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Calnan, Michael, Gadsby, Erica W., Kondé, Mandy Kader, Diallo, Abdourahime and Rossman, Jeremy S. (2017) *The response to and impact of the Ebola epidemic: towards an agenda for interdisciplinary research*. *International Journal of Health Policy and Management*, 7 (5). pp. 402-411. ISSN 2322-5939.

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1 **Manuscript type: original article**

2 **Title of manuscript:**

3 **The response to and impact of the Ebola epidemic: towards an agenda for interdisciplinary**  
4 **research**

5 *International journal of Health Policy and Management: Accepted for publication 20/08/2017*

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18

19 **Keywords: Ebola; Guinea; Research priorities; Survivors; Social impact**

20 **Acknowledgements:** This research prioritisation exercise was funded by a grant from the University  
21 of Kent. JSR was supported by the European Research Council (FP7-PEOPLE-2012-CIG: 333955).

22 **Authors' contributions:** MC, EG and JS designed and conducted the study and co-wrote the paper.  
23 MK and AD were involved in organisation and conduct of the study, and helped with analysis of data  
24 and producing a final draft of the paper.

25 **Conflict of interest: None**

26 **Ethical issues:** The study was granted ethical approval by the appropriate committee (SSPSSR) at the  
27 University of Kent in November 2016. The chair of the Guinean national research ethics committee  
28 approved the conduct of the study without requiring full ethical approval in country.

29

30 **Word count: 6186**

31

## 32 **Abstract**

### 33 Background

34 The 2013-16 Ebola virus disease (EVD) epidemic in West Africa was the largest in history and resulted  
35 in a huge public health burden and significant social and economic impact in those countries most  
36 affected. Its size, duration and geographical spread presents important opportunities for research than  
37 might help national and global health and social care systems to better prepare for and respond to future  
38 outbreaks. This paper examines research needs and research priorities from the perspective of those  
39 who directly experienced the EVD epidemic in Guinea.

### 40 Methods

41 The paper reports the findings from a research scoping exercise conducted in Guinea in 2017. This  
42 exercise explored the need for health and social care research, and identified research gaps, from the  
43 perspectives of different groups. Interviews were carried out with key stakeholders such as  
44 representatives of the Ministry of Health, NGOs, academic and health service researchers and members  
45 of research ethics committees (N=15); health practitioners (N=12) and community representatives  
46 (N=11). Discussion groups were conducted with male and female EVD survivors (N=24) from two  
47 distinct communities.

### 48 Results

49 This research scoping exercise identified seven key questions for further research. An important  
50 research priority that emerged during this study was the need to carry out a comprehensive analysis of  
51 the wider social, economic and political impact of the epidemic on the country, communities and  
52 survivors. The social and cultural dynamics of the epidemic and the local, national and international  
53 response to it need to be better understood. Many survivors and their relatives continue to experience  
54 stigma and social isolation and have a number of complex unmet needs. It is important to understand  
55 what sort of support they need, and how that might best be provided. A better understanding of the virus  
56 and the long-term health and social implications for survivors and non-infected survivors is also needed.

### 57 Conclusion

58 This study identified a need and priority for interdisciplinary research focusing on the long-term socio-  
59 cultural, economic and health impact of the EVD epidemic. Experiences of survivors and other non-  
60 infected members of the community still need to be explored but in this broader context.

### 61 **Implications for policy makers:**

- 62
- The recent EVD epidemic in West Africa presents an important opportunity for research that  
63 will help to inform efforts to strengthen health systems, and enhance disease preparedness and  
64 control measures in the future.
  - Some of the key priorities for research are to understand the long-term socio-cultural, economic  
65 and health impact of the EVD epidemic on Guinea, and to relate that to the local, national and  
66 international responses to the outbreak.
  - Interdisciplinary research is required to ascertain the best ways of supporting and/or treating  
67 the survivors of EVD, and of minimising risks of future outbreaks.
  - Research combining epidemiological and biological studies with a sociological analysis of  
68 community members' beliefs and behaviours may help to develop better policies and practice  
69 for future disease containment.
  - 70
  - 71
  - 72

73

74 **Implications for public:** The development of intervention programmes aimed at mitigating the  
75 impact of disease epidemics need to be based on evidence derived from direct experiences of the local  
76 population. This research scoping exercise carried out in Guinea in relation to the recent Ebola  
77 epidemic identified seven research questions for further research. Each of these research questions  
78 was identified by key stakeholders and infected and non-infected members of the community and  
79 each has important implications for future disease prevention and health protection programmes.  
80 Engaging key groups in research at an early stage can help to shape the research agenda so that it is  
81 more meaningful and useful to these groups, resulting in research with greater impact.

82

83

## 84 **Background**

85 In 2013, Guinea was the first country in West Africa to experience the recent outbreak of the Ebola  
86 virus disease (EVD) which as a whole resulted in over 28,000 cases and 11,000 deaths in 10  
87 countries, making it the largest Ebola outbreak ever recorded.<sup>1</sup> The epidemic took considerable time  
88 to contain, despite the extensive mobilisation of personnel, equipment and resources by national and  
89 international agencies.<sup>2,3</sup>

