WORKSHOP REPORT

Joint workshop: community engagement in and for ethical research in outbreaks of infectious diseases and other humanitarian crises

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ALERRT
African coaLition for Epidemic Research, Response and Training

IRESSEF
INSTITUT DE RECHERCHE EN SANTÉ, DE SURVEILLANCE ÉPIDÉMIOLOGIQUE

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NUFFIELD COUNCIL ON BIOETHICS

Themes from the workshop discussion and recommendations put forward by participants

This two-day workshop was a collaboration between the EDCTP-funded ALERRT consortium (African coaLition for Epidemic Research, Response and Training); the Institute for Health Research, Epidemiological Surveillance and Training (IRESSEF) in Dakar, Senegal; the UK Nuffield Council on Bioethics Working Group on the ethical conduct of research in global health emergencies; and the Wellcome Centre for Ethics and Humanities (WEH) at Oxford University. It brought together experts from survivor, policy, research, and implementing organisations with experience of conducting community engagement in and for research during humanitarian crises.

The workshop took the form of one day of presentations by participants, followed by a second day of small group discussions around the theme of 'what needs to change' in order better to support and facilitate effective community engagement. While the focus of debate was on the role of community engagement in different forms of health-related research (from clinical trials to social science research), it became clear that there are many overlaps and synergies between such engagement and the important role of community engagement in appropriate and effective emergency response. It should also be noted that, although many of the experiences cited related to the recent and current Ebola outbreaks in West Africa and the DRC, the relevance of discussions extended beyond Ebola.

This report draws together participants' contributions under common themes, and highlights the recommendations that emerged from individual participants during the discussion. While clear themes emerged from the discussion, it should not be assumed that all present agreed with every point made. Quotations in **speech marks** are direct quotes from participants.

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Values underpinning community engagement

- Effective and respectful community engagement (CE) **starts from a recognition of the experiences of people affected by the emergency**, and the history associated with those experiences.
- The intrinsic value of CE in the context of research lies in its **contribution to supporting a mutually respectful partnership between researchers and communities** (participatory engagement – the opposite of people being used as a tool for others' aims and ambitions).
- **Everyone involved in research inevitably plays a part in engagement – either positively as an 'engager' or negatively (e.g. through attitude) as a 'dis-engager'**. Engagement is not a separate task conducted only by community mobilisers.
- The results of CE should include promoting **transparency and well-founded trust** in the research endeavour – removing causes of doubt and suspicion. CE is both an art (the practice of **empathy and human connection**) and a process.
- At best CE should actively involve affected populations from the beginning and throughout the course of the research endeavour, as a **two-way process contributing to the design, conduct, and outcomes of research**. This is not a challenge to the need for scientific rigour, but rather recognition that research always needs to be contextually sensitive, and that affected populations are positioned to provide important expertise on how that can be achieved.

Implications for research and the interdependence of research and effective response[1]

- Research needs to be conducted in ways that are **compatible with the public health and healthcare response**, and CE needs to be aligned with both research *and* response. **Where available, clinical interventions in response to clinical need should always take priority: it is not acceptable to ask people to take part in research when their basic health needs are not being met**.
- Research associated with the public health response can play a valuable part in improving the health response through better understanding of needs; and an outbreak may offer the only window of opportunity for developing effective treatments for diseases that currently lack them. However, it is essential to recognise that the motivations of researchers may be distrusted during an outbreak, and that **research will not be possible unless a trusting relationship between researchers and potential participants can be developed**.
- **It is not enough for the emergency response effort to respond only to the disease at the heart of the outbreak**: this may not be the only, or even main, concern of

[1] A number of these points go beyond the specific question of CE in research, and are concerned more with the response effort, and access to health services more generally. However, the point was strongly made by some participants that it is very difficult to create trust in a research study if people's basic needs are not being met through the general response effort.

affected populations. The emergency response (incorporating both national and international actors) needs to include a wide range of essential services, including primary health services. The provision of care only to those suffering from one disease, while others in the immediate vicinity face dire needs arising from other conditions, reinforces the belief that international organisations are primarily interested in limiting harm to other countries. In such circumstances, contributing to research may not be seen as a priority – and this focus only on the outbreak condition (**"the business of Ebola"**) may also reinforce beliefs that the disease has been imported precisely in order to test new treatments. Creating a supportive environment for research therefore depends on a sufficiently holistic and effective response effort.

