

# Institutional trust and misinformation in the response to the 2018–19 Ebola outbreak in North Kivu, DR Congo: a population-based survey



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## Summary

**Background** The current outbreak of Ebola in eastern DR Congo, beginning in 2018, emerged in a complex and violent political and security environment. Community-level prevention and outbreak control measures appear to be dependent on public trust in relevant authorities and information, but little scholarship has explored these issues. We aimed to investigate the role of trust and misinformation on individual preventive behaviours during an outbreak of Ebola virus disease (EVD).

**Methods** We surveyed 961 adults between Sept 1 and Sept 16, 2018. We used a multistage sampling design in Beni and Butembo in North Kivu, DR Congo. Of 412 avenues and cells (the lowest administrative structures; 99 in Beni and 313 in Butembo), we randomly selected 30 in each city. In each avenue or cell, 16 households were selected using the WHO Expanded Programme on Immunization's random walk approach. In each household, one adult (aged  $\geq 18$  years) was randomly selected for interview. Standardised questionnaires were administered by experienced interviewers. We used multivariate models to examine the intermediate variables of interest, including institutional trust and belief in selected misinformation, with outcomes of interest related to EVD prevention behaviours.

**Findings** Among 961 respondents, 349 (31.9%, 95% CI 27.4–36.9) trusted that local authorities represent their interest. Belief in misinformation was widespread, with 230 (25.5%, 21.7–29.6) respondents believing that the Ebola outbreak was not real. Low institutional trust and belief in misinformation were associated with a decreased likelihood of adopting preventive behaviours, including acceptance of Ebola vaccines (odds ratio 0.22, 95% CI 0.21–0.22, and 1.40, 1.39–1.42) and seeking formal health care (0.06, 0.05–0.06, and 1.16, 1.15–1.17).

**Interpretation** The findings underscore the practical implications of mistrust and misinformation for outbreak control. These factors are associated with low compliance with messages of social and behavioural change and refusal to seek formal medical care or accept vaccines, which in turn increases the risk of spread of EVD.

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## Introduction

On Aug 1, 2018, the DR Congo declared its tenth outbreak of Ebola virus disease (EVD). Responding to EVD outbreaks entails a multifaceted control strategy that includes the early detection, active finding and isolation of suspected cases, identification and tracing of contacts, as well as risk communication, specialised medical care, support for safe burial practices, and vaccination for individuals at high risk.<sup>1,2</sup> These measures are particularly challenging in an active conflict zone.<sup>3</sup> They assume some level of public cooperation to report suspect cases, confidence in response workers, and freedom of movement for public health teams.

Eastern DR Congo has had violent conflicts for over two decades, leading to the protracted presence of humanitarian agencies. Over the past 4 years, the epicentre of the current EVD outbreak around the city of Beni has endured recurring violence resulting in thousands of deaths and injured people.<sup>4</sup> Such violence limits the free movement of the population and health

workers and leads to the collapse of trust and social capital.<sup>5–7</sup> Longitudinal data from the region show that the perception of security and trust in government, security, and humanitarian workers has been declining, complicating what is already a complex and challenging EVD response operation.<sup>8</sup> Community trust and support for the EVD response is undermined by misinformation exploited by local politicians<sup>9</sup> and the contrast between the rapid mobilisation to contain the EVD outbreak and chronic failure to protect civilians.<sup>10</sup> Violent incidents, including targeted attacks on response teams, led to the temporary suspension of EVD response activities.<sup>11</sup> These activities include important local engagement efforts by the International Federation of Red Cross and Red Crescent Societies, UNICEF, WHO, and others to dispel misinformation and provide crucial information and services for prevention and care.

The role of public trust is recognised in medicine and public health. Trust is central to the legitimacy of health systems.<sup>12</sup> Trust and legitimacy have been associated with

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### Research in context

#### Evidence before this study

We searched PubMed and Google Scholar for publications in English and French published from Jan 1, 1950, to Aug 20, 2018, using various combinations of the terms “trust”, “Ebola outbreaks”, “behaviour change”, “protective behaviours”, and “preventive behaviours”. We obtained few studies and broadened the search to include other epidemic-prone diseases, using the terms “cholera”, “malaria”, “Zika”, “HIV-AIDS”, and “infectious diseases”. The relevant published studies suggested that mistrust and misinformation are obstacles to public health interventions. However, most studies were qualitative and few had attempted to rigorously characterise and quantify these issues, and only one had done so during an Ebola outbreak. No previous studies have attempted to define these issues in the context of active conflict.

