Respondent Fatigue & Research Co-Operation

We are now halfway through the third month of our project, which explores the ethical challenges faced by British military personnel who deployed to Sierra Leone to deal with the Ebola crisis. So far we have conducted thirteen interviews, and the initial analysis of the transcripts is under way. Based on the data collected so far, and working with members of the COST Action Disaster Bioethics, we are making good progress with producing training materials. Heather has also contributed to the pre-deployment ethics training for Tranche 4 and observed part of the simulation field hospital at the Army Medical Services Training Centre near York, which contains a replica of the Ebola Treatment unit in Sierra Leone. Some striking themes are arising from these preliminary data, and these will form the main findings of the study. However, they are not the only thing that the team has learnt so far from the project. We have encountered our own ethical challenges in doing the project. Challenges like these will be familiar to anyone undertaking formal research, and fall into the area of "research ethics".

A road from Kenema to Kailahun District, Sierra Leone

One issue we have encountered arose from the fact that we are not the only research team undertaking a study targeting returning military medical personnel as participants. This raised the interesting question of whether there would be some benefit in co-ordinating our recruitment strategy with the other research team, in spite of the fact that the studies are largely unrelated except insofar as they are targeting the same relatively small population of potential participants.

Reasons for co-operation between studies are first the possibility of overloading potential participants by asking them to revisit what may be sensitive ground twice, and second that in competing for participants their good will may be depleted such that neither study is able to recruit sufficient numbers. Alternatively, they may take part in multiple studies, but the answers they give might become less and less detailed throughout, affecting the quality of the data – this might be

viewed as a cross-study form of respondent fatigue. A third reason relates to working as economically as possible to avoid duplication of effort.

Co-operating with other researchers might therefore yield better results (both in terms of data quality, consideration for participants and cost effectiveness) than both projects making maximal efforts to recruit to their own studies. We therefore agreed to temporarily forgo recruitment from Tranche one (T1) and concentrate our efforts on Tranche two (T2) (who had very recently returned to the UK). The other research team could only recruit from T1 because they were conducting a 'before and after' study and had already collected pre-deployment information from T1, whereas we could sample from each returning group. Indeed, this would be desirable given that the military healthcare worker who became infected was from T2 (and the rest of her team may offer very different perspectives from those who deployed when no such infection occurred) and also because the number of infected people in Sierra Leone has been falling for the past couple of months. We discussed the possibility of trying to combine data collection as both studies are using qualitative interviews. On further examination we concluded that this may impact the quality of the data. Although we could each ask the questions on both topic guides, our different backgrounds would influence how responses were probed, which may leave gaps in the data that we were collecting for each other. We were also concerned about memory fade in terms of our own study if we delayed recruitment from T1. Nevertheless, we felt that on balance, leaving T1 to the other research group and targeting T2 ourselves was the option that would maximise the prospects for both studies, and we felt that it was better to foster cooperation than competition in research practice.

Constructing a UK treatment centre in Sierra Leone

As part of our MODREC application, we considered whether or not we should interview anyone who was actually, or suspected themselves of being, infected with Ebola. In this application we reasoned that those who have been infected with Ebola during their deployment may be at greater risk of

becoming upset as a result of being interviewed, especially in light of the tight project timetable, which meant that they may be interviewed within a few weeks of returning to work from sick leave. We decided, however, not to exclude such participants, for the following reasons:

i) If the potential participant was infected with Ebola during our recruitment period they would be too poorly to answer emails (or may not actually have access to the means to do so) and would not therefore be recruited.

ii) If on the other hand, a potential participant had been successfully treated and returned to work/started answering emails in time to participate, we are inclined to think that a) whether or not they wish to participate should be their own decision as an autonomous adult – such that excluding them would be paternalistically making this decision (about the balance of burdens and benefits) for them, and b) it would actually be really important to interview them for scientific reasons to see whether the experience of being infected affected their views. The obligation of the researcher – or so we felt – was not to make this decision for them, using exclusion criteria, but rather to proceed sensitively with the interview.

iii) We would not necessarily know whether or not a potential participant had been infected unless they told us this and for them to do this, we would have to contact them. So it was not clear how an exclusion related to infection could be implemented unless we introduced a screening tool.