- **Time is a challenging factor** for CE in emergencies. Sometimes the process may need to be one of **"learn-adapt / learn-adapt"** in recognition of the limitations of early engagement, but pressure of time cannot be a reason for failing to engage altogether.[2] It is not the fault of communities if research fails or leaves a legacy of mistrust because research protocols fail to be responsive to community needs and concerns.
- **The role of national governments** is essential in moving towards a more integrated, partnership-based approach to emergency response and research, and shifting away from one-off responses to particular outbreaks, with everyone working in silos. However, in many countries there is a strong tension here: **genuine local empowerment by civil society organisations can be politically disruptive**, and hence sometimes unwelcome to national governments; and researchers can be caught in the middle.

Starting from an understanding of community experience and expertise

- CE for research in outbreaks and other emergencies needs to be grounded in an understanding of the broader situation and experience of the affected communities. This may include factors such as weak health systems with inadequate staffing, structures and resources; poverty and deprivation; a history of civil war and associated trauma, or ongoing civil unrest; little trust in the system or in government; limited literacy; and a lack of knowledge about clinical research. These factors can lead to fears that the disease outbreak has been deliberately imported.
- CE must also take into account the effect of epidemic disease on all aspects of life, including the impact on family duties, workplace discrimination, loss of property, school life, self-esteem, and traditional culture (for example in eating bushmeat) – all factors that collectively erode communities. Health impacts outside the immediate physical and mental effects of the disease include the ongoing psychological impacts of stigma, trauma in children, remembered trauma of civil war, and ongoing health complications.
- A disease such as Ebola is also perceived as 'taking over': everything and everyone concentrates on fighting Ebola, regardless of other health and economic needs.

[2] The existence of the Good Participatory Practice guidelines for researchers was noted here.

- Seeking to understand these background and contextual factors may help researchers interpret local depictions of the epidemic disease: for example images in the DRC of Ebola as 'nothing' (doesn't exist), 'politics', 'money', 'evil', 'witchcraft', and 'corruption' as well as 'disease'.

Box 1: Experiences of being involved in research: examples of participants' perspectives

- Research can feel very intrusive: for example one experience in the Ebola treatment unit (ETU) of researchers wanting to know **"what we eat, how we sleep, how we are"** when patients are very unwell.
- Researchers may be seen as being responsible for people's suffering: why are they not concerned with patients' / survivors' wellbeing and support? Why are researchers only concerned with Ebola when there are so many other pressing needs?
- Research doesn't benefit participants now, so why participate? People have lost relatives and are grieving.
- Research brings back what happened to them: being in hospital for a research study may be like being back in the ETU.
- The perception that researchers should compensate people heavily before they participate: if this research is important, why shouldn't they benefit?

Identifying stakeholders and recognising complexity (who is the community?)

- Stakeholders include: participants and their families; relevant disease communities (e.g. those living with HIV or Ebola survivors); traditional chiefs, faith leaders and informal influencers; local and district government entities; national governments; local NGO and response agencies; international organisations, and international NGOs.
- There is an important distinction between 'gatekeepers' (those with formal leadership roles through whom communities must be approached for local legitimacy) and 'influencers': those respected in different parts of the community because of their role or activity. Both gatekeepers and influencers play an essential role in CE.
- 'Power-mapping' (which can be relatively quick) helps identify significant networks and influencers within any particular population: examples cited included women's associations of market traders, traditional healers, football coaches, and taxi-drivers / bike riders. This may also include local militias: they are respected because they are seen as keeping communities safe.
- Groups such as survivor groups can play an essential role as project partners (see Recognising community agency, below).