#### Added value of this study

We present the most comprehensive study of trust and misinformation and their association with preventive

behaviours during an outbreak of Ebola virus disease in an active conflict environment. Our data indicate that low institutional trust and belief in misinformation about Ebola are inversely associated with preventive behaviours on an individual level. This study more precisely defines the socioanthropological factors that are important for outbreak control, which provides evidence to guide prioritisation of response activities.

#### Implications of all the available evidence

Trust and the circulation of accurate information by reliable sources are crucial to control Ebola outbreaks and pose a major challenge in conflict environments. Despite substantial advances in the public health response to Ebola outbreaks in general, the precise mechanisms by which misinformation and mistrust undermine outbreak response are poorly understood, especially in conflict settings.

See Online for appendix

acceptance of and compliance with preventive or curative interventions, including vaccine acceptance and changes in individual behaviours to reduce risk.<sup>13–19</sup> Public trust in the health-care system, the understanding of EVD transmission risks, perceptions of and experiences with EVD survivors, and long-term effects of violence also appear to be associated with compliance.<sup>20,21</sup> Fear and the perception of risk might also influence the adoption of EVD preventive behaviours, as shown during the 2014 west Africa outbreak.<sup>22</sup> Despite this evidence, the association between institutional trust and individual-level responses to outbreaks during conflict is underexplored, especially concerning EVD.

We aimed to explore two hypotheses: (1) whether institutional trust is associated with the adoption of preventive measures, including exposure avoidance and vaccination; and (2) whether belief in EVD misinformation is associated with lower adoption of preventive measures. This study builds on underdeveloped but crucial research examining misinformation about the motives or results of interventions as important obstacles to public health programmes.<sup>23</sup>