90 Viral, health and epidemiological factors alone do not appear to account for this difficulty in  
91 controlling the outbreak.<sup>4</sup> It has been suggested that some of the social conditions that contributed to  
92 the size, extent and spread of the epidemic in Guinea and surrounding countries included war,  
93 population growth, poverty and a poor health infrastructure.<sup>5</sup> These social conditions might be  
94 reflected in the relatively low life expectancy rates in Guinea, which stood at 59 years in 2015.<sup>6</sup>  
95 Certainly, the capacity of the health system in Guinea appeared to be weak at the time of the outbreak,  
96 with several essential functions not performing well.<sup>7,8</sup> It was reported that there were inadequate  
97 numbers of qualified health workers; infrastructure, logistics, health information, surveillance,  
98 governance and drug supply systems were weak; the organisation and management of health services  
99 was sub-optimal; and government health expenditure was low whereas private expenditure (mostly in  
100 the form of direct out-of-pocket payments for health services) was relatively high.<sup>9</sup>

101 In addition to health system weaknesses, one of the major barriers to controlling the disease appeared  
102 to be community resistance to the Ebola response.<sup>10</sup> For example, the WHO reported, in a 6-month  
103 retrospective analysis on the first cases of the outbreak, they were sometimes met with violence from  
104 a fearful population.<sup>11</sup> The communities' fear appeared to be in response to the way intervention  
105 programs had been introduced.<sup>12</sup> It also appeared to be due, in part, to the nature of the disease itself,  
106 which, as with other infectious diseases, disrupted the traditional cultural customs and behavioural  
107 practices for caring for the sick and dealing with a dying - or the death of - a relative, friend or  
108 member of the community.<sup>5</sup>

109 The scale of the emergency in West Africa was such that the international response has progressed  
110 through three phases:<sup>1</sup> 1) The rapid scale-up of the response, which included increasing the number of  
111 Ebola treatment centres, hiring and training teams in safe and dignified burials, and strengthening  
112 social mobilisation capacities. During this time, a UN Mission for Ebola Emergency Response was  
113 launched. 2) The strengthening of capacities for case finding and contact tracing, and the engagement  
114 of communities. During this time, clinical trials of Ebola vaccines and anti-viral therapeutics were  
115 initiated in Guinea which demanded considerable capacity with regards to ethics and governance,  
116 communication, surveillance, laboratory testing and trial management. And 3) the interruption of all  
117 remaining chains of Ebola transmission, which entailed: enhancing the rapid identification of all  
118 cases, deaths and contacts; establishing and maintaining safe triage and health facilities; building

119 multi-disciplinary rapid response teams at regional and zone levels; providing incentives for  
120 individuals and communities to comply with public health measures; engaging in community-owned  
121 local response activities; improving Ebola survivor engagement and support; and ending human-to-  
122 human transmission of EVD in the populations and communities of the affected countries. This  
123 emergency response - particularly the last phase - was complemented by the joint West African  
124 government-led Ebola Recovery Assessment programme which aimed to lay the foundation for short,  
125 medium and long-term recovery. The focus in this programme was on four areas: health, nutrition and  
126 water, sanitation and hygiene; governance, peace building and social cohesion; infrastructure and  
127 basic services and socio-economic revitalisation.<sup>13</sup>

128 It has been recognised that outbreaks of emerging infectious diseases are sources of instability,  
129 uncertainty and sometime crises.<sup>14,15</sup> There has been some sociological and political analysis of the  
130 way the Ebola epidemic was constructed as a problem or crisis outside Africa in high income  
131 countries,<sup>3</sup> and how it became a global political as well as a health event.<sup>2</sup> This analysis has tended to  
132 emphasise the importance of the influence of the international agencies in shaping the response but  
133 also the moral discourse or panic associated with this response.<sup>3</sup> The role played by the global media  
134 has been highlighted, for instance, in enhancing the stigmatisation of those directly or indirectly  
135 linked with the outbreak.<sup>3</sup> However, much of this research has been carried out 'at a distance' and  
136 there is limited detailed research evidence about the local and national responses to the EVD  
137 epidemic, and consequent missed opportunities to improve policy and practice responses in the  
138 future.<sup>10,16</sup> There is also increasing recognition of the need for interdisciplinary research to examine  
139 the social dimensions of the epidemic, the policy response to it, the communities' reactions to the  
140 response and how these factors intersected with the biological transmission of the virus, physical  
141 containment measures and community medical treatment.<sup>2,17</sup>

142 This paper addresses the lack of detailed analytical research to date on the perceptions and needs of  
143 those with direct experience of the Ebola epidemic in Guinea. It presents evidence from a study  
144 exploring research needs from the perspective of a number of key groups, including members of local  
145 communities. The original aim of the exercise was to identify priorities for health and social care  
146 research with and for survivors of EVD in Guinea. Survivors' experiences have been the subject of  
147 limited previous research in Guinea which highlights the stigma associated with Ebola and the  
148 consequences of social isolation for the mental health of survivors.<sup>18,19</sup> The aim was to see if this was  
149 still a priority from the perspective of survivors and/or if there are other research questions that might  
150 need to be explored particularly in relation to the long term experiences of survivors and their family  
151 and communities. The objectives were: to explore survivors' experiences of their various interactions  
152 with health, care and associated services delivered by local, national and international providers and  
153 agencies, including NGOs; and to explore and discuss the need for health and social care research,  
154 and identify research gaps and priorities, from the perspectives of different groups - men, women,

155 EVD survivors, community leaders, health practitioners, traditional healers, and local and national  
156 government stakeholders.