What counts as 'engagement'?

- The term 'engagement' is used to cover a wide spectrum of activity: from a one-way process of 'sensitisation' at one end of the spectrum (perhaps better described as 'communication' – see below) to genuinely equal partnerships in research between communities and researchers at the other. In between lie degrees of engagement: providing reasons and justifications for what is happening; offering the opportunity for feedback; and conducting consultative processes that lead to recognisable influence.
- There are both intrinsic reasons (respecting affected populations as equals) and instrumental reasons (achieving better targeted, more acceptable, more effective research) for engaging communities. While the evidence base for the instrumental claims is still developing, and there is little clarity on what constitutes best practice in particular settings, there is clear evidence that failure to engage leads to poor outcomes.

Community engagement as both art and process

- At the heart of CE is two-way communication seeking mutual understanding: **"two worlds face-to-face to build consensus"**. It is thus both an art or attitude (empathy, human connection), and an ongoing process that can help provide the platform for partnership between researchers and communities. Without the space first to express emotion and stress, people will not engage.
- Mutual understanding is *not* the same as agreement: it is about understanding different perspectives and potentially different objectives, and starting to recognise what will be gained or lost in changing views or behaviour. It is based on mutual respect.
- CE should be a continuous process: from involvement in the design of a study, through the conduct of the study, to feedback to communities of the outcomes of the research in which they have participated. Such an approach also helps develop preparedness for any future emergencies (or future research).
- Understanding CE as a relationship reinforces why it is important for those leading CE activities to show hospitality and generosity: for example through the provision of refreshments during meetings, and reimbursing the costs involved in attending.

Recognising community agency and exercise of citizenship

- The role of survivor organisations in the West African Ebola outbreak illustrates the agency of those affected by emergencies (see Box 2). **"Seeing victims as leaders was so powerful."**
- There appear to be important differences between experiences of infectious disease outbreaks, where the response tends to be institution-led, and natural disasters where communities are more likely to take the lead, demand information, and mobilise themselves. The use of separate health structures to respond to the outbreak disease may add to the experience of disempowerment associated with

the whole response 'apparatus', as may top-down approaches to communities via local hierarchies. Organisations like survivor groups, who are uniquely positioned through their direct lived experiences of public health emergencies to represent potential research participants, need to be supported in their ability to lead.

- The recognition of the scope for CE to contribute to the empowerment of civil society organisations and the exercise of citizenship also highlights the potentially disruptive (political) nature of such engagement. This may lead to tensions with government approaches to the emergency response / research. The balance between working with government structures and with locally-active NGOs will depend on the circumstances: what works best may differ, for example, between Liberia, DRC, and Senegal.

Box 2: Patient and survivor-led action in Sierra Leone

- Organising improvised theatre and talent competitions in ETUs to help maintain hope among patients (described as "these talented friends").
- Coaxing fellow patients in ETUs to eat, to maximise chance of recovery.
- Once recovered, volunteering as staff members in ETUs and acting as community mobilisers.
- Acting as advocates for the needs of other survivors, including capturing and documenting the impacts of Ebola, such as joint pain, concern about miscarriages, and need for eye care. Such advocacy contributes to the ongoing research agenda: for example concerns about high miscarriage rates led to this factor being investigated and the causes (anxiety about accessing health services rather than physical consequences of Ebola) to be recognised and addressed.
- Working alongside other peer-led initiatives, for example supporting groups of people living with HIV in developing techniques for maintaining self-esteem.

Role of social science research alongside community engagement practices

- Social science research and CE practices are two distinct processes, using different sets of skills, that provide distinct perspectives and a richer understanding of community concerns. Social science research, for example, can highlight divergent views that may not be emerging through formal CE practices; and can use 'power-mapping' to find groups who might otherwise have been excluded. They should therefore be seen as complementary, not interchangeable practices: CE practitioners need specific engagement skills and cultural immersion in a locality that social scientists do not necessarily have, for example.