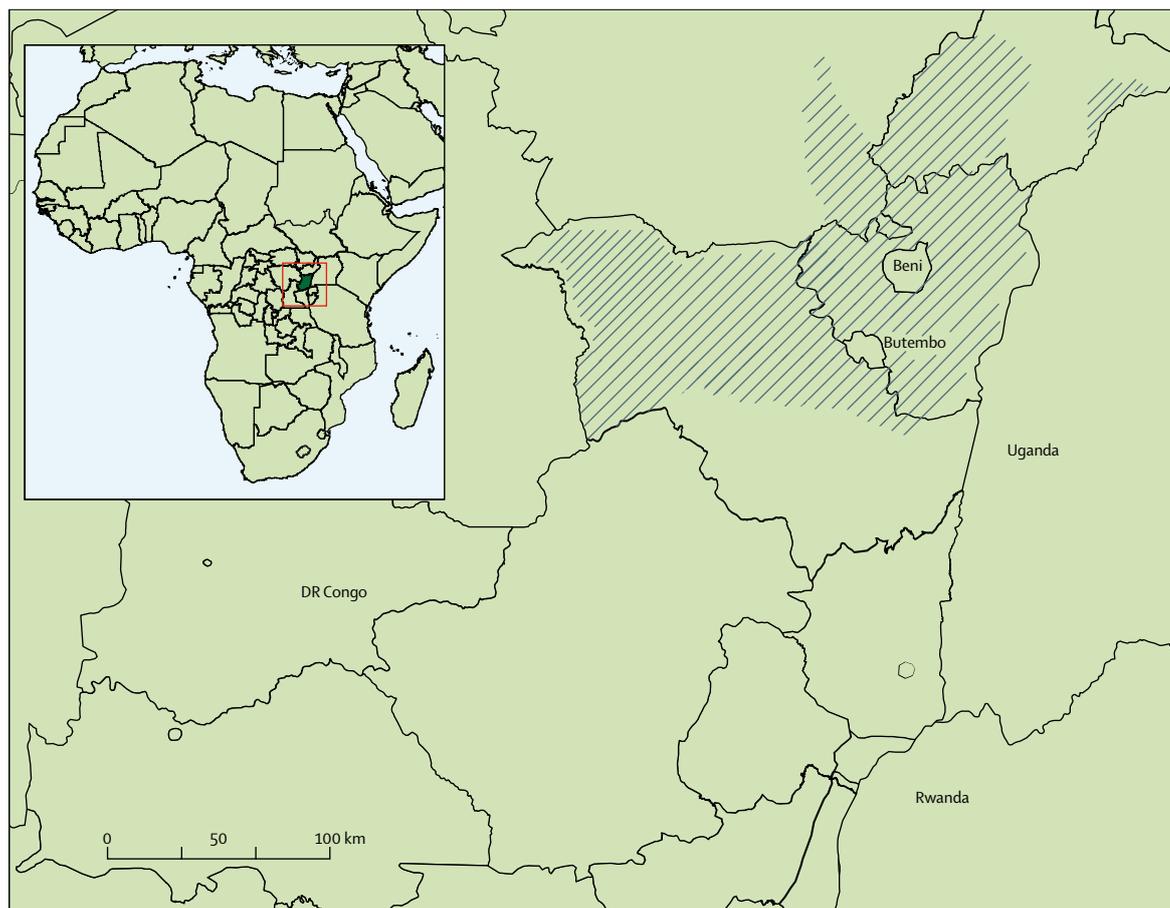
## Methods

### Study design and participants

We did a population-based survey 1 month after the EVD outbreak was declared (Aug 1, 2018), in the cities of Butembo (population 670 000) and Beni (230 000), in the province of North Kivu, eastern DR Congo (figure). As of Feb 25, 2019, WHO reported 875 probable and confirmed cases of EVD and 486 confirmed deaths due to the current outbreak, including 235 (26.9%) of those confirmed and probable cases in Beni and 78 (8.9%) in Butembo.

Respondents were selected using a multistage cluster sampling procedure (appendix). Out of 412 avenues and cells (the lowest administrative structures; 99 in Beni and 313 in Butembo), we randomly selected 30 in each city, using a list of all avenues and cells and with a systematic random approach, generating a random number then using a constant interval to select the next avenue or cell. In each avenue or cell, 16 households were selected using the WHO Expanded Programme on Immunization's random walk approach. In each household, we randomly selected one adult for interview. When first contacted, any individual that was present in the randomly selected household was asked how many adults (aged ≥18 years) lived in the household. Three attempts were made to contact the selected individuals over the course of 1 day. If the third attempt failed, interviewers proceeded to the next randomly selected respondent, first within the same household, or in the next household if no other eligible adult was available. Female interviewers selected eligible adult women, and male interviewers selected eligible adult men. Because interview teams comprised equal numbers of men and women, this method ensured sex-matching and equal sex representation in the sample.

Participation was anonymous, voluntary, and no compensation was provided. Interviewers were trained on preventive measures to reduce risk of exposure, and all households were provided with EVD information sheets in local languages at the end of the interview. The survey was approved by the Human Research Committee at Brigham and Women's Hospital (Boston, MA, USA) and a similar body that was convened by the Research Center on Democracy and Development in Africa, Free University of the Great Lakes Countries in the DR Congo (Goma, DR Congo).



**Figure: Study sites**  
Shaded areas represent Ebola-affected health zones within, North Kivu, DR Congo.

## Procedures

Interviews were done using a standardised, structured questionnaire developed by a team with experience in public health, medicine, anthropology, and EVD in DR Congo and west Africa. The questionnaire was developed in English and translated into French and Swahili. Independent experts reviewed and validated the translation. Local experts established face validity. Pilot interviews were done to test and validate the questionnaire. Questions covered demographics, measures of institutional trust, trust in the EVD response, exposure to EVD-related information, knowledge about and changes in behaviour due to the EVD outbreak, and health-seeking behaviour. Interviewers were experienced in community survey methods and participated in a 1-week training course on the questionnaire content and sampling protocol. The survey was done using tablet computers.

We computed several scores to combine the outputs of multiple questions covering similar topics. The government trust score, developed for longitudinal research in eastern DR Congo,<sup>8</sup> was computed using questions related to community perceptions of how authorities represent the interest of the population at

different administrative levels (neighbourhood, city, provincial government, and national government). Each of the four questions was scored from one to five with one reflecting the lowest level of trust. A cumulative score was computed and scaled from one to five.

A summative EVD information score quantified exposure to six specific categories of EVD information (prevention, symptoms, where to seek health care, what to do if a relative or neighbour has EVD, updates on EVD in the province, overall EVD response). An open-ended question assessed where, if at all, respondents would seek care if they suspected they had EVD. Formal health services included hospitals or health centres and informal settings included friends and traditional healers. Acceptance of EVD vaccine was assessed using two items: belief that the vaccine was safe and acceptance of the vaccine, if offered. The EVD risk-perception score was a measure of perception of personal risk of contracting Ebola in the month following the survey.