## 157 **Methods**

158 The study followed a structured, participatory, inclusive approach guided by the principles and values  
159 of the Essential National Health Research (ENHR) strategy for priority setting.<sup>20</sup> These principles  
160 include: placing country priorities first; working towards equity in health; and linking research to  
161 action for development. The ENHR strategy, developed by the Commission on Health Research for  
162 Development, advocated the use of a systematized approach to priority setting that involved all  
163 stakeholders. The Council on Health Research for Development (COHRED) – established to assist  
164 with the implementation of this strategy – recommended a three stage approach (planning the priority-  
165 setting process, setting the priorities, and implementing the priorities) to increase the effectiveness of  
166 the priority-setting process.<sup>21</sup> Since then, several WHO committees,<sup>22,23</sup> and the Global Forum for  
167 Health Research,<sup>24,25</sup> amongst others, have further elaborated methods, tools and frameworks for  
168 research priority setting, that are underpinned by the principles and values of the ENHR.

169 The study reported in this paper was a preliminary rapid assessment, rather than a full research  
170 prioritisation exercise. Due to time and resource constraints, it required a pragmatic approach guided  
171 by established conceptual frameworks for compiling information relevant for investigating health  
172 research priorities. The Combined Approach Matrix in particular guided us to explore not just the  
173 public health dimension (in terms of the magnitude of the problem, determinants and present level of  
174 knowledge), but also the institutional dimension (including the individual, household and community,  
175 health sector and sectors other than health), and the equity dimension (in particular gender, poverty  
176 and survivor status).<sup>25</sup> The starting point for this work was that, in the specific area of EVD research,  
177 whilst investment was (at least initially and understandably) prioritised towards biomedical scientific  
178 research aimed at treating and preventing infection, it is likely that there are a number of areas where  
179 research and development could make an important difference to global health, but which are  
180 currently not recognised or not receiving appropriate attention (and resources).

181 The preparatory work for this study included the identification of key stakeholders, the collation and  
182 analysis of background information, and discussions with a range of interdisciplinary experts in health  
183 systems and policy research in Guinea, and in EVD research. The field visit included public  
184 engagement activities that enabled us to progress three elements of the ENHR process: getting to  
185 know the stakeholders; situation analysis / stocktaking; identification of research priority areas; and  
186 discussion and ranking of identified research priority areas. The goals of the public engagement  
187 activities were to become better informed about a range of people's views and concerns about EVD  
188 research, to hear different perspectives and insights, and to become more sensitive to the social and

189 ethical issues that relate to it. The aim was also to develop collaboration with stakeholders in Guinea,  
190 where research questions could be developed and explored in partnership with the public.

191 *Data collection and Sampling:* Data collection consisted of face-to-face interviews and focus group  
192 discussions. The purposive sample of key stakeholders (N=15) selected for interviews included  
193 representatives from the Ministry of Health (N=5), NGOs (N=4), academic and health service  
194 researchers (N=4) and members of ethics and research committees (N=2). These data were  
195 complemented by interviews with health practitioners (N=12, of which 2 were traditional healers) and  
196 community representatives (N=11) and focus group discussions with male (N=12) and female (N=12)  
197 EVD survivors from two distinct communities in Guinea. Both communities were small townships.  
198 Site one was approximately 50km from the capital (Conakry), and was affected towards the end of the  
199 epidemic. Site two was in the more remote, forest region of Guinea, and was within the prefecture  
200 where the first cases were identified in 2013.

201 Questions posed in interviews and discussions varied according to participants, and on information  
202 gathered during the field visit. However, they included questions to elicit information on: health status  
203 and social position (e.g. information on the main health and health-related/social needs of people who  
204 have survived EVD, how these needs have changed over time, and the extent to which these needs are  
205 understood by others); health and social care systems (e.g. the services available for local people,  
206 particularly in relation to needs expressed); health and social care research programmes (e.g.  
207 awareness of and involvement in research for or with EVD survivors); and needs and values of  
208 survivors and other key stakeholders (e.g. most important issues related to life after the EVD  
209 outbreak, now and in the future).

210 The study was granted ethical approval by the appropriate committee (SSPSSR) at the University of  
211 Kent. The chair of the Guinean national research ethics committee approved the conduct of the study  
212 without requiring full ethical approval in country. Informed consent (using appropriate verbal or  
213 written methods) was sought from all participants.

214 *Fieldwork and Analysis:* The analysis made pragmatic compromises between timeliness and resource  
215 requirements and scientific rigour and validity. It drew on the technique of rapid appraisal, seeking to  
216 gain community perspectives of local health and social needs and to translate these findings into  
217 action.<sup>26-29</sup> Data collected from one source were validated or rejected by checking with data from at  
218 least two other sources or methods of data collection. The majority of the interviews and discussion  
219 groups were recorded and notes were taken on the content and conduct of discussions. The interviews  
220 with key stakeholders were mainly carried out in French, and translated to English during the course  
221 of the discussion. The discussion with survivors at the two sites were conducted in two groups – one  
222 male, one female – and facilitated by a French speaker and a helper from the local community who  
223 spoke the local language. All were experienced facilitators and all participants contributed to the



224 discussion. They used the same discussion guide for both groups. Both groups lasted for  
225 approximately one and a half hours

226 The analysis was conducted iteratively within the research group (which constitutes the authors of this  
227 paper), through reviewing and summarising audio files and field notes, by identifying and sorting key  
228 themes, and by comparing and contrasting different perspectives. The researchers took particular note  
229 of, and sought to explore further, issues associated with equity in health. The analysis was limited by  
230 the multiple languages used within the data. A more complete analysis, involving the full translation  
231 and thematic coding of transcripts in a single language, would likely uncover further depth and  
232 nuance within the data. This paper is based on an initial descriptive analysis of salient themes which  
233 emerged from the interviews and discussions based on the field notes and summaries. It does not,  
234 therefore, contain direct quotes. The field work as a whole was carried out in Guinea in January 2017.

