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Using a People-Centred Participatory Approach to Explore Community and Stakeholders' Perceptions to Enable Research Teams to Design Plans that Meet Community Needs

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ABSTRACT

Background and Challenges to Implementation: Community stakeholders' perceptions can influence community members participation in clinical research trials or support the research. It is for this reason that research teams need to have a deep understanding of the communities they research. The Aurum Klerksdorp CRS engages in a people-centred participatory process with the community and stakeholders before engaging in active recruitment activities.

Intervention or Response: The process involves a bottom-up learning process and not a top-down blueprint approach. The diversity and complexities of people and communities were respected and taken into consideration when designing community engagement, recruitment, and retention plans in collaboration with identified key stakeholders. During this process the key stakeholders, as result of established trust, felt comfortable sharing their inputs on the most effective strategies for reaching the community. Research teams enable communities to tailor their own responses to the research, meeting their specific need.

Results/Impact: The co-created plans had a high degree of fit where the research fits into the lives of the people, resulting in better recruitment, accrual, and retention outcomes.

Summary: Adopting a people-centred participatory approach contributes to the enhancement, quality and relevance of the research and increases research literacy in communities.

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Introduction

To successfully implement clinical trials, it is of utmost importance that clinical research sites. (CRS's) facilitate a people-centred participatory process. The Aurum Clinical Research Site Klerksdorp was intentional about rooting our community engagement in a people-centred participatory approach (PCPA). The CRS started where the people were at and built from there, focusing on their strengths and assets. Community stakeholders are important to the research process; without people, research will not be possible. During the COVID-19 pandemic, we witnessed high levels of vaccine hesitancy and mistrust. Amid the COVID-19 pandemic, widespread vaccine hesitancy and mistrust surfaced, fuelled by myths such as the virus being fabricated in a lab, concerns about the safety of rapidly developed vaccines, and the beliefs that vaccines will contain the COVID-19 virus [1]. Community members, through vaccination choices, often communicate not just what they think about vaccines but also who they are, what they value and with whom they identify [2]. Failure to address these views could hinder CRS's ability to recruit people. This makes it necessary for research teams to develop an awareness of the communities we conduct clinical research with. The aim was to use this approach to engage meaningfully, develop a profound understanding and appreciation of the community and stakeholders, and dismantle stigma and misconceptions. This article discusses how the community engagement team (CET) facilitated a PCPA and how this approach can benefit clinical research and lead to meaningful engagement. Meaningful community engagement enhances the quality and relevance of research [3]. Meaningful stakeholder engagement occurs at all stages of the clinical research life cycle [4].

The People-Centred Participatory Approach

The community is a holistic organism that includes its experiences and perceptions, values, attitudes, behaviour, emotions, ideas, aspirations, and meanings that are all interrelated [5]. The PCPA places people at the centre of interventions and promotes the building of authentic relationships. Authentic relationships are important in facilitating clinical research with community stakeholders. It is not only about putting people first but also about using people first language which is language that does not objectify or exclude people. The PCPA facilitates processes where community stakeholders are not passive but active participants in the research process. People are treated with respect and

dignity; they are not viewed as objects, but there is a genuine acknowledgement that community is made up of perceptions, views, values, beliefs and experiences [7].

People are interconnected and cannot be separated from their culture, values, beliefs and relationships [5]. The PCPA is humanistic, respects people, and focuses on the capabilities of people, not their limitations [6]. The CET did not focus on the barriers and limitations, for example, vaccine hesitancy myths and limited knowledge on research but viewed these as opportunities for learning. In participatory community practice, the people, their experiences, perceptions, and values are central [5]. People-centred community practice requires change that is intentional and behaviour that is goal-directed. Behaviour is accompanied by emotions, and strong emotions will lead to action for change [6]. An illustration of this during the COVID-19 pandemic: individuals older than 60 years felt strongly about COVID-19 and did not deny its existence as they may have personally experienced the loss of loved ones and acquired COVID-19 themselves. When engaging with older people, the CET was able to build on this to develop a shared belief. To understand the emotions of people with regards to certain issues such as clinical research, vaccines, HIV and TB, it is vital for CET to build sustainable relationships with people that are grounded in the PCPA and good participatory practice (GPP) principles. The GPP principles are described as trust, integrity, respect, autonomy, and transparency. The process starts with how the CET enters communities. The entrance into communities was carefully planned and negotiated.

Negotiating Entry

The CRS carefully planned the entrance strategy beforehand. This was achieved by the CET orientation to the surroundings and establishing a plan of entry into the community. The CET avoided making any decisions but kept up to date with useful information and community contacts [8]. Intentionality was placed on not invading communities and the CET avoided taking up the expert role during this phase. The view of stranger was adopted, and the CET continued to be curious about developing a deep understanding of the community [8]. The CET was curious about which relevant and credible organisations to approach. Which individuals in the community are trusted by the people we seek to recruit? How does the community want to be engaged? What are the challenges/ barriers facing the community that may impact autonomous trial participation? During this phase, the CET were able to establish who the influencers, opinion makers and gate keepers were, and a stakeholder matrix was developed which included individuals and organizations that includes key stakeholders in the research life cycle. The stakeholder matrix is updated continuously during the research life cycle.