To understand the relationship between the intermediate variables of interest (trust, exposure to EVD information, and exposure and belief in misinformation) and the outcomes of interest (EVD avoidance or preventive

	Unweighted (n)	Weighted (% [95% CI])
Total	961	..
Generalised government trust		
Trust local authorities	349	31.9% (27.4–36.9)
Trust city authorities	198	15.1% (11.9–19.0)
Trust provincial authorities	75	4.9% (3.6–6.7)
Trust national authorities	29	2.1% (1.2–3.4)
Ebola-related trust		
Trust government for Ebola response	419	40.5% (36.8–44.3)
Trust health professionals for Ebola response	620	61.5% (56.9–65.9%)

**Table 1: Trust in state and institutions**

	Government trust score (mean [SD])	Government EVD trust score (mean [SD])	Health professional EVD trust score (mean [SD])
Total	2.69 (0.67)	3.20 (0.84)	3.59 (0.84)
City			
Beni (n=481)	2.86 (0.60)	3.36 (0.72)	3.73 (0.67)
Butembo (n=480)	2.64 (0.68)	3.15 (0.87)	3.54 (0.88)
Sex			
Female (n=482)	2.65 (0.80)	3.08 (0.97)	3.49 (0.99)
Male (n=479)	2.74 (0.50)	3.33 (0.66)	3.68 (0.63)
Age group (years)			
18–30 (n=450)	2.67 (0.67)	3.18 (0.84)	3.63 (0.85)
31–45 (n=295)	2.78 (0.64)	3.22 (0.80)	3.51 (0.79)
≥46 (n=216)	2.63 (0.70)	3.23 (0.90)	3.60 (0.88)
Education			
None or incomplete primary (n=255)	2.76 (0.62)	3.13 (0.79)	3.54 (0.84)
Primary completed (n=363)	2.63 (0.69)	3.15 (0.90)	3.53 (0.91)
Secondary completed or higher (n=343)	2.72 (0.67)	3.31 (0.80)	3.69 (0.74)
Wealth			
Poorest quartile (n=270)	2.71 (0.71)	3.08 (0.89)	3.48 (0.96)
Second quartile (n=206)	2.67 (0.73)	3.22 (0.86)	3.60 (0.81)
Third quartile (n=263)	2.68 (0.60)	3.26 (0.76)	3.67 (0.76)
Richest quartile (n=222)	2.71 (0.63)	3.27 (0.83)	3.62 (0.77)
Ethnicity			
Non-Nande (n=105)	2.78 (0.75)	3.15 (0.95)	3.72 (0.70)
Nande (n=856)	2.69 (0.66)	3.21 (0.83)	3.58 (0.85)

EVD=Ebola virus disease.

**Table 2: Trust score by demographic characteristics**

behaviours), we explored changes in behaviour at the individual level that participants reported undertaking because of the EVD outbreak. Respondents were asked whether they engaged in a list of specific behaviours, as well as an open-ended question on changes in behaviour. A total of 12 behaviours were grouped into five categories: direct avoidance (three), social interaction avoidance (three), physical contact avoidance (two), public space avoidance (three), and hygiene (one). The items were

identified in consultation with local and international anthropologists, risk communication specialists, and epidemiologists with expertise in EVD. Items were scored one and zero for change versus no change in reported behaviour.

### Statistical analysis

The sample size was calculated to estimate proportions in the given population for a 95% CI and 10% precision. We used a 0.5 proportion estimate, for a target sample size of 96. The sample size was multiplied by four (384) to allow for comparison by sex within cities and account for an estimated design effect of two. The sample size was increased by 20% to account for non-response and further adjusted to reflect logistical constraints, resulting in a target sample size of 480 interviews per city (960 total).

We calculated frequencies, odds ratios (ORs), 95% CIs, and all other analyses using the complex sample module in SPSS (version 25). Data were weighted to reflect the unequal probability of sampling between the two cities. We built four separate stepwise binary logistic models with direct avoidance behaviour (all and any), formal health seeking, and EVD vaccine acceptance as the outcomes of interest. The outcomes represent key aspects of EVD response—behaviour change, care seeking, and vaccination. For the four models, the independent variables were location, age, sex, education level, wealth, ethnicity, the government trust score, government EVD trust score, health professionals EVD trust score, EVD information score, EVD risk perception score, and belief in rumours. The independent variables of greatest interest were the measures of trust and belief in rumours. For belief in rumours, statements were tested independently and in combination. One item (belief in the rumour that Ebola does not exist) entered the model. The selection of independent variables was guided by the literature review, measures of associations, and expert opinion.