235 *Key stakeholders' ranking of research priorities:* The final phase of the research scoping exercise  
236 involved a presentation and discussion of findings to a meeting of the key stakeholders in Conakry,  
237 and (separately) to a meeting of key stakeholders in the more remote site two. The group of key  
238 stakeholders in Conakry did not include representatives from survivors' groups, but did include  
239 participants with an in-depth understanding of the issues faced by survivors in Guinea. In site two,  
240 the group of key stakeholders included leaders of survivors' groups. The research team proposed and  
241 explained the key themes that arose from the scoping exercise, emphasising the links between  
242 research and action for development. The stakeholders discussed these themes within the group  
243 setting, and were then asked independently to rank the topics in order of priority, according to their  
244 own perspectives and interests. No attempt was made at this stage to develop consensus within the  
245 group, and no temporal or financial parameters were defined. This allowed the research team to see  
246 how priorities of different stakeholders varied, and to rank the questions in order of averaged priority.  
247 It is important to acknowledge that priorities will change over time, and that research priorities can  
248 sometimes be individual. In this exercise, explicit criteria for the ranking exercise were not set.

249

## 250 **Results**

251 This section describes the themes that arose in the interviews and discussion groups. They provide the  
252 basis for the research agenda set out in the final discussion section.

### 253 **The EVD survivors**

254 The initial focus of this research scoping exercise was on the survivors' experiences. In group  
255 discussions, the survivors described the ways in which they and their lives had been affected by EVD.  
256 The issues that arose, clustered into key themes, are summarised in table one. The discussions showed  
257 that the social and economic implications of experiencing the virus were as important as the implications

258 for physical health. Some of the concerns already noted in the literature about survivors' experience  
 259 were reinforced. For example, being stigmatised and excluded from the family and the community, and  
 260 feeling lonely and isolated due to family break up were common sentiments expressed by both men and  
 261 women. There were also major economic implications such as losing jobs and accommodation and  
 262 generally suffering a serious reduction in income. Experiencing this illness and its consequences,  
 263 perhaps not surprisingly, also had serious implications for well-being, happiness and mental health.  
 264 There was a clear indication that these psychological needs were not being met.

265 **Table 1: summary of key issues raised by men and women in group discussions (in both sites).**

266  
 267

Key themes	Men	Women
<b>Family</b>	<ul style="list-style-type: none"> <li>- Isolation from family activities</li> <li>- Families broken up/divided</li> <li>- Loss of spouse and/or other relatives</li> <li>- Stigma (rejected by or treated differently by the family)</li> </ul>	<ul style="list-style-type: none"> <li>- Stigma (being rejected by family)</li> <li>- Family breakup / abandonment by parent</li> <li>- Concern about meeting the needs of their children</li> <li>- Loss of many members of the family</li> <li>- Changed behaviours towards survivors (e.g. separate utensils, keeping distance)</li> </ul>
<b>Relationships</b>	<ul style="list-style-type: none"> <li>- Stigmatisation</li> <li>- Difficulties with re-integrating into community</li> <li>- Not allowed access to toilets</li> <li>- Difficulty in finding a partner</li> <li>- Feeling alone</li> <li>- Keeping secrets (because of the fear of stigma)</li> <li>- Using isolation as a way of coping</li> </ul>	<ul style="list-style-type: none"> <li>- Victim blaming</li> <li>- Stigma (being excluded / rejected, being rejected by friends, isolation, in school)</li> <li>- Enforced migration</li> <li>- Suspicion amongst family members that any future illness may be Ebola again</li> </ul>

<b>Health</b>	<ul style="list-style-type: none"> <li>- Frequent health problems including: <ul style="list-style-type: none"> <li>• Joint pain/problems</li> <li>• Trembling</li> <li>• Fever</li> <li>• Insomnia</li> <li>• Memory problems</li> <li>• Vision problems</li> <li>• Fatigue</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Varied health problems including: <ul style="list-style-type: none"> <li>• Stomach pains</li> <li>• Joint pain/problems</li> <li>• Head aches</li> <li>• Frequent colds</li> <li>• Fatigue</li> </ul> </li> </ul>
<b>Economics</b>	<ul style="list-style-type: none"> <li>- Loss of rented accommodation</li> <li>- Loss of work</li> <li>- Affected professional life</li> <li>- Loss of property (land, house)</li> <li>- Restriction of economic activities</li> <li>- Reduction of income</li> </ul>	<ul style="list-style-type: none"> <li>- Reduced income (sometimes because of loss of clients)</li> <li>- Loss of or reduced income generating activities</li> <li>- Loss of money</li> <li>- Loss of accommodation</li> <li>- Increase in debt</li> <li>- Loss of family property</li> <li>- Reduced performance at work (related to health issues)</li> </ul>
<b>Wellbeing</b>	<ul style="list-style-type: none"> <li>- Traumatized</li> <li>- Lack of consideration of the psycho-social needs of survivors</li> <li>- Difficulties in forgetting the past</li> <li>- Isolating oneself</li> <li>- Stress</li> <li>- Unhappiness</li> </ul>	<ul style="list-style-type: none"> <li>- Considering oneself a half-person</li> <li>- Unhappiness</li> <li>- Feeling pitied</li> </ul>

268

269 There was a great deal of consistency in the issues raised by men and women, and within the two very  
270 different communities. However, in site two, more stories were heard about very large numbers of  
271 people dying within single families and villages than in site one. This is likely because the outbreak  
272 went undetected here for a while before infection control and containment measures were put in place.  
273 Both the men and women in site two identified the circulation of false rumours as a particular issue.