- Social science research helps provide in-depth understanding of the wider context, including issues of gender, poverty, the relevance of the physical location, and perceptions of ethics / morality.

- Shared structures (such as a shared advisory board for both social science research and CE practices) avoid duplication and help ensure maximum benefit by ensuring that lessons learned in one strand of work are passed on to the other. For example, better understanding of perspectives of disease gained through social science

research can feed back into, and improve, communication strategies; and a more nuanced understanding of motivations of those taking part in a study can help reduce misunderstandings and distrust. Such shared structures can also help to identify ways forward if social science findings appear to be incompatible with messages emerging from CE.

Ethical guidance for researchers and others

- Ethical considerations should always relate to context: in *this* particular context what is the right thing for a researcher to do? Ethics is not about simply applying principles inflexibly (such as **"you can't provide food for research participants because this is undue inducement"**). An understanding of local traditions, including what is considered courteous and hospitable, is an essential part of that context.
- Ethics should be understood as the practice of compassion and empathy: the reverse of treating people simply as **"carriers of a virus"**, or as **"an instrument for research"**.
- When considering any risks of 'undue inducement' to participate in a study, ethics committees should be alert to the related question of what constitutes 'fair compensation' for participation. Participants should be reimbursed the actual costs of their involvement (e.g. the cost of travel), and also receive compensation for the time they are being asked to give. Such compensation needs to be realistic and expectations need to be managed – not least to ensure sustainability for locally-led research initiatives.

Participant recommendation:

- Research ethics committees should be encouraged to review their approach to compensation. The 2016 CIOMS guidelines make clear that both monetary and non-monetary means of compensation, reflecting the inconvenience involved in study participation, are ethically acceptable, and give further guidance on what might constitute 'undue inducement'.

Scope to influence study design

- Although international guidance, such as Good Participatory Practice (GPP), emphasises community input in the design of studies, this is an aspect of CE that researchers are struggling with at present, especially in the middle of an emergency. Yet the lack of such input may hinder effective relationships all the way through the research, and jeopardise the possibility of successful outcomes. It is not an answer to people's concerns about a research project simply to say 'this is the protocol', treating CE primarily as an attempt to pacify or educate people. **"When you don't see the problem the same way, you can't craft solutions together."**
- It is important to note that CE is about understanding different perspectives and exploring what these might mean for meaningful research. It is *not* the same as

giving people whatever they ask for – and it is also very important not to promise what cannot be delivered. Some aspects of a protocol may not be amenable to change at all without losing scientific validity, and if concerns about these cannot be resolved, then it may simply not be possible to carry out the study in a particular setting. However, there will always be some aspects of *how* procedures are carried out that are contextual. For example, in the response context, what constitutes a 'safe' burial may be relatively fixed, but what constitutes a 'dignified' one may be very different in different contexts.

- In order for community involvement in study design to be normalised, action will be required by all those with the power to influence this, including: national governments, in their ongoing commitment to CE (see 'Legacy', below); national research ethics committees, in how they review proposals; and funders, whose operating procedures influence what, in practice, is possible.

Participant recommendations:

- Flexibility should explicitly be written into study protocols, highlighting those elements where *how* things can or should be done is likely to differ in each research site.
- Research funders should routinely expect to see plans for CE in funding proposals, while recognising the need to allow for flexibility of approach so that CE activities can be guided by reality on the ground. (See also below regarding funding under *Practical elements*)
- Ethics committees reviewing research proposals in the country where the research will be conducted should strongly encourage CE, beginning as early as possible in the development process, drawing on the expertise of survivor or patient groups where these exist. As a minimum, ethics committees should expect CE in the development of appropriate tools for communication and consent procedures.

