HOW CAN SOCIAL SCIENCE BE USED IN COVID-19 CLINICAL AND VACCINE TRIALS?

Conducting research with prospective participants and communities can help understand political and economic dynamics, perceptions of COVID-19, concerns or expectations of clinical research and identification of ethical issues around the trial.

Understanding how trust is gained or lost and who is trusted by identifying both formal authority structures and informal sources of influence to support effective information and engagement campaigns.

Supporting integration of participant and community perspectives into deliberations about aspects of trial design and procedures will ensure these consider specific benefits, concerns and sociocultural context.

Informing community and participant engagement so it does not focus simply on ‘misinformation’ or the need for more information but also sources of mistrust and the potential for dialogue.
LESSONS FROM SOCIAL SCIENCE RESEARCH IN TRIALS DURING OUTBREAKS

Social science research has highlighted broader issues around running clinical trials such as political and economic contexts, engaging relevant communities and prospective participants, perspectives on disease and illness, participant experiences and infrastructure and resources.

Different political systems and economies will raise different questions for the implementation of an emergency response, including for clinical research, e.g. communities’ levels of trust in the health system.

Information about trials should be free flowing from and to communities to sufficiently address issues of (mis)trust and hesitancy, as well as represent community dynamics and needs.

Perceptions and experiences of illness, disease and health affect people’s engagement with clinical research and are important for understanding hesitancy (e.g. relations with different service providers or concerns about COVID-19).

Participants’ hopes and expectations from involvement in clinical research need to be taken seriously as do fears and experiences of stigma or marginalisation.

Staffing of trials, expectations placed on trials by participants and their communities, and the impact of trials on existing health services must be planned for.
WHY IS IT IMPORTANT TO UNDERSTAND THE NEEDS OF RESEARCH PARTICIPANTS?

Community engagement and patient and public involvement in the design, conduct and dissemination of clinical trials is now understood as essential by the global research community.

Engagement with participants is important for ethical research and has a positive impact on quality, uptake, and relevance of research that can contribute to an outbreak response.

Social science can be used to inform good practice community engagement and patient and public involvement efforts by collecting data (through interviews, ethnography, surveys etc.) on societies where trials are conducted.

Given the challenges of conducting clinical trials during outbreaks there is a risk that the concerns of trial participants and communities are neglected, rather than being central to this research.
Social science integrated with community engagement activities can inform the design and recruitment stages of COVID-19 trials, involve prospective participants in deliberations about key procedures, and inform the implementation strategies of these trials.

Engagement with communities should feed into trial protocols and design, acceptability of designs (e.g. debates around randomisation in emergency contexts, and times where many participants risk infection).

Creating reciprocal relationships with trial participants during and after trials have been conducted is a key tenet of ethical research and will help maintain trust in future.

Community groups and stakeholders should be consulted to test language and ensure that informed consent forms are translated.

The impact of clinical trials on existing health services and the standard of care provided within those services should be considered (e.g. how care can be provided to participants during a pandemic).

Trialists should consider local economies and how the recruitment of staff, as well as participant reimbursements, might fuel local tensions in contexts of high poverty.

Clear and accessible communication following the publication of results is needed so that these are shared with a range of audiences including participants.
DEPLOYMENT OF A COVID-19 VACCINE

Upon licensure of a vaccine, community deliberation and research on local dynamics and trust, need to be integrated and adapted for developing locally relevant, inclusive and just vaccine deployment strategies.

Clear communication at national and local levels with the public about equitable distribution according to gender, ethnicity and age is vital.

Rapid social science research should be integrated alongside national distribution mechanisms to ensure that rumours, concerns, and anxieties are identified in real-time including analysis of social media.

Vaccine deployment protocols must be adaptive to respond to evidence from social science.