274 Survivors in all groups were worried about their health and what the virus is still doing to them. There  
275 was no clear understanding of virus persistence in their body, and anxiety and confusion about the  
276 lingering effects of the initial infection. Survivors reported still experiencing a number of symptoms –  
277 many bordering between mental and physical health. For example, whilst many reported experiencing  
278 fatigue, it is not known whether this was as a result of ongoing effects of the virus, or as a result of  
279 depression or post-traumatic stress. The support provided for physical health symptoms varied.  
280 Participants in certain research studies (e.g. the ‘Postebogui’ study<sup>18</sup>) were able to get free health care.  
281 However, many of the survivors in the discussion groups expressed the need for help with their medical  
282 charges. In addition, informants told us that there was no formal support provided for mental health  
283 care, even for those involved in the research studies. This appears to be very important as many  
284 survivors in the discussion groups faced considerable difficulty obtaining informal support from the  
285 community as a result of the stigmatisation that they faced. Isolation and mental ill-health were  
286 sometimes extreme – leading to two recent suicides amongst the survivors in site two. Survivors’  
287 groups organised by the local authorities were able to provide informal peer support to a limited degree,  
288 but this was hindered by difficulties with geographical spread and communication, and a lack of  
289 financial support to maintain the network.

290 The wider social and financial needs that survivors faced were met to a certain extent following  
291 discharge from the treatment centre. They received food donations from the World Food Programme,  
292 financial assistance from National Coordination Ebola response, international agencies and local  
293 authorities and NGOs, and free health care and other material support for short periods. However, some  
294 survivors expressed concern that not all the donations were reaching the survivors and the communities  
295 as intended. The support, whilst appreciated and beneficial, was short-lived compared with the ongoing  
296 needs of the survivors. Participants emphasised their desire to live and work independently rather than  
297 rely on other, external, hand-outs. They talked about their need for education and capacity building,  
298 both to become more literate, and to open opportunities for employment.

299 Most of the survivors in the discussion groups were aware of, or active participants in, some form of  
300 research on EVD. Many of them had signed up to give blood and/or semen samples for scientific  
301 analysis. Some had conducted health questionnaires. However, participants explained that they had  
302 not been involved in any research that asked them about their experiences either being infected or of  
303 the treatment they received, or the impact, for them, of having survived the virus.

304

### 305 **Health practitioners and community representatives**

306 There were many common themes expressed by both health practitioners and community  
307 representatives in both site one and site two. All the informants talked about the experiences and needs  
308 of survivors in much the same way as the survivors themselves – indeed many of the informants were

309 themselves survivors. In addition, the informants described the ways in which their communities had  
310 been affected, and the ways in which their communities responded, both to the outbreak itself, and to  
311 the authorities' response to the outbreak. It was clear that community representatives saw whole  
312 communities as having been profoundly affected by the outbreak, and the notion of communities  
313 surviving the experience, in addition to individuals surviving the virus, began to emerge. The key  
314 themes are outlined below, in no order of priority:

#### 315 *Misunderstandings / trust*

316 There were many rumours surrounding Ebola, particularly with regards to where it came from and how  
317 it was spread. Negative reactions from some communities to the authorities' (including government,  
318 local/international agencies and NGOs) response were triggered by a lack of understanding which  
319 seemed to emerge both from the initial message from authorities that Ebola cannot be cured, and from  
320 the practices of those engaged in the response (e.g. spraying of areas, secure burials). For example, the  
321 communities' perception of the ineffectiveness of treatment was reinforced by the fact that health  
322 practitioners – including both traditional healers and those practising scientific medicine - contracted  
323 the disease, and sometimes died from it. This was particularly the case in site two, since communities  
324 in this region were affected much earlier than elsewhere in the country. False rumours have been  
325 pervasive, damaging and lasting. These misunderstandings have contributed to a lack of trust not just  
326 with the authorities, but also with medical practitioners. Because of this, traditional healers played an  
327 important role (particularly in the early stages of the outbreak), where they received people who did not  
328 have trust/confidence in professional healers. The lack of trust that emerged as a result of  
329 misunderstandings extended to neighbours and communities and has persisted, resulting in the survivors  
330 facing stigma and discrimination. Sometimes, the misunderstanding and fear were such that individuals  
331 and groups acted in extreme ways towards each other, for example, by burning the house and  
332 possessions of survivors. Several health practitioners who themselves survived the virus reported  
333 difficulties in re-integrating at work, due to a lack of trust from their colleagues and patients.

#### 334 *Fractured communities*

335 The impact of the epidemic and the response to it appeared to have fractured communities. Whilst this  
336 was due in part to misunderstandings, it partly arose as a consequence of the need to break cultural  
337 traditions and social norms (such as caring for relatives who are sick or visiting friends when sick) in  
338 order to break the chain of transmission. This enforced separation and created discord within families,  
339 villages and larger community groups. Sometimes, family separation was caused by the social and  
340 practical necessities of caring for children who had lost one or both parents to the disease. This itself  
341 was complicated by extreme economic hardship, which sometimes forced difficult decisions to be made  
342 – for example, where a surviving parent lost their income and felt no longer able to look after their  
343 child(ren). The social cohesion that was affected during the outbreak appears to be taking time to be

344 rebuilt. One informant explained how his mother, who refused entry to her house of a sick neighbour at  
345 the height of the outbreak, is still shunned by that neighbour's friends and family.