Practical elements of planning and conducting CE

- Planning CE has to be done *with* communities: it is not something to be decided in the abstract outside the community. **"Ask the community what the rules [of engagement] are, and then follow the rules."**
- Many different forms of expertise need to be recognised in the CE planning process, including: government structures and local health systems; international organisations; and importantly the **"natural expertise"** of those directly affected by the emergency (accessed initially through influencers). The expertise of anthropologists and social scientists is particularly important in the context of the time pressures of an emergency; and developing and drawing on local capacity in these disciplines is essential.
- CE cannot be planned in a vacuum: the message that 'we value your input' is unlikely to be believed in a context of wider coercion, where armed guards may enforce curfews or quarantines. Nor can CE be conducted without reference to

other pressing needs: otherwise it will be impossible to build trust. This applies both to needs directly related to the message (offering advice on hand-washing when there is no access to water, for example), and to basic survival or healthcare needs.

- *Who* is employed both to lead and to conduct CE is very important: the more local the CE practitioners, the better (supported appropriately by the research team). Those leading CE processes need to have the ability to gain trust and facilitate genuine two-way engagement, recognising also the diversity of groups within any geographical population. The knowledge of who has these capacities is inherently local – and yet in practice contracts for CE will often be handed top-down through national and international organisations without that local knowledge. Gender is also an important factor: if the CE role is mainly performed by men, then women's views may not be heard, even though they tend to carry the burden of an epidemic.
- CE practices need to be well co-ordinated with, and integrated in, existing services and structures, such as community health workers or volunteers. This integrated approach should include working with groups such as traditional healers who tend to be excluded in response to infectious disease outbreaks, and who yet have an essential role within many communities.
- How CE practitioners are paid should be considered carefully in the light of local circumstances: on the one hand, it is a skilled job that should not simply be remunerated through an 'inconvenience allowance'; but on the other hand there is a risk that practitioners will be assumed to be 'promoting' research because they are being paid to do so. The role of CE practitioner may offer an important employment opportunity in an environment lacking such opportunities, and the question of sustainability should also be taken into account (see below under 'Legacy').
- CE needs to be properly funded: not only to cover the costs of staff time, but also the costs of conducting activities (including venues and refreshments), and the costs incurred by community members as a result of their involvement (such as travel, or lost work time). Budgets need to allow for a degree of flexibility – enabling CE practitioners to meet urgent needs, including those arising in connection with local traditions (examples cited included meeting the costs of sacrificing a goat where this was traditionally required).
- Planning for CE must include scope to respond appropriately to feedback, alongside recognition of the importance of not promising what cannot be delivered. Options include creating mechanisms for an iterative process within the research team, such as weekly meetings, or reflective spaces, alongside more immediate means of consolidating and disseminating information acquired.

Participant recommendations:

- Budgets for CE need to cover the costs of actually conducting CE activities – not simply the staff costs of CE practitioners. This would include the costs of refreshments during activities, and the reimbursement of the costs incurred by community members in taking part. Budgets should also include a flexible element

to enable CE practitioners to respond appropriately to the needs that they may encounter, and to the demands of hospitality (for example taking a small gift when visiting people's homes).

- Wherever possible, the allocation of contracts for CE should be informed by local power mapping (identifying local sources of influence), to ensure that those appointed to conduct engagement activities have the ability to gain the trust of different parts of the community.

Communication

- Communication is one of the three 'pillars' of social mobilisation, along with advocacy and CE. A clear policy covering these three areas (which should not be confused with one another) is needed, and must be aligned across both response and research.
- Rumours should be understood as reflections of concerns grounded in valid and important historic experiences – never just dismissed. Where there is misunderstanding, rumour, or lack of trust, this is the problem of those conducting response / research, not that of the community. University courses need to prepare researchers in empathy and listening skills, and there is a long way to go to change attitudes. (As researchers and responders, we need to be able to challenge our own practices and assumptions, as well as seeking to understand those of others.)
- Survivor groups can play a key role in helping research institutions reframe their messaging and explain what they are aiming to do in locally appropriate ways.
- Everyone involved in research is, in their role and through their behaviour, acting either as an 'engager' or as a 'disengager': engagement is not a separate activity conducted only by community mobilisers or other experts. The messenger is as important as the message. This has significant implications for team support and supervision.
- Communication involves **"mastering your own concepts"**: researchers need to be able to explain and justify what they are doing and why in a meaningful way. CE can help researchers to look at their message from a different perspective, and work out how to present it more meaningfully.
- Local media play a vital role in communication about both response and research, but there is currently very limited capacity in science journalism in many countries.

