings were perceived to be interactive and allowed for open discussions. Breakout rooms were used from time to time and facilitated by a research team member to increase opportunities for sharing.

Communication Communication included the monthly zoom meetings, email communications and phone calls. One-on-one communications matched the preferences of community leaders. Community leaders at all sites mentioned high rates of communication from the team but were satisfied with the amount. Reminder emails were appreciated for upcoming meetings. Community leaders felt that the research team were quick to respond. Multiple research team members were identified by different community leaders as having excellent communication skills. At Site T, one community leader noted the importance of the meeting minutes to understand what happened at a meeting especially if they had to miss a meeting.

Overall satisfaction

All of the community leaders were highly satisfied with their participation in the OPTimise study. Many found it challenging to give suggestions for improvements due to being highly satisfied with their participation while others indicated that the team learned and incorporated feedback during the study. One suggestion for improvement was to have more OPTimise study community leaders and participant interviews to reflect more of the community.

Community leaders reflected on the following factors which made their experience highly satisfactory: the calming demeanor of the research team who led by example, the willingness to adapt and listen to feedback, the desire of the research team to learn and support the communities, creating a safe space to share different perspectives and the diversity of people engaged.

Citizen partners

The engagement level of two citizen partners in the study can be classified as lead using the Levels of Public and Patient Participation in Health Research classification system for the engagement plan and execution of the OPTimise study. One with an extensive history as a patient and community advisor in research, and the other a nurse and researcher who had previously led other community engagement studies.

Relationship management

Trust Citizen partners suggested that building trust required discussing and clearly outlining the roles for the OPTimise study especially since many people were part of the study. Throughout the study, good working relationships were built especially during times when a citizen partner brought forward an issue. One citizen partner pointed out that without trust they could and would choose to work on a different study. The PI is key in building trust and creating relationships with citizens engaged in research. One strategy for building trust in this case was having a patient and academic citizen partner on the research team. The citizen partners supported each other with their expertise and discussed together before bringing their ideas to the larger research team and implementing their ideas.

Demeanor A citizen partner shared that the PI set the tone and atmosphere for the study and building relationships with citizens. The PI needed to be visible and approachable. The PI for this study constantly checked in with the citizen partners and was willing to be adaptable. The citizen partners felt that the PI was cognizant of their time and desire to participate in the study. For example, the PI realized that the scope of commitment for citizen partners increased beyond their initial agreements during grant writing. But the PI consistently checked in with citizen partners to ensure that they were still comfortable with their duties and time commitment.

Overall positive interactions Overall, the relationship between the citizen partners and the rest of the research team developed positively throughout the study and in different ways as capacity varied. In the first two sites, (sites O and T) the citizen partners led the engagement with the researchers. This involved creating the engagement strategy, working with community leaders directly, presenting with the researchers during meetings and being part of the working groups for the OPTimise study. With the last site, (site P) both citizen partners took on less of an upfront role with the community leaders, but they still felt informed and involved in decisions being made. This led to a united research team inclusive of the citizen partners. Citizen partners felt that the research benefited from a diverse research team with people of varying ages, languages, gender identities and expertise.

Supporting processes One citizen partner saw their role as a bridge between researchers and the community, the other was a nurse who has conducted post-doctoral research with community engagement. They worked together on developing the engagement strategy for the study and divided up their work promptly (one focusing on site O, one on site T, and both on P with lessons learned from site O and site T).

The citizen partners lead the development of the Community Engagement strategy and agreed that different levels of engagement for community leaders across sites and OPTimise study participants were acceptable based on the activities each community leader was interested in engaging in. Some community leaders wanted different engagement levels in the research process, so the citizen partners and researchers tried to accommodate their preferred level of engagement rather than prescribe it. Citizen partners provided much input and led the engagement strategy for the research. Throughout the study they had to adapt along the way as different communities preferred different levels of engagement.

Power sharing

Joining the study Both citizen partners had a connection via collaboration on other studies with the researchers on the research team prior to joining. They were both included in grant writing to bring their experience in community engagement to the study.

Power sharing Both citizen partners agreed that they saw themselves as part of the research team. Although the (non-academic) citizen partner said that it was not guaranteed that they would be part of the team rather it was due to the actions of everyone in the study. They felt like an equal leader and that the team mitigated power imbalances wherever possible by making decisions together in weekly meetings, sharing who led meetings with community leaders, and developing and refining the engagement framework used in the study.