346 *Needs of communities*

347 Survivors returning from the treatment centres often struggled to reintegrate within these fractured  
348 families/communities. Whole communities felt the effects of the outbreak in a number of ways, with  
349 reduced opportunities for income generation, and consequent lack of ability to support families  
350 (including orphans), and pay for food, education and health services. Community leaders emphasised  
351 that whilst some additional resources had been provided, they were insufficient to meet the ongoing  
352 needs of the survivors and the community as a whole.

353 Both the community leaders and health practitioners talked a great deal about the specific ongoing needs  
354 of survivors. These were entirely consistent with the discussions within the survivors' groups.

355 *Capacity to meet needs*

356 Informants reflected that the authorities and national and international NGOs had provided various ways  
357 of meeting the needs of survivors, including financial support, food donations and health care.  
358 However, communities continue to have unmet needs, such as employment, financial stability, mental  
359 health services and social support services (such as with looking after children, orphans, and other  
360 dependents).

361 In some ways, the ability to provide good quality health services is stronger now, with improved  
362 knowledge, better sanitation, improved supplies and better surveillance/reporting systems. However,  
363 there are signs that some of these improvements are not being / will not be sustained. Participants  
364 explained how there had been problems with the ongoing supplies of drugs and sanitation supplies, and  
365 how the initially improved sanitation practices (such as handwashing) were not being maintained by  
366 either health workers or communities. In some ways, capacity is weaker – for instance, with rejection  
367 of health workers, affected relationships (lack of confidence) between communities and health workers,  
368 and fewer patients with the ability to pay, leading to reduced income for hospitals.

369 **Perspectives of key national and international stakeholders**

370 *The needs of survivors:* Key stakeholders in general emphasised that there is a continued need for  
371 research that focuses on EVD survivors. A greater understanding of the virus itself is still required,  
372 including the risks of reinfection/transmission and the long-term health and social implications for  
373 survivors. It is clear that some survivors continue to experience stigma and discrimination leading to  
374 social isolation and loss of employment; and such exclusion can have consequences for mental health.  
375 Stakeholders responsible for large scale response and relief efforts (including Government, WHO and  
376 UNICEF) recognised the wider, longer-term impact of the virus, but did not have the information

377 required to understand the extent of need faced by the survivors. In addition to the potential for  
378 vulnerability to mental health problems, stakeholder participants understood that survivors may have a  
379 number of complex unmet needs, including health, psychological and social needs, and the need for  
380 assistance with community re-integration. Policy makers and providers described the importance of  
381 identifying these and other ongoing long-term needs of survivors so that they know where to focus their  
382 support now, and to be better informed for any future outbreaks. Moreover, survivors have been given  
383 a range of short-term support from the Government, as well as local and international agencies, and  
384 stakeholders felt it was important to know how that has been received and the impact that it has had.

385 *Social and economic impact:* Stakeholders also highlighted the need for research beyond the survivors,  
386 in order to more fully understand both the national and international response to the EVD epidemic in  
387 Guinea, and its wider social, economic and political impact. They described the ways in which the  
388 responses of, for example neighbouring national governments, and the international media, had  
389 sometimes profound outcomes for the people of Guinea. It was also recognised that certain aspects of  
390 the response (such as closing ports and shipping routes) could act to hinder the country's ability to  
391 contain the outbreak (for instance, when equipment and supplies cannot easily be brought in)..  
392 Discussions confirmed that it is important to make an analytical distinction between the impact of the  
393 epidemic, and the impact of the (micro, meso and macro level) responses to it, even though they are  
394 interrelated. There was clearly sometimes an element of conflict between national priorities (to contain  
395 the outbreak whilst at the same time limiting its impact on the country's economy), and international  
396 priorities (to ensure the virus did not cross- country borders).

397 Informants identified the need to focus on the micro, meso and macro level responses to the epidemic  
398 and gave two reason for this First, there was considerable variation between areas in Guinea in the  
399 disease incidence, virus transmission and the time it took to achieve containment. The reasons for this  
400 variation are not understood, yet they may hold some important lessons for improving responses to  
401 future outbreaks. Secondly, it is clear that in some communities there was resistance to the national  
402 and international response - including case management, contact tracing, sanitation practices and burial  
403 of the dead. This had important consequences for trust, community engagement and ultimately for the  
404 ability to locally contain the disease. The authorities' initial response to the outbreak seemed to  
405 influence the ways in which the local communities reacted, affecting both disease containment and the  
406 subsequent community/family reintegration of survivors. The consideration of trust, raises the general  
407 question articulated by one informant from an academic background about whether trust relations  
408 between communities and authorities had been eroded and were at a low level prior to the epidemic,  
409 and the Ebola virus outbreak exacerbated or brought to a head the tension between the different groups  
410 or if trust relations were specifically damaged by the authorities' response to the outbreak.

411 However, the key stakeholders, particularly those representing the NGOs, also emphasised that there  
412 was little evidence available about the full, wider impact of the epidemic on the country, the  
413 communities and the survivors. Key stakeholders informed us that there are a number of partial analyses  
414 of the impact of the EVD epidemic which focus on discrete areas (e.g. health services, impact on  
415 economic activity) but we were not given access to these, and there appears to be no comprehensive  
416 socio-cultural, economic and policy analysis of the impact as a whole. There are also areas of impact  
417 that seem not to have been explored in the academic literature, such as: the closure of transportation  
418 routes and trade links, community cohesion, impact on religious practices and the restrictions on travel,  
419 Guinea's capacity for research and emergency response, and the role of the global media.