Participant recommendations:

- Research teams need to invest in communications training for all staff involved in a trial, recognising everyone's role as an 'engager', and reducing the risk of team members inadvertently contributing to disengagement.
- Local and national media organisations, researchers and patient / survivor groups should collaborate to increase journalists' awareness of science, and help avoid media communication contributing to panic during an emergency.

Supporting informed participants

- There is a strong need to promote 'research literacy' – many people do not know why researchers are there or understand what it is they are being asked to do. Promising initiatives include a toolbox of open-access, multilingual resources being developed through a participatory research approach by researchers from Guinea and Canada for communicating about research with limited-literacy adults in sub-Saharan Africa. Schools also have an important role in helping to develop knowledge about research.
- Feedback to participants and communities of what researchers have learned as a result of their research is absolutely essential, for a number of reasons:
    - Sharing information about study outcomes reinforces an approach to research that is about respectful partnership rather than exploitation.
    - It provides the opportunity for participants to reflect on those findings, contribute further to the interpretation and, where appropriate, use them for advocacy (for example findings around motivations for use of traditional medicine in Liberia informed advocacy around improved access to western medical services).
    - Such dissemination also offers a further opportunity to identify needs and concerns that have not yet been met, and which may inform future research projects or advocacy.

Participant recommendation:

- Feedback to participants about what a study has learned should routinely be required: research ethics committees should look out for this when asked to authorise studies, and funders should provide ringfenced (and audited) funding to ensure that it takes place.

The legacy of research

- Research is an intervention in a community, and hence always leaves some kind of legacy. The question is whether it is a legacy of mistrust – or a positive legacy?
- Research during an emergency should translate into action that makes real and tangible change. In the planning and conduct of research, as much attention should be paid to questions of implementation as to obtaining good data.
- The legacy of research is not limited to questions of benefit – but if there is no prospect of benefit to this particular community, there can be no justification for research taking place there in the first place. Questions of post-trial access are particularly important in clinical trials: an intervention should only be researched in a country if there is some possibility of it subsequently being made available in that country if the research shows the intervention to be effective.

The legacy of community engagement

- The 'instrumental' rationale for CE (the use of CE to improve the quality, acceptability, and effectiveness of the research) should also include consideration of how those instrumental gains come back to the community – particularly with respect to building and supporting capacity.

    - At the national level, developing capacity for future emergencies is essential. Alongside scientific capacity, there is also a burning need to develop **academic social science capacity** so that countries have their own sources of expertise to draw on, to facilitate understanding and promote effective engagement with affected populations. Such capacity is needed in every country: it cannot be assumed that what works in one country in a region will necessarily be the same in another. Networks such as the Ebola Response Anthropology Platform can help develop and sustain networks at regional level.

    - At the community level, the opportunity for community members to learn new skills, for example through roles in CE or as research assistants, is valued. Skills learned by survivor group members, for example, are now being used to support other patient groups, and are enabling them to partner with other international research groups.

- Sustainability is a big challenge once the emergency is declared to be over, and international organisations and funding move on. This is critical both for maintaining the CE structures that have developed during emergencies and which risk being lost, and for providing opportunities and employment for those who have developed new skills during the emergency. Embedding these structures and roles in existing local organisations, with local ownership and control, can help ensure sustainability.

- Accountability is essential: who is monitoring or requiring that CE is done well, and that benefits accrue to the community as a result of their involvement in research? Accountability should also include mechanisms for passing on learning from the past, so that common concerns (such as the stigmatising issue of burning personal goods in epidemics) are not having to be rethought from scratch each time. Platforms such as MESH can help support the sharing both of research and CE findings, and good practice.