Keeping the infection rate as low as possible was obviously a concern for all involved with Operation Gritrock. To date, only three confirmed cases have occurred in UK citizens (one of which happened prior to Operation Gritrock), and only one of these was in our target population. We understand that incidents such as needlestick injury and contact with infected bodily fluids were also very infrequent. This is good news. However, it has raised a further ethical concern for us. The only confirmed infection to date in our target population is readily identifiable even with serious redaction; any discussion of the impact of this case will clearly be about this person. Likewise, it is unlikely data collected from a single, identifiable person about how being infected changed personal perspectives on the ethical challenges could be used anonymously. This was not an issue that was anticipated at the start of our study but we mention it here – without providing our solution, since this also has data security implications – as we feel it should be debated more broadly outside of the context of this particular study.

Personal Protective Equipment (PPE) in use to minimise infection risk

Returning to the issue of cooperation with the other research team: unfortunately, the first study was beset by unexpected delays, which created a new ethical problem for us: although we wanted to honour the agreement, the reasons for having the agreement at all were being undermined by the delay. The potential participants were not likely to feel bombarded with requests to participate in research, as the requests could in theory now be spaced out, with the other study potentially not recruiting for several months. Thus the purpose of the agreement would be accomplished equally well if we brought forward our recruitment from T1. We were also keen to avoid the possibility that we would end up not recruiting from this cohort at all, which we thought would have two potentially negative consequences. First, the potential participants would have been deprived – as a result of the agreement – of the chance to participate, and we were finding that those we were speaking to suggested that the interview was a useful experience (something that Schwartz et al had also reported). Second, our study would be less effective if we lost the opportunity to collect data from those who had deployed first, when the situation on the ground was most uncertain and there was no one whose previous experience could drawn on to help with their preparation and execution of their mission. Our concerns were compounded by the vague unease that the cooperation agreement was somewhat paternalistic – as indeed are many attempts by others, researchers and research ethical committees alike, to protect research participants – since we the researchers on the two teams had decided for the participants that their interests would best be protected if we controlled the choices they were given.

This latter unease was exacerbated when a few individuals from T1 contacted us expressing a willingness to take part having heard about the study from others we had interviewed. These individuals really wanted to share their experiences of the ethical challenges they had faced. Would it be breaking the agreement to interview these people given that they had initiated contact? We had not after all attempted to recruit them. Nor could we politely direct them to the other study, or attempt to delay arranging an interview because at that point the other study was not ready to recruit. We were also worried that procrastination or hesitation on our part may actually deter them

from participating, or worse, undermine trust in our project: it may seem as though we didn't want to hear what some people had to say. We were already getting the impression from those we had spoken to that the operation was highly politicised and we knew from the medical press (and our key informants) that the Medical Rules of Eligibility had proved controversial.

Fortunately, the other project was able to resolve its difficulties and is now well on the way to completing data collection. Our ethical dilemma was thereby solved by changing circumstances. It looks as though everything is going to turn out as both teams hoped, and both teams are grateful that so many people have been willing to participate and that the data provided has been so rich. We remain of the view that it is better to cooperate with other researchers than to compete against them. Nonetheless, we are still reflecting on the experience with the nagging concern that both research teams may have been overly paternalistic. After all, the population in question are healthcare workers, many of whom are independent professionals knowledgeable about the value of research and used to forming and acting on their own judgement. Some are even quite senior within the chain of command; all are likely to be resourceful and resilient given their military background. So we wonder whether, on balance, both research teams should have been willing to accept the consequences of simultaneous recruitment – namely that the participants freely decided to take part in both, one, or neither of the studies.

We have found the process of reflecting on these ethical issues interesting. We would encourage other researchers to reflect openly on the ethical challenges they have faced, sharing solutions they found with a view to increasing awareness and consideration of the complexities of the 'bread and butter' ethical issues in research practice, which are every bit as important as the more dramatic issues usually debated in the literature. We would suggest that this kind of reflection might occur as a more regular, perhaps even an expected, feature of publications that report research studies.

Simon Jenkins (Research Fellow)

Heather Draper (PI)