420 *The need for international comparative research:* Finally, participant stakeholders suggested that  
421 evidence from comparative research would aid the understanding of how distinctive both the response  
422 to the epidemic and its long-term impact was in Guinea. There appears to be some research collaboration  
423 between low-income countries such as Guinea, Sierra Leone and Liberia which were most affected by  
424 the outbreak, but the focus appears to be mainly on biomedical/clinical research. There is limited  
425 evidence of comparative social science research investigating, for example, variations in policy  
426 response and impact.

#### 427 **Towards an agenda for research**

428 The research team identified, through a thematic analysis, seven broad areas for further research that  
429 emerged from the scoping exercise. These were phrased as research questions, and discussed during a  
430 debriefing meeting with key stakeholders, who were then asked to rank them in order of priority. The  
431 priority ranking given to each key question varied considerably amongst the stakeholders, with the  
432 result that the average rankings were closely clustered. The questions, in order of average priority  
433 ranking score were:

- 434 1. What is the long-term socio-cultural, economic and health impact of the EVD epidemic on the  
435 country of Guinea?
- 436 2. What is the nature and impact of social stigma associated with EVD, and what are the factors that  
437 have contributed to the stigmatisation of survivors?
- 438 3. What can we learn from the local, national and international responses to the EVD outbreak about  
439 the nature of communication required for effective community engagement?
- 440 4. Why was the response to and effect of the Ebola virus so variable between different communities?
- 441 5. What is the impact of the EVD outbreak on non-infected community members as compared to  
442 infected survivors?



443 6. Are the neurological symptoms experienced by EVD survivors a consequence of direct effects of  
444 the virus, or the unmet mental health needs associated with the experience the survivors went  
445 through?

446 7. How did the response to and impact of the EVD outbreak vary between different countries in the  
447 region?

#### 448 **Discussion**

449 The aim of this study was to explore ideas and priorities for further health and social care research  
450 related to the EVD outbreak in Guinea from the perspective of members of the local population. A list  
451 of seven broad research questions were identified from this scoping study. However, before each of  
452 their implications are discussed, it is important to recognise the limitations of this rapid assessment.

453 Due to time and resource constraints, it was not possible to conduct a full research prioritisation  
454 exercise. Rather, this exercise should be seen as a pre-cursor to such a study, and results interpreted  
455 accordingly. Informants were not selected randomly but purposefully – that is, a range of people who  
456 are in an appropriate position to understand the issues, were asked to participate. The sample of key  
457 stakeholders was limited in terms of whether it fully represented the key voices in the national and local  
458 populations. It was also overwhelmingly male (all but 2). Whilst this reflects the much smaller number  
459 of women in senior positions, it might have been possible to identify and include additional female  
460 stakeholders in a more extensive field study. The discussion groups cannot be taken to represent the  
461 beliefs of the survivors as a whole. For example, they might have been more likely to have higher levels  
462 of literacy than the general population, which is reported to have relatively low levels of literacy  
463 compared with neighbouring countries. Data collection and analysis conducted using rapid appraisal  
464 techniques may have a risk of researcher bias. This was minimised by using local ‘communicators’  
465 (community liaison) for interviewing, as they might more easily tap into the private accounts which  
466 people would be reluctant to release to foreigners/strangers. Interviewers were given brief training by a  
467 member of the research team who is experienced in rapid appraisal methods. Analysis was conducted  
468 by an interdisciplinary team (the authors) so as to take on board a range of professional training,  
469 ethnicity, gender and theoretical perspectives.

470 There was evidence that some of the participants were involved in other research projects, which raises  
471 the question of whether survivors’ groups might become ‘over researched’. However, the participants  
472 reported that whilst many had undergone repeated biological testing, this had been their first opportunity  
473 to share their thoughts, experiences and beliefs. This study began by focusing on the experiences of  
474 survivors. However, it became evident that during the course of this scoping exercise, other topic areas  
475 were identified by key stakeholders. This illustrates the flexibility and iterative nature of the  
476 methodological approach adopted but also raises the question of the extent to which the study was able

477 to explore wider research questions when much of the focus was on survivor's experiences. Thus, it is  
478 necessary to be cautious about the interpretation of these data particularly in terms of their transferability  
479 to other contexts.

480 The top priority for research for informants tended to vary according to the interests of the stakeholders.  
481 Many of the key stakeholders saw the need to assess the long-term impact of the EVD outbreak whereas,  
482 perhaps unsurprisingly, the survivors identified the question related to social stigma as being more  
483 important than did the other stakeholders. Several studies have been carried out evaluating the short-  
484 term impact of the EVD outbreak on different aspects, such as the economy and the health  
485 infrastructure.<sup>8</sup> However, there has not been any comprehensive analysis of the long-term impact on  
486 Guinea as a whole, evaluating both positive and negative aspects. The field work suggested that whilst  
487 many regions of Guinea were severely affected by economic and personal loss, there are also some  
488 ways in which country capacity is now stronger, for instance for health protection and scientific  
489 research. Therefore, a systems analysis of the response and its impact could be important, utilising  
490 similar approaches and methods to those used for infectious disease preparedness or strategic  
491 planning.<sup>30,31</sup> Such an analysis might probe deeper into the nature of contributory factors both for the  
492 (non)containment of the virus, and the scale of the repercussions at individual, community, country and  
493 international levels. A wide ranging and comprehensive analysis might begin by carrying out a review  
494 of the available evidence. The gaps identified in this review could then be explored through further  
495 interdisciplinary research. This analysis could provide evidence to inform policy options if there are  
496 any further epidemics of Ebola or outbreaks of similar diseases in Guinea and comparable low-income  
497 countries.