- The legacy of research also includes recognising how some aspects of research continue to be important and contentious for long afterwards: for example, the ongoing question of consent for the use of biological samples given the stressful circumstances in which they were obtained. Researchers need to maintain continuing engagement with survivor organisations and those who donated samples.

Participant recommendations:

- National governments have a responsibility, under the International Health Regulations (IHR), to strengthen their emergency preparedness. This responsibility should be seen as including strengthening academic capacity, particularly in social science, to support the development of national /regional expertise in future. The Global Health Security Agenda, which supports emergency preparedness, is one possible source of funding for governments who would struggle to fund such capacity directly.
- National governments need to embed CE practices in local health systems, for example through community health promotion workers, so that the systems necessary for CE developed during emergencies are not lost. The role of civil society organisations in working with affected organisations similarly needs to be recognised and supported, to ensure sustained capacity building in research literacy among stakeholders beyond the lifetime of specific research projects.
- Research funders should explicitly fund capacity development as part of research projects, by recognising the capacity needs of academic collaborators in low income settings. In addition to supporting formal collaborations, funders could also consider how to support maximum flexibility at the micro level – for example enabling project leads to approach local partners and explore mutually beneficial arrangements.
- ALERRT should explore ways in which it could support sustainable local social science capacity in countries where ALERRT research centres are based: for example through supporting networking and mentoring programmes for local social scientists.

Participants in the March 2019 Dakar workshop

Sharon Abramowitz
Consultant
UNICEF

Anani Badjé
WP1 Coordinator in ALERRT Network
PAC-CI

Bonny Baker
Project Coordinator
The Global Health Network, University of Oxford

Aphaluck Bhatiasevi
Team lead (a.i) Social Science Interventions & Risk Communication
WHO Health Emergencies

Primus Che Chi
Social Scientist
KEMRI-Wellcome Trust Research Programme

Sara Dada
Research Fellow at the Vaccine Confidence Project
London School of Hygiene & Tropical Medicine

Luisa Enria
Lecturer in International Development
University of Bath

Amb. Patrick Seeco Faley
Former President, Now Ambassador
National Ebola Survivors Network Liberia

Morenike Oluwatoyin Folayan
Coordinator
New HIV Vaccine and Microbicide Advocacy Society

Nina Gobat
Senior Researcher
University of Oxford

Theresa Jones
Senior Research Associate/Clinical Psychologist
Anthrologica

Yusuf Kabba
President
Sierra Leone Association of Ebola Survivors

Shelley Lees
Assistant Professor, ALERRT WP6 Co-Lead
London School of Hygiene & Tropical Medicine

Mark Marchant
Research Fellow
London School of Hygiene & Tropical Medicine

Vicki Marsh
Associate Professor
KEMRI Wellcome Trust/CTMGH Oxford

Birahim Pierre Ndiaye
Director of Clinical Trial Platform
IRESSEF

Cheikh Ibrahima Niang
Social Anthropologist
ISE-University Cheikh Anta Diop

Palmer M. Netongo
Senior Lecturer, ALERRT WP 5 Lead
University of Yaounde I, Cameroon

Nicole Nkoum
Research Associate
IRESSEF/EBODAC World Vision Ireland

Elysée Nouvet
Assistant Professor
Western University, London, Canada

Michael Parker
Director of Wellcome Centre for Ethics and Humanities
University of Oxford

Julian Sheather
Ethics consultant and adviser
British Medical Association, Médecins Sans Frontières

Khoudia Sow
Researcher
CRCF

Manya van Ryneveld
Researcher
University of Oxford

Samantha Vanderslott
Postdoctoral Researcher
University of Oxford

Barthalomew Wilson
Social Mobilization, Communication and Community Engagement (SMC) Lead at the Partnership for Research on Ebola Virus in Liberia (PREVAIL)

Sophie Wodon
Health promotion and Patient support education and counselling technical referent
MSF Switzerland

Katharine Wright
Assistant Director
Nuffield Council on Bioethics