

Identifying and Enrolling Survivors to Donate Blood

Ebola Response Anthropology Platform

Briefing Note for Investigators involved in Convalescent Blood & Plasma Trials,
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Key points

1. Identification of Survivors:

- a. Many survivors are already incorporated into outreach teams. Working first through these groups and through health workers may enhance the sensitivity through which survivors are identified. However, care needs to be taken not to unduly burden a sub-set of survivors who are being enrolled in a number of other activities as 'immune' agents and for communications campaigns.
- b. Survivors must be seen as a heterogeneous group, despite their shared distinguishing feature, and some may more keen than others to become active 'survivors'. Keeping in touch should have its primary objective to provide ongoing health care and support and secondary objective to elicit help for the outbreak response.
- c. Understanding the support (economic, social) these people require it could make sense to try to link this research cohort with NGOs who may be able respond to the needs of the cured and their families. However, if activities are seen as clandestine and linked with divisive institutions these associations can only make matters worse.

2. Blood Donation:

- a. Blood donation is not a trivial act in West Africa: concerns about the impact of reducing the quantity of the blood should not be dismissed. In some cases, certain foods are regarded replenish blood and build strength (e.g. groundnuts, milk).
- b. Some care should be taken about the location where blood is given – i.e. close to Ebola Treatment Centers, rural or urban areas. In some areas where blood banks are in place – e.g. Koinadugu (SL) – it may be important to understand who the key donor populations have been in the past (military) and the rationale for donation (e.g. Mamaye initiative linking blood giving with maternal health)
- c. There should be as much clarity as possible regarding the destination of blood; if samples have to be processed at a distance from the hospital that is it important to reinforce the altruistic nature of the donation

3. Informed consent

- a. The process of receiving and giving consent should provide an opportunity for communication with survivors, not merely about the discrete research project but about their role in mobilizing and engaging communities.
- b. Information provided in a consent form should be carefully pretested, adapted and retested – for each piece of information and as a whole – in order to adapt to ensure points are understood as intended, are relevant and sufficiently comprehensive.
- c. Survivors should be followed up through the process of research to extend a relationship with the cohort, enhance their trust of the project and potentially help activate

networks. Being a survivor is a 'new' identity without social anchoring, particular care must be taken to (re)connect survivors with networks of support that may be more relevant for their social wellbeing than their disease status – e.g. local organizations, women's groups and survivors should not be assumed to be a homogeneous group.

4. Compensation

- a. Giving of money in this situation can be highly problematic, resulting in further anxieties about the transactional nature of blood.
- b. That being said, many survivors are in economic dire straights, and are providing a potentially life saving treatment, so it may be possible to support survivors in other ways – food, clothing, medicine, health insurance for themselves and family?

5. Care and Follow up

- a. Investigate how to provide ongoing health coverage for the person and critically his "family", understanding that this may mean relatives beyond those living in the immediate household and that participants may be residing in areas at a distance from the experimental sites.
- b. The economic situation facing survivors should not be underestimated; efforts should be taken to meet their basic life needs.
- c. Survivors should be remembered for their identity and lives beyond this defining characteristic.

Background: Identifying and enrolling survivors to donate blood

Survivors are rapidly becoming a strategic population for the Ebola Outbreak response. The public health potential of this group appear to be manifold—from safe burials and the care for orphan children to community outreach and the donation of blood for clinical trials. There are a number of stories emerging from the field of survivors who refuse to leave Ebola Treatment Units, offering their support in caring for new patients. Regarding the status and experience of survivors the data is somewhat thin and a number of questions are raised about how best to engage survivors in containment efforts relevant for the procurement of convalescent blood, including:

1. Stigmatization: Survivors of Ebola have faced ostracism by their communities.¹ However, stigmatisation is a western term that can obscure not only the social realities of illness, isolation and healing but also the systemic inequities that shape these dynamics.² It is thus, critical to contextualize the local perceptions of survival within the particular fears attendant to a disease (contagion etc) and the socio-economic burdens and consequences attendant to becoming well. For instance, Ebola's high mortality rate and unclear origins might associate survivors with invisible networks of power or nefarious plans of the west.³ Following the death of kin and the depilation of their social networks, survivors may also find it difficult to integrate back into communities; they may also face dire economic

¹ Catholic Relief Services, Focus 1000 and UNICEF (2014). "Study on Public Knowledge, Attitude, and Practices Relating to Ebola Virus Disease (EVD) Prevention and Medical Care in Sierra Leone"

² Castro, A and P. Farmer. (2005) "Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti." *Am J Public Health*. 95(1): 53–59.

³ Bolten, Catherine E. (2014) "Articulating the Invisible: Ebola Beyond Witchcraft in Sierra Leone." *Fieldsights - Hot Spots, Cultural Anthropology Online*, October 07, <http://www.culanth.org/fieldsights/596-articulating-the-invisible-ebola-beyond-witchcraft-in-sierra-leone>

situations as all their belongings, including their house, working tools and food may have been burned.⁴⁵

2. Significance of Blood: The Significance of blood varies between West African groups and ethnicities. However, anthropologists across the working across the region have noted that blood is understood as a 'vital force' associated not only with good health but also with individual strength and prosperity. A similar set of logics link illness and misfortune to reductions in the quality and quantity of blood⁶⁷⁸ or the 'drying of the body' brought about through a wasting of blood, which had formerly been plentiful.⁹

The importance of clean or strong bodily fluids can attribute to the popularity of interventions such as vaccines that injected directly into the bloodstream; while the emphasis on a limited 'economy of blood' can also generate fears and anxieties of blood giving (for research or transfusion), which can render the patient vulnerable to other diseases (c.f. Cham 2003¹⁰) increasing vulnerability to other illness. This is particularly true of women and children who are often understood to have less blood to begin with; in the case of the latter their workload might also indicate a greater need for blood.