498 There was some consensus that survivors' experiences need to be further investigated, although the  
499 clinical and psychiatric experience of survivors is being explored in current research carried out in the  
500 POSTBOGUI study.<sup>18</sup> More information is required about the nature and impact of social stigma,  
501 including its impact on the personal, social and economic lives of the survivors and their families.  
502 Qualitative methods might be appropriate for eliciting in-depth information about felt, enacted and  
503 courtesy stigma.<sup>32</sup> This could build on and be compared with the considerable sociological research  
504 literature related to stigma and chronic illness for example, in relation to HIV/ AIDS.<sup>33</sup> Evidence from  
505 such research could be used to inform the development of policies aimed at enhancing the social  
506 integration of survivors, as well as national and international responses to any future epidemics.

507 The majority of EVD survivor studies are specifically focused on previously infected individuals.  
508 However, many non-infected members of the community have been similarly impacted, for example  
509 through financial loss, bereavement, trauma, isolation and the disruption of family and social networks.  
510 It may be beneficial to broaden the definition of 'survivor' to include both disease survivors as well as

511 the non-infected survivors. By better understanding the needs of all survivors, it may be possible to  
512 identify strategies for reintegration, and for strengthening resilience within local communities.

513 The field work illustrated a significant number of neurological issues of unknown origin. These include  
514 symptoms such as headaches, chronic pain, fatigue, vision impairment and tremors. In addition, it  
515 seemed that survivors were suffering from a range of mental health issues that could include depression  
516 and post-traumatic stress disorder.<sup>34</sup> It is not clear if these neurological issues are a direct result of viral  
517 infection or are a consequence of mental health problems associated with the outbreak. By investigating  
518 the biological persistence of the virus in the central nervous system, in conjunction with a detailed  
519 mental health assessment, it may be possible to ascertain the best ways of supporting and/or treating the  
520 survivors.

521 Trust or the lack of it appeared to be a key issue associated with dialogue and engagement and more  
522 generally between communities and the health and political authorities.<sup>35</sup> Communications between  
523 populations and local and national government, NGOs, health professionals and others played a vital  
524 role in the response to the outbreak and in disease containment. The explanations for the resistance of  
525 some sections of the community have received some attention from anthropologists.<sup>10,12,36</sup> There is some  
526 research evidence about why some sections of the community were resistant to the Ebola emergency  
527 response, although this research needs to be more extensive.<sup>10</sup> The ways in which messages were framed  
528 and communicated, for instance through the local, national and international media and through the  
529 country's community networks, are likely to have had an important influence on community response.<sup>3</sup>  
530 The focus of further research might be on how the nature of communication affected trust relations  
531 within communities and between communities and health and political authorities.<sup>36</sup> Trust covers both  
532 confidence in competence (doing a good job), and trust in intentions (working in the interests of the  
533 client/public).<sup>37</sup> An improved understanding of the relationship between communication and trust might  
534 identify strategies for building or repairing trust relations, which could inform policy recommendations  
535 for achieving effective community engagement in health care programmes. However, it has been argued  
536 that these relatively low levels of trust relations are more deep-seated - such as at the level of governance  
537 - suggesting that more extensive strategies might need to be considered for restoring trust in  
538 institutions.<sup>38,39</sup> It echoes the suggestion from the **UDP13** that '*Trust in public institutions could be*  
539 *strengthened through inclusive dialogue, efforts to enhance accountability, and equitable and*  
540 *harmonized service delivery*' (p15).

541 A related question is associated with the considerable variation in the transmission of the virus between  
542 and within communities.<sup>40,41</sup> In addition, different communities responded in different ways to the  
543 disease outbreak and to the authorities involved in disease containment. There is epidemiological data  
544 that has mapped the spread of the virus during the course of the outbreak.<sup>1,4,40,41</sup> In addition, there are  
545 ongoing biological surveys investigating community-to-community differences in survivor responses

546 to the virus. In order to fully understand these community differences, it would be necessary to combine  
547 the ongoing epidemiological and biological studies with a sociological analysis of community  
548 members' attitudes, beliefs and behaviours. By understanding the reasons for community variation in  
549 EVD, it may be possible to develop better policies and practice for future disease containment. Certainly  
550 the role of communities have been identified as crucial to the success of containment and recovery  
551 programmes.<sup>13</sup>

552 Finally, the outbreak had significantly different impacts on Guinea, Sierra Leone and Liberia, and also  
553 affected many other countries within the region that are not included in any ongoing analysis.  
554 International comparative research would attempt to explain why there may be differences and  
555 similarities across countries.<sup>42</sup> This would provide opportunities for policy learning that could be used  
556 to enhance resilience, infrastructure and response for future emergencies.

557 In conclusion, despite the limitations, it is clear that this scoping exercise has generated a wealth of key  
558 research questions that need to be explored further. It identified an expressed need for research focusing  
559 on survivors. It also emphasised the importance of research which analyses the social response to and  
560 impact of outbreaks of epidemics such as Ebola and to discover if the Ebola epidemic was distinctive  
561 in terms of pandemics, both in the way it was responded to and its impact. More generally, it highlighted  
562 the need for this research to be inter-disciplinary, and emphasised the importance of the contribution to  
563 this of the social sciences.

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