Unpacking translational gaps in engaging communities in HIV biomedical research in India.

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Despite the expanding landscape of prevention products, the challenge of HIV prevention continues, demanding more cutting-edge research and new age trial design. Communities have played a critical role in supporting HIV research and will continue to do so. Despite multiple efforts to address gaps in meaningfully engaging communities in HIV prevention research, there are regional and contextual challenges that hinder the translation of recommended best practices like GPP to action. IAVI in India collaborated with C-SHaRP and Quicksand to conduct 11 virtual discussions community representatives and researchers using human-centred tools to understand a) current HIV biomedical research related engagement practices, assess translational gaps in engaging communities across research continuum b) community and researcher expectations and explore the points of convergences and divergences to inform solution design that can help build capacities across stakeholder groups to strengthen participatory practices in research. Our study highlighted for communities constructs of ‘meaningful engagement’ are based on trust, credibility of researchers, feeling valued and respected. Lack of representativeness and familiarity with researchers or lack of reciprocity can lead to distrust. Researchers and community advocates agreed on the need for building research literacy, communication of research benefits, assurance of confidentiality, easing research participation through incentivisation, digital platforms, convenient timings etc. However, more alignment is needed between the two groups on level of engagement across research continuum, especially during trial design and post research credit sharing. Additionally, communities expect improvements in researchers’ non-verbal communication, soft-skills, and their empowerment for effective two-way communication. It was also shared that despite best intent, researchers often lack socio-cultural, community-engagement, communication, user-centred design competencies and need more capacity building is needed in these areas. Also, for communities including CABs, capacity building efforts need to focus on building research and scientific competencies. Future pathways of change need to ensure a) investment in skill-building of researchers and b) understand translational gaps - systemic, process, and capacity gaps c) invest in behaviour change of researchers as well d) invest in capacity building of communities.