This 'blood calculus' is further amplified in contexts where volunteer blood banks are not supported by systems of national health care and where blood transfusion demands sacrifices from relatives or can result in expensive charges, which in turn, can lead to the clandestine purchase and sale of blood. Recent work on the intersection of the International Committee of the Red Cross (ICRC) activities with military and governmental groups in the civil war in Sierra Leone suggests historic tensions in the collection of blood that may refract on current research efforts to use plasma from survivors (Ferme, forthcoming). The HIV/AIDs epidemic and the politics associated with access to therapies has also played a role in the association between the drawing of blood and access to social, political and economic resources.¹¹

⁴ Hewlett BS and Amola R. (2003) "Cultural contexts of Ebola in Northern Uganda." *Emerging Infectious Diseases*, 9, 1242-1248

⁵ Hewlett B, Hewlett B. (2005) "Ebola, Culture and Politics: The Anthropology of an Emerging Disease." *Wadsworth*.

⁶ Bierlich, B. (2000) Injections and the fear of death: An essay on the limits of biomedicine among the Dagomba of northern Ghana. *Social Science & Medicine*, 50:703-713.

⁷ Fairhead J, Leach M, Small M. (2006) Public engagement with science? Local understandings of a vaccine trial in the Gambia. *J Biosocial Science*, 38:103-116.

⁸ Leach, Melissa & James Fairhead. (2008) Understandings of immunization: some west African perspectives. *Bulletin of the World Health Organization*. 8(6): 418-418A.

⁹ Ferme MC, Schmitz CM. (2014) Writings on the wall: Chinese material traces in an African landscape. *Journal of Material Culture* 2014.

¹⁰ Cham, M. (2003). Maternal mortality in the Gambia: Contributing factors and what can be done to reduce them. M.Phil. Thesis, Faculty of Medicine, University of Oslo

¹¹ Nguyen VK. (2010) *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Duke University Press.

Critically, blood is highly differentiated and ambiguous; depending on the context it can mean life or death.¹² Critically, the removal of blood is understood within a broader set of concerns; if people are in vulnerability the therapeutic purpose of giving blood can quickly be re-read as inappropriate exchange (Luise White, personal communication).

3. Blood Theft and Research: Concerns about blood theft, sale and vampirism are common across the Africa continent.¹³¹⁴¹⁵¹⁶ While often dismissed as ‘misunderstandings’, ‘traditional beliefs’, ‘rumours’, ‘metaphors’ or ‘coded expressions of resistance’, anthropologists and historians have shown that these anxieties reflect upon, and make sense of, ambiguous exchanges, resource flows, new technologies and forms of labour—dynamics particularly characteristic of medical research.¹⁷

‘Sensitizing’ populations to the procedures of medical research—e.g. explaining or showing how blood is processed—often does little to dispel ‘rumours’ or ensure the ‘acceptability’ of research. Indeed, blood theft stories are not merely the province of the uneducated and far-flung, often highly nuanced observations interweaving common sense and observations, rumours articulate collective anxieties grounded in long-term engagements with biomedicine, legacies of unequal relations of power, extraction and exchange.¹⁸¹⁹²⁰²¹

Ethnographic accounts of clinical trial communities have pointed to the social relations that underpin research, the interactions between researchers and past and often fraught encounters with foreigners, government officials and biomedical expertise.²² The deep ambivalence about giving blood – matter of significance but also an expression of the distribution of benefits, ensuring that benefits are balanced, communities are cared for, that there is a trust and commitment to the institution.

¹² White L (1993) Vampire Priests of Central Africa: African Debates about Labor and Religion in Colonial Northern Zambia. *Comparative Studies in Society and History* 1993, **35**:746-772.

¹³ Fairhead J, Leach M, Small M (2006) Public engagement with science? Local understandings of a vaccine trial in the Gambia. *J Biosocial Science*, **38**:103-116.

¹⁴ Geissler, Paul Wenzel. (2010) "Transport-to where?"-Reflection on the problem of value and time a propos an awkward practice in medical research. *Journal of Cultural Economy*.

¹⁵ Kelly, A.H. (2012) Global Clinical Trials and the Contextualisation of Research, in M. Konrad, *Collaborators Inside Collaboration: Anthropological Ethics and Knowledge Relations Across Worlds of Research in Action*, New York & Oxford: Berghahn Books

¹⁶ White, L. (2000) *Speaking with Vampires: Rumor and History in Colonial Africa*. Berkeley: University of California Press.

¹⁷ Geissler, P. W., & Pool, R. (2006). Popular concerns with medical research projects in Africa. *Tropical Medicine and International Health*, 11(7), 975-983.

¹⁸ Birungi H. (1998) Injections and self-help: risk and trust in Ugandan health care. *Social Science & Medicine* 47:1455-1462.

¹⁹ Feldman-Savelsberg, P., Ndonko, F. T. and Schmidt-Ehry, B. (2000), Sterilizing Vaccines or the Politics of the Womb: Retrospective Study of a Rumor in Cameroon. *Medical Anthropology Quarterly*, 14: 159–179.

²⁰ Leach, Melissa & James Fairhead (2008). Understandings of immunization: some west African perspectives. *Bulletin of the World Health Organization* 8 (6): 418-418A.

²¹ G. Lachenal (2010) Le médecin qui voulut être roi. Médecine coloniale et utopie au Cameroun. *Annales, Histoire, Sciences Sociales*, 65, n° 1, p. 121-156 .

²² Sunder Rajan (2002) Banking (on) Biologicals: Commodifying the Global Circulations of Human Genetic Material. *Sarai Reader 02: The Cities of Everyday Life*, 277-289.

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