### Role of the funding source

The funders of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

### Results

Between Sept 1, and Sept 16, 2018, 961 adults from 977 households that we approached were interviewed in Beni (480) and Butembo (481; appendix). Ten households declined, and no one was home at the time of visitation at six households. The mean age was 34.3 years (SD 14.0) and the median age was 31.0 years (IQR 22–42). As per study design, there was equal sex representation.

Overall trust in how administrative authorities represent the interests of the population was low and decreased from local, to city, to provincial, to national levels (table 1). When considering the EVD response

specifically, 419 respondents trusted the government and 620 trusted health professionals to act in the best interests of the public (table 1). These items were used to compute the government trust score, government EVD trust score, and health professional EVD trust score (table 2).

All respondents had heard about the EVD outbreak, including 932 (97.6%, 95% CI 96.1–98.6) in the past week. Most respondents had received information about how to protect themselves, where to seek care, and symptoms of EVD (table 3). Fewer received information about what to do if a relative was affected, cases in the province, and ongoing efforts to control the outbreak (table 3). This information was used to compute an EVD information score summing the types of information received by respondents. The mean EVD information score was 4.7 (SD 1.48) out of a maximum of 6.

Respondents received Ebola information from friends and family (863 [88.8%, 95% CI 86.0–91.1]), community radio stations (803 [82.4%, 77.4–86.5]), national radio stations (657 [67.9%, 59.9–75.0]), religious leaders (691 [73.1%, 66.4–78.9]), and health professionals (562 [52.8%, 46.8–58.8]). Fewer had heard about EVD from local authorities (248 [21.3%, 16.3–27.2]) or national government (305 [28.7%, 23.5–34.5]).

Most respondents had heard statements that the EVD outbreak does not exist, was fabricated by the authorities for financial gains, or was fabricated to destabilise the region (table 3). One in four respondents believed in the statement that Ebola does not exist (table 3). A higher proportion of respondents believed that the Ebola outbreak was fabricated for financial gains, or was fabricated to destabilise the region; 446 (45.9%) respondents believed at least one misinformation statement to be true and 171 (18.2%) believed all were true (table 3). The EVD information and government trust score, government EVD trust score, and health professionals EVD trust scores were significantly lower among those who believed in all or any misinformation statements than among those who did not believe in misinformation statements (appendix).

Among all respondents, 220 (33.9%, 95% CI 25.7–43.3) thought contracting EVD was likely or very likely, 239 (21.9%, 17.4–27.2) were uncertain, and 502 (44.2%, 38.0–50.5) thought that contracting EVD was unlikely or very unlikely.

Respondents said that they engaged in protective behaviours following the outbreak declaration, including avoiding physical contact with people exposed or potentially exposed to EVD (table 4). Few people reported general avoidance of social interaction, such as avoiding visiting family members or neighbours (table 4). More respondents reported avoiding any public space, including church or public transport. Reduction in any physical interaction, including shaking hands or hugging with relatives and others, was commonly reported (table 4).

	Unweighted (n)	Weighted (% [95% CI])
Total	961	..
Type of information received		
Cases of Ebola in the province	605	63.7% (54.3–72.2)
Intervention to combat Ebola in the province	641	63.7% (54.5–72.1)
Symptoms of Ebola	831	85.0% (81.2–88.2)
How to protect oneself	896	91.6% (89.1–93.5)
Where to seek care	824	80.3% (77.0–83.2)
What to do if a relative has Ebola	747	72.3% (68.8–75.7)
Heard misinformation		
Ebola does not exist	850	86.5% (82.9–89.4)
Ebola is fabricated for financial gains	826	84.7% (80.2–88.3)
Ebola is fabricated to destabilise the region	837	86.1% (81.8–89.4)
Heard any of the three statements	899	92.2% (88.8–89.4)
Heard all three statements	768	78.0% (73.0–82.4)
Belief in misinformation		
Ebola does not exist	230	25.5% (21.7–29.6)
Ebola is fabricated for financial gains	312	32.6% (28.2–37.3)
Ebola is fabricated to destabilise the region	371	36.4% (32.1–41.0)
Believe any of the three statements	446	45.9% (41.7–50.2)
Believe all three statements	171	18.2% (14.3–22.7)