How the Community Engagement Team Facilitated Participatory People-Centred Engagement

Community engagement is not a once-off event but a process that evolves. The CET created platforms where power and control were given to community and stakeholders to co- lead the process. The CET treated community stakeholders as equals and did not impose or direct the research process. Community stakeholders were trusted to co-lead the research. The CET was serious about placing people first, upholding people's human rights, freedom of speech and learning from the community and stakeholders. It is important to note that apathetic silence may exist in communities where people have been oppressed, placing them at risk of exploitation, especially in South Africa, where people's human rights have been violated by the apartheid regime [9]. It is important for CET to be cognizant of this and not enter communities with the attitude of wanting to change and instruct people. Change should be facilitated with people and is meant to give them power and control. The CET refrained from informing people how the CRS planned to conduct the research but was about creating platforms of mutual learning. Real participation was key, and participation was not just about informing, involving, listening, consulting, or bringing stakeholders on board. This meant creating opportunities for participation, for example, through discussions and small working groups where vaccine misconceptions were explored. The CET acted as catalysts by posing critical questions regarding vaccines and clinical research and encouraging people to engage in dialogue with each other to find their own answers. Dialogues, which included the sharing of ideas and opinions and collectively creating new meanings, were facilitated, and encouraged. The CET supported and initiated events that were focused on people the trials aimed to recruit and enrol, and this also included gatekeepers. The local events were, community meetings, dialogues, society meetings, small group discussions, formal and informal discussions, and stakeholder consultative meetings. Attending the events contributed to a deeper understanding of the trial population and building rapport and how the trial population wanted to be engaged.

The Bottom-Up Process

The PCPA is a bottom-up learning process and not a top-down blueprint approach [10]. What does this mean? The CET did not come to communities with pre-established community engagement, recruitment, or retention plans. Engagement was conducted from the community and key stakeholders' frames of reference which sets a climate for trust [5]. This means engaging community stakeholders when developing plans. This ensures that people are at the centre and that plans have a strong community voice and considers the diversity and complexities of people. Planning from the bottom up and placing people and community stakeholders first results in co-ownership of the research, which is the direct result of participation [5].

Benefits of Applying a People-Centred Participatory Approach

PCPA and community stakeholder participatory participation made it possible for CET to identify limitations, barriers, key stakeholders, and opportunities for growth. Collaborative efforts with key community stakeholders integrated these elements into plans for community engagement, resulting in the development of strategies to address limitations and barriers.

Results

- The CET identified key and influential community leaders, structures, and ward committees' key opinion leaders. Following the identification of community leaders, it is important to arrange a meeting with leaders before consulting the broader community. The purpose of the meeting was to meet the leaders at their level and the CET was able to discover what their understanding is of clinical research and trials, and explored their views on vaccines, clinical research, TB, HIV and COVID-19.
- Displaying respect and openness were towards diverse viewpoints from a wide range of stakeholders, ensured active participation and co-ownership, and enhanced commitment and support.
- Securing the trust and buy in of the leader's made it easier to gain entry to the broader community.
- Gained a deep understanding of community dynamics, including the challenges faced by the community.

- Better understood the roles and responsibilities of each stakeholder and how best each stakeholder can contribute to trial success and the research life cycle.
- An understanding of the structure of each stakeholder, the appropriate protocol, and channels of communication, including who to liaise with, was acquired.
- The identification of areas of collaboration between the CRS and community stakeholders and the establishment of mutually beneficial relationships. This was illustrated during the COVID-19 pandemic, when vaccine hesitancy, ignorance and myths were at an all-time high. The CET viewed this as an opportunity for growth. Ignorance was not viewed as negative but as circumstances in which people do not yet possess an adequate understanding but as an opportunity for change [11]. The CRS mitigated this by partnering with key stakeholders and facilitated social learning opportunities. Doing this assisted with dealing with stigma, mistrust, fear, and misconception. The CRS was able to share accurate information about vaccines and the clinical research process, which was based on evidence. This increased vaccine and clinical research literacy, trust, and confidence in the research process.
- It is important to bear in mind that stakeholders have different interests and to sustain community and stakeholder commitment, a shared belief needs to be developed.

Summary

Placing people first contributes to meaningful community engagement and enhances community stakeholder trust and buy-in in the research process. Social learning opportunities contributed to increased vaccine literacy and clinical research knowledge. When people understand clinical research and how trials are conducted the can participate with autonomy. Co-creating plans with key stakeholders results in co-ownership of the research and research that speaks to people, not at people.

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Conflicts of interest

None

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