Value Both citizen partners felt like their contributions were valued. The researchers made it clear that the citizen partners were valued by verbalizing the impact of their contributions and keeping communication open. The citizen partners co-wrote a paper from their perspective on the community engagement aspects of the research study [28].

Satisfaction with operations

Meetings The citizen partners were engaged in weekly team meetings but did more than just provide advice or guidance on community engagement. They also helped develop slides, supported plain language document creation, communicated with community leaders, and led meetings with community leaders especially at Sites O and T. The weekly meetings also functioned as a form of capacity building of research and engagement skills for the citizen partners by being able to work through challenges faced in the study together as a team.

Time Citizen partners perceived that there was flexibility throughout the study which enabled them to contribute the time they had. Other research team members could take on more of the work when needed to match the capacity of the citizen partners while still maintaining active engagement for the engagement approach and being informed during the entire study.

Overall satisfaction with operations

The citizen partners reported that the study balanced theoretical and practical applications well. Recruiting people to be community leaders from equity deserving groups was a rewarding experience requiring different strategies for engagement. This led to a nurturing environment where the citizen partners felt like they were learning and working together on ideas pertaining to engagement. Citizen partners were not just being told what to do but led the engagement work through exchange of ideas and decision-making. Citizen partners sometimes had emotional responses from their participation in the study due to feeling the importance of the work and the chance that the community leaders might engage in future research studies due to their positive experiences in this study.

Knowledge users and connectors

For Site O there was another formalized step in the engagement process involving a PHU KU sharing the OPTimise study proposal with Connectors at community organizations. Those connectors then met with OPTimise study staff to learn more about the study prior to making connections between the OPTimise research team and Community Leaders.

Relationship management The research team connected with the Site O PHU and spoke with the person responsible for community engagement. They got consulted due to the depth of community connection being sought in this study. The PHU KU trusted the research team, so they connected them to connector agencies. Although, ideally had more time been available it might have strengthened the relationships between the PHU and research team and made them deeper.

The connectors felt connected to the research study due to the linkage and endorsement from the KU who they already had a relationship with. Getting the invitation to support the research study from a trusted source facilitated their joining the study. The connectors felt that they played a similar role with community leaders. Since community leaders had a pre-existing relationship with them, the community leaders may have been more likely to join the research study. One area for improvement identified by the connectors would be to provide clearer expectations about their role and their level of engagement with the study. One connector was not aware that after they made connections between the research team and community leaders their engagement would be limited to receiving updates. They indicated wanting to be further engaged throughout the project. This reduced connector engagement to the inform level for the remainder of the study.

Supporting processes The KU felt that the researchers were genuinely interested in the community which led them to be involved in the OPTimise study. They felt that the warm referral process enhanced the chances of connectors participating in comparison to an email from a researcher unknown to the connectors. Additionally, other factors considered by connectors in deciding to engage in the study were the legitimacy of the study, the ethics proposal, endorsements, compensation for community leaders, and having a concise description of the study to be able to forward to community leaders after an initial phone call.

Another area of improvement related to the process of sharing the study results with community leaders. A clear plan was identified by the research team for writing an academic paper and a brief to be used by Public Health to support their work. However, the connectors and KU were unaware of a summary being shared with the community leaders. Although there was acknowledgment that it may have happened without their awareness or be in development.

Power sharing The KU and Connectors felt like they were the gatekeepers to the community leaders. Having the steps in the process with the researchers meeting with Public Health and Connectors added protective factors to the study prior to engaging with the community directly. Some of the challenges with the study were the language and terms used were not always the same as the language used on the ground. The language dynamics inherently created an unequal power dynamic. But the research team was accepting of feedback and changed language based on the KU and connectors' recommendations making them feel valued and listened to and reduced power dynamics.

Satisfaction with operations

Meetings All study interactions were virtual which was understood since the research was conducted during COVID-19 and virtual meetings were highly accessible for many.

Time Connectors appreciated that their involvement was limited due to having many other roles and responsibilities. The timing of the study was also supportive because their involvement happened in the summer when many other meetings are not happening. This improved their capacity to be part of the study. When there were changes to study timelines, such as a delayed start due to recruitment of community leaders being slower than anticipated, connectors felt like they were appropriately kept informed.

Clarity Connectors and the KU felt up to date on the study and that expectations were clearly defined. An area that was less clear was the roles of all members on the OPTimise study team since there were many people engaged although it was not reported to hinder the work.

Communication Connectors shared that the study was clearly laid out to them by the research team. But it took mental capacity to comprehend due to the complexity of the study. This was seen as a challenge since connectors were already operating over-capacity due to Covid-19 and the nature of their roles. The research team could have worked to have been even more diligent in keeping connectors and the PHU KU more connected to the OPTimise study as it progressed. Responses and updates on the study were reported by connectors and the knowledge user to be professional and timely. Meetings and emails were reported by the connectors and knowledge user to be effective methods of communication. One person suggested creating a supporting document that outlined the names and roles of each person engaged in the study to improve clarity due to the size of the team.

Methods researchers group

Methods researcher participants reported positive experiences with all themes. One noted that they had worked together and with the PI for 10 +years. The methods researchers shared that they viewed relationship building as part of the process of developing trust. The methods group led the development and implementation of the methods for the OPTimise study. They felt that all team members had space to contribute, researcher and non-researcher throughout the study.

Discussion

We evaluated the engagement processes used during the OPTimise research study, and the qualitative data from the interviews were mapped to the Levels of Patient and Researcher Engagement in Health Research Scale. Then the quantitative data were mapped to PEIRS-22 levels of meaningful engagement (see Table 1). First, we outline how the PEIRS-22 survey and interview data related to each other. From this, three main observations and recommendations emerged related to the types and experiences of engagement in the OPTimise study: 1) the value of trust building, power and credibility, 2) the importance of relationships especially for recruitment of community leaders, citizen partners, knowledge users, and connector organizations 3) the role of the Connector Organization. Finally, we related the engagement of different groups in the OPTimise study through the PEIRS-22 survey to the Levels of Patient and Researcher Engagement in the Health Research Scale, finding different levels of engagement with different groups.

Relating the PEIRS-22 survey and interview data

The results of the PEIRS-22 survey and the interview data suggest high levels of engagement according to PEIRS and satisfaction with the OPTimise study. The PEIRS-22 domain with the highest mean level of engagement is "Feels Valued." This was confirmed in interview discussions in which many participants reflected on their experience of feeling valued in the study, demonstrated through the research team incorporating their suggestions in future work. These findings are very similar to the experiences of a hospital advisory panel of community members who made recommendations to the hospital board that were accepted [35]. Seeing most of the recommendations be put into action allowed the community members to see the impact of their efforts. Alternatively, if leaders are unable or willing to incorporate community feedback then it can lead to disengagement [36].

The two lowest domains on the PEIRS-22 survey were "Convenience" and "Procedural." The *convenience* domain examines contributions during the study through statements about the ability to determine study tasks, having enough time to complete tasks and opportunities to share their views [25]. During interviews some community leaders shared that there was not enough time during meetings to get through all of the planned topics which may have somewhat limited their ability to share their views. The *procedural* domain examines participants' experiences in the study generally through statements about proper introductions of research team members and participants, generally having enough opportunities to contribute, being able to perform their tasks, participating in decision-making, receiving updates on the study status, clear communication and understanding if participants felt the study was worth the time they spent on it [25]. During the interviews some participants mentioned that the study required a large time commitment which hindered the ability for some to participate in the study, further supporting the lower procedural domain score. This study identified a tension between providing enough meeting time to contribute satisfactorily while at the same time not overburdening participants with the time required to participate in the study as a whole. Due to the anonymous nature of the survey, we were not able to do a more nuanced analysis of specific group responses.

Common takeaways from individual and focus group interviews

Trust building, power and credibility

Building trust virtually required time because participants first needed to understand the intentions of the study. Then, trust was earned through each interaction. This process was time-consuming because it needed to happen organically, not only by doing research but also through genuine relationship building including one-on-one conversations. Throughout the study trust was continually earned and built, e.g., each safe interaction, especially when differing views were expressed, built trust. Others have also noted that trust is built up through interactions including hosting meetings at convenient times, considering the language needs of those engaged and cultural sensitivity [37–39]. The demeanor of the team to lead by example as open, friendly and with active listening was key. Participants perceived that the PI ultimately set the tone for the researcher team, which influenced the citizen partners, and cascaded throughout the study. A panel experienced in community engagement in health and social settings also identified having one professional leader as the main contact for information and support throughout an engagement opportunity [40]. Being able to choose to leave the study if it did not suit them also gave a sense of power. Compensating citizen and community leaders contributed to their willingness to participate, initiating trust at the beginning. But it also showed the leaders that they were valued and seen as credible resulting in power being shared.

Black communities at Site T identified trust building as being even harder due to historical trauma. Marginalized communities were hit hard during COVID-19 making it even more important to engage carefully with them [16, 19]. Others have found that people from equity-deserving communities may need more time, relationship, and skill-building to create the trust needed to use their voice in engagement opportunities which was also evident in our findings [16, 39]. Community leaders recommended that researchers truly understand and learn about traumatic histories prior to trying to engage with diverse groups.

Relationships are key for the recruitment of community leaders, citizen partners, knowledge users, and connector organizations

Forming the citizen partner and methods research groups utilized pre-existing relationships with the PI of the research team. Having this history sped up the process of trust and understanding of how they work well together. Similarly, at Site O there was a clear connection between the different groups engaged. At Site O, these pre-existing linkages facilitated the recruitment of Community Leaders. Other studies have similarly recruited from pre-existing linkages [40–42]. Further, having citizen partners as part of the research team may have aided the recruitment of citizen partners as previous studies have shown including community members to inform recruitment is a facilitating factor for recruitment [43, 44].

At Sites T and P, the pathway of relationship building was less clear. The PHU KUs did not have pre-existing relationships with organizations serving the target populations for this study. This led to the research team needing to build relationships directly with Community Leaders organically. The process was slower and citizen partners and research team members built relationships with different organizations who eventually shared the study with their communities. At Sites T and P, many of the Community Leaders who joined mentioned knowing someone else participating or learning about the opportunity through work, school or volunteering. As noted by others, relationship building is essential to successfully recruit individuals from equity deserving populations into studies [36–39].

The connector organizations

This study identified an important intermediary organization that was crucial for working with some communities: the Connector Organization. Connector Organizations involve individuals working at community organizations who are connected to community leaders. (e.g., Community Resource Centers and Community Health Centers). The PHU KU frequently works with research institutions and Connector Organizations. The KU used their relationships with members at Connector Organizations to share the OPTimise study and link them to the research team. We only were able to speak with a few Connector Organization members, but they shared that the endorsement from the Knowledge User they already had a relationship with was key. This was due to prioritizing putting the time into this work when their roles are quite demanding, and trusting that the study would be beneficial to the community. Many of the Community Leaders at Site O had connections to the Connector Organizations or other Community Leaders who had already joined. Again, this experience of trusting the recommendation to join the study due to already having a relationship facilitated joining.

Our findings strongly suggest that researchers and practitioners who are trying to reach new communities should work with organizations who have strong ties to these communities. In this way an element of trust and credibility are built in when a connection is made to a community leader, both for the community leader and for the researcher. A link with a Connector Organization can also pave the way for productive future research with these communities [44, 45]. Table 5 contains practical steps and challenges research teams may use when designing engaged research based on the lessons learned by the OPTimise study.

Levels of patient and researcher engagement in health research evaluation

Varying levels of engagement occurred with different groups throughout the study, as shown in Fig. 5. The community leaders were involved over a longer time period. They "work directly with a research team throughout the project" as members who meet regularly for several months (14 p3). The research team and citizen partners went to the meetings prepared with topics and questions of focus to get feedback from the community leaders primarily relating to engagement with the OPTimise study participants.

Citizen partners lead engagement by making "final decisions and lead research activities" (14 p3). Citizen partners identified themselves as leading the engagement work with community leaders in two of the sites (O and P) but had less to do with the research methods and analysis. They described their experience and expertise as being more aligned with leading the engagement steering committee work. One of the citizen partners was a co-investigator in grant writing and both lead in

Table 5 Practical steps and challenges for implementing engagement in research

Relationship Management	
Practical Steps	***Challenges***
Prior to the start of the study, sufficient time is needed to contact connector organisations to establish a relationship with them	Trust building with connector organizations may be limited if done late within research process and consequently limit buy-in from research participants
Initial contact with research participants should be facilitated by a connector organization that has strong ties to the community of interest	Thorough pre-research must be done to identify appropriate connector organizations. Failure to identify the correct organizations may limit buy-in from research participants
Consider usage of citizen partner(s) on the research team for increased trust building with research participants	Identifying the appropriate citizen partner who is also relevant to the community of interest is essential
Invest in developing authentic relationships with research participants that does not solely focus on the research study	This requires extensive time commitments and availability of the research team to be able communicate via research participants' preferred ways
Focus on creation of a safe space for meetings	Requires knowledge of the context of research participants and any historical trauma related to research
The PI and research team are responsible for setting the demeanor with research participants. There should be a focus on creating an open, inclusive, safe and professional environment	The way in which the environment is set is context-specific to research participants. It requires flexibility and adaptability by the research team to understand the needs of the participants
The research team needs to be available to answer questions	Can be resource and time intensive to maintain research team availability
Ending the study with a community-relevant event highlights appreciation of the research participants' project commitment	A social event post-study requires additional resources
Supporting Processes	
Practical Steps	***Challenges***
Pre-existing relationships with citizen partner and connector organizations can be leveraged for recruiting them to the study to support research participant recruitment	Limited pre-existing relationships with external research members such as citizen partners or connector organizations may hinder recruitment processes
Consider community-specific methods of outreach and compensation to maximize participant enrolment	Requires extensive knowledge of communities and may require additional resources
Language(s) used in the research community of interest should be considered when facilitating interactions	Requires investment of resources, i.e. translators
Some in-person attendance of core research team is recommended	Based on time and availability of core research team
Development of community engagement strategy should be led by citizen partners if possible	Engagement may vary by research participants. The research team should be accommodating to the desired level of engagement
Genuine interest in conducting research with research participants should be demonstrated when possible	Disingenuous pursuits with research community are likely to be noted and harm the relationship between researcher and participant
To increase buy-in of connector organisations, share characteristics of the study within a formal document including: - Legitimacy of the study - Ethic proposal - Endorsements - Compensation - Concise description	N/A
Power Sharing	
Practical Steps	***Challenges***
Role and expectations of connector organisations within the study should be clarified	Unclear expectations may lead to confusion. Scope of commitment from connector organizations may vary, and research team should be mindful of this
Listening and sharing among all members included in the research is necessary. Sufficient time is needed for thorough discussion given that trust-building is continual and has to be maintained	Research processes should not overburden research participants
Including contributions of the research participants in the final recommendations is necessary	Careful consideration as to what should be included in final recommendations to balance everyone's needs and concerns
Value should be prescribed to external research groups (i.e. citizen partners) within research processes	N/A
Tailor language used by core research team members to the language used by external research members and research participants	Failure to do so may result in unequal power imbalances and confusion
Satisfaction with Operations	
Practical Steps	***Challenges and Drawbacks***
Identify and describe the roles of all members of the team	Clear outline of roles should be specified to limit confusion

Table 5 (continued)

Describe all study processes and background of all members on the research team	This is a lengthy process; sufficient time should be given for these preliminaries before the start of the study
Consider meeting on a timely basis (monthly, bi-weekly) via preferred methods identified by research participants (Zoom, in-person)	Ensure efficient use of time to cover all necessary material. Be aware that lengthy meetings may dissuade research participants to commit to the study
Interactivity for meeting should be considered	Interactivity may lead to longer sessions
Communication should be continual and relevant	There is a trade-off on what is the appropriate amount of communication is without overburdening research participants
Consider asking citizen partners to develop documents supplied to research participants	Requires more engagement from citizen partners

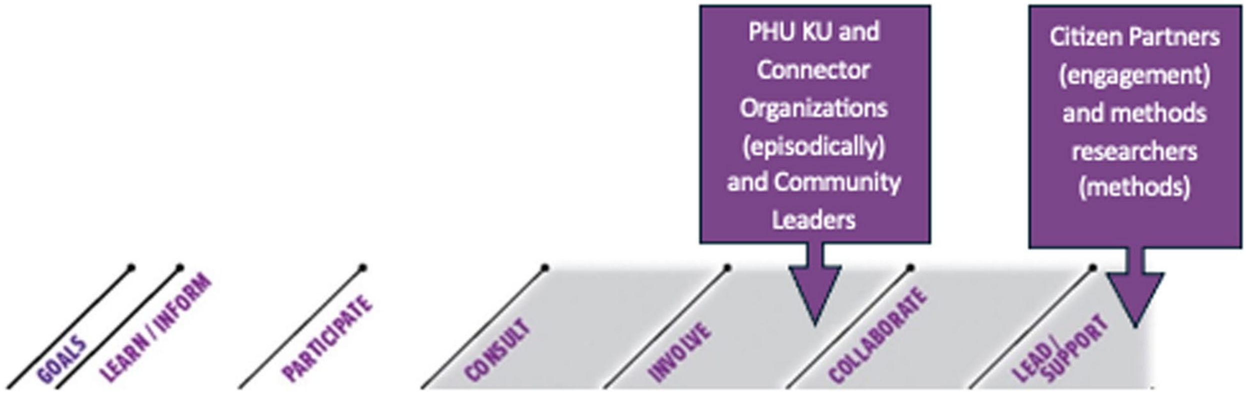


Fig. 5 Cropped levels of patient and researcher engagement in health research. Framework adapted from Amirav et al. [13] and Vandall-Walker [14] with the engagement levels of the study groups added. Citizen partners and methods researchers were added to the "lead" level for their areas of focus which are engagement and methods respectively, community leaders to the "involve" level, and KU and connectors to the "involve" level episodically

the engagement steering committee. Overall, the citizen partners were engaged throughout the study and worked at the level of lead on specific components of research.

The PHU KU and connectors were involved episodically throughout the OPTimise study. For specific periods they provided feedback on the recruitment of community leaders for the research and the PHU KU was involved in grant writing. This was done through different methods at each of the three sites but was always time-limited in certain phases of the project.

The methods researcher group lead with the research team on the methods and analysis of the research project.

The evaluation reveals that differing levels of engagement occurred with different groups at different periods in the OPTimise study lifecycle. Some are further to the right of the engagement continuum than others and more frequent. However, all groups were very satisfied with their level of engagement. This highlights the need for different levels of engagement and time commitments in research. Moving further left on the engagement continuum to episodic involvement has benefits such as the limited time commitment needed. For groups like the connector organizations, many said that if more time was required, they would not have been able to participate at all.

Strengths and limitations

This evaluation has several strengths. Multiple groups were invited to participate in the evaluation including community leaders, citizen partners, knowledge users and connectors and methods researchers. This allowed for a fuller picture of the types and experiences of engagement across different groups. The evaluation included three OPTimise study sites to identify similarities and differences in engagement practices across different geographies and sociodemographic groups.

This evaluation has several limitations. Ideally the recruitment of some of the groups invited to participate in the evaluation (e.g., KUs and connectors) could have been larger. Additionally, some time had passed between some group's engagement with OPTimise and the external evaluation interviews. This may have affected their recall of what occurred during the OPTimise study. The evaluation did not have a patient or community partner as part of the evaluation team. A community partner may have refined our methods, data collection or analysis. The PEIRS-22 surveys were conducted anonymously so there is no way to directly compare survey data with interviews.

The arm's length nature of the evaluation was a methodological strength but also a weakness in that we, the new evaluation team, had limited time to build trust with evaluation participants. Nevertheless, it allowed data collection and analysis to be independent from the OPTimise study research team so study participants could more freely express their perspectives during interviews and surveys.

Conclusion

Evaluation participants generally felt that they were engaged meaningfully in the OPTimise study, as demonstrated through the PEIRS-22 survey and qualitative data. Community leaders were involved in the OPTimise study, citizen partners led engagement, KU and connectors were involved for episodic periods of time, and methods researchers led the methods and analysis. Many different engagement processes were successfully designed and used to meet the needs of the communities and the research objectives. The OPTimise research team was able to lead by example by providing a safe environment for all OPTimise participants where trust could be earned over time. A key takeaway of this evaluation is that relationships were key, especially in the early phases of the OPTimise study. Pre-existing relationships with the methods researchers and citizen partners allowed for early engagement.

Future research should focus on understanding how research teams can speed up the process of building trust with equity deserving communities to optimize their recruitment as study participants. Alternatively, researchers should plan adequate time for meaningful relationship building, especially in diverse communities that may face historical or ongoing traumas. Researchers could do this trust-building work prior to the grant being submitted with equity groups as equal partners rather than waiting until after the grant submission. Once engagement has started researchers should listen to the groups they engage in the research. Demonstrating that they incorporate feedback shows they value those they are working with and this could mitigate some power differentials.

Abbreviations

ABC	African Black and Caribbean
FG	Focus Group
KU	Knowledge User
PEIRS-22	Patient Engagement in Research Scale with 22 questions
PHSM	Public health and safety measures
PHU	Public Health Unit
PI	Principal Investigator
SD	Standard deviation

Supplementary Information

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Supplementary Material 1.

Authors' contributions

EP conducted interviews and FGs, completed data analysis, and was a major contributor to preparing the first draft of the manuscript. AK conducted interviews and FGs, led the concept for the study, supported data analysis, preparing and providing critical comments on the manuscript. IG conducted interviews and FGs, led the concept for the study, preparing and providing critical comments on the manuscript. JP led the OPTimise study, was involved in conceptualizing the evaluation and funding it. All authors approved the final manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The OPTimise evaluation was approved by the Western University Non-Medical Research Ethics Board (NMREB). The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941) and complies with the Helsinki Declaration. Written informed consent was obtained for all participants recruited for qualitative interviews and quantitative surveys.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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