**Table 3: Respondents who had received or heard information or believed misinformation about Ebola**

Most respondents (876 [89.7%, 95% CI 86.1–92.4]) reported that they would first seek care from formal rather than informal sources if they believed they had EVD. However, among those who believed in all misinformation statements, 123 (70.8%, 59.6–80.0) of 171 would seek care from formal health service providers, compared with 753 (93.9%, 90.6–96.1,  $p < 0.0001$ ) of 790 among those who did not believe the statements. The government trust score was significantly higher among respondents who would seek care from formal sources than it was among those who would seek care from informal sources (2.7 (SD 0.65) vs 2.4 (0.72) out of 5,  $p < 0.0001$ ). Similarly, the government EVD trust score (3.3 SD 0.78) and health professional EVD trust score (2.5 SD 1.04) were significantly higher among respondents who would seek care from formal sources ( $p < 0.0001$ ) than they were among those seeking care from informal sources (government EVD trust score 3.7 SD 0.73, and health professional EVD trust score 3.0 SD 1.12).

Confidence in vaccines in general was high and most respondents believed that vaccines work (899 [90.7%, 95% CI 87.0–93.4]) and are safe (852 [88.5%, 85.4–91.0]). Fewer believed that EVD vaccines work (641 [65.7%, 59.9–71.0]). 589 reported they would accept the EVD vaccine (63.3%, 58.0–68.3). Reasons for not accepting

the vaccine included that it was unsafe (225/313 [71·5%, 64·1–77·9]), did not work (75/313 [23·4%, 16·4–32·1]), or was not needed (45/313 [12·0%, 8·2–17·4]). Those who

believed that the EVD vaccine is effective were more likely to accept vaccination if offered than were those who did not believe it is effective (crude OR 27·3, 95% CI 16·9–44·1).

Among those who believed all misinformation statements, 31 (24·2%, 95% CI 16·7–33·8) of 171 would accept the vaccine, compared with 558 (72·0%, 67·4–76·2) of 790 among those who did not believe all three statements. We did not find a significant difference in government trust score between those who would accept the vaccine (2·8 SD 0·68) and those who would not (2·6 SD 0·64). However, the government EVD trust score was significantly higher among respondents who would accept the vaccine compared to those who would not (3·4 SD 0·74 vs 2·9 SD 0·90,  $p < 0·0001$ ), as was the health professional EVD trust score (3·8 SD 0·74 vs 3·3 SD 0·91,  $p < 0·0001$ ).

Men had higher odds of avoidance behaviour and vaccine acceptance than did women; however, they had lower odds of seeking care from formal providers if they suspected having EVD (table 5, appendix). Each one-point increase in government trust, government EVD trust, health professionals EVD trust, and EVD information scores increased the odds of adoption of avoidance behaviours, Ebola vaccine acceptance, and seeking care from formal providers when suspecting Ebola (table 5). Belief that Ebola is not real was associated with lower odds on all the outcomes of interest. Each one-point increase in EVD risk perception score was associated with higher odds of avoidance behaviour. Among those who believed that Ebola is real, increased risk perception was

	Unweighted (n)	Weighted (% [95% CI])
Total	961	...
Direct avoidance		
Avoid contact with people suspected to have Ebola	757	75·5% (68·1–81·7)
Avoid contact with body of suspected Ebola death	801	78·8% (72·2–84·2)
Avoid contact with people suspected of recent contact with someone infected by Ebola	743	74·9% (68·9–80·0)
Any direct avoidance	846	82·2% (75·7–87·2)
All direct avoidance	613	67·5% (60·7–73·6)
Social interaction avoidance		
Avoid visiting extended family members	11	1·1% (0·4–3·1)
Avoid visiting neighbours	10	0·9% (0·3–2·8)
Stay home more than usual	21	2·3% (1·4–3·9)
Any social interaction avoidance	26	2·8% (1·7–4·7)
Physical contact avoidance		
Reduce physical interactions with relatives	369	30·6% (26·7–34·7)
Reduce physical interactions with others	591	53·9% (50·1–57·6)
Any physical contact avoidance	601	54·9% (51·0–58·8)
Public space avoidance		
Avoid public spaces like markets or stadiums	121	11·5% (9·1–14·5)
Avoid going to church	40	3·7% (2·3–5·8)
Avoid taking public transport	83	7·9% (5·8–10·6)
Any public space avoidance	196	19·6% (16·3–23·4)
Hygiene (washing hands more frequently)	885	89·9% (87·2–92·0)

Table 4: Respondents who adhered to preventive behaviours

	Any avoidance behaviour (OR [95% CI])	All avoidance behaviour (OR [95% CI])	Formal health-care seeking (OR [95% CI])	Ebola vaccine acceptance (OR [95% CI])
Sex (men vs women)	11·04 (10·82–11·27)	3·04 (3·00–3·07)	0·62 (0·61–0·63)	1·10 (1·09–1·11)
Age (1-year increase)	1·00 (1·00–1·00)	0·99 (0·99–0·99)	1·03 (1·03–1·03)	0·99 (0·99–0·99)
Education (vs incomplete primary or less)				
Primary completed	0·87 (0·85–0·88)	0·86 (0·84–0·87)	1·99 (1·95–2·03)	0·98 (0·96–0·99)
Secondary completed or higher	0·81 (0·80–0·83)	0·81 (0·79–0·82)	1·80 (1·76–1·84)	1·14 (1·13–1·16)
City (Butembo vs Beni)	0·17 (0·17–0·18)	0·57 (0·57–0·58)	0·61 (0·60–0·63)	2·28 (2·25–2·31)
Nande (Nande vs non-Nande)	0·85 (0·83–0·88)	0·93 (0·91–0·95)	0·62 (0·60–0·64)	0·72 (0·71–0·74)
Wealth (vs poorest quartile)				
Second quartile	0·86 (0·84–0·88)	0·71 (0·70–0·72)	0·97 (0·95–0·99)	0·89 (0·88–0·90)
Third quartile	0·96 (0·94–0·98)	0·62 (0·61–0·63)	0·65 (0·63–0·66)	0·92 (0·91–0·93)
Richest quartile	0·68 (0·66–0·69)	0·64 (0·63–0·65)	0·60 (0·58–0·61)	0·80 (0·78–0·81)
Belief Ebola does not exist (yes vs no)	0·57 (0·55–0·59)	0·45 (0·44–0·47)	0·06 (0·05–0·06)	0·22 (0·21–0·22)
EVD risk perception score*	1·60 (1·59–1·61)	1·54 (1·54–1·55)	0·95 (0·94–0·96)	0·99 (0·98–0·99)
Belief-risk interaction*	1·30 (1·28–1·32)	1·49 (1·48–1·51)	1·73 (1·70–1·75)	1·09 (1·08–1·10)
Government trust score*	1·61 (1·59–1·62)	1·44 (1·43–1·45)	1·40 (1·39–1·42)	1·16 (1·15–1·17)
Government EVD trust score*	1·65 (1·63–1·66)	1·32 (1·31–1·33)	1·38 (1·37–1·40)	1·47 (1·46–1·48)
Health professionals EVD trust score*	1·08 (1·07–1·09)	1·20 (1·19–1·21)	1·25 (1·24–1·26)	1·28 (1·27–1·29)
EVD information score*	1·49 (1·48–1·49)	1·32 (1·32–1·33)	1·08 (1·08–1·09)	1·22 (1·21–1·22)

All p values <0·001. OR=odds ratio. EVD=Ebola virus disease. \*One-point increase.

Table 5: Adjusted odds ratios for EVD avoidance, health seeking, and vaccine acceptance behaviours

associated with lower odds of care seeking and vaccine acceptance (table 5, appendix).

## Discussion

We collected data during an active EVD outbreak in eastern DR Congo, with the aim to better characterise the role of institutional trust and misinformation on individual behaviours of EVD prevention. The EVD outbreak is occurring in an active conflict zone, where low institutional trust is linked to a long-term decline in security and political confidence.<sup>24,25</sup> We identified low levels of trust in government institutions and widespread belief in misinformation about EVD. Exposure to violence reduces political trust in general. Local authorities were more frequently trusted than were provincial and national levels of government, which might reflect enhanced access, visibility, and direct delivery of services. Health professionals were more frequently trusted than were authorities, although we did not distinguish between government, private, and humanitarian health providers.

Confidence in vaccines in general was high, reflecting similar findings in the region,<sup>26</sup> but reduced when considering Ebola vaccines. This difference might reflect fear of contamination or considerations of cost if the vaccine is not perceived as being offered for free, or also because it is new. Our findings suggest that low institutional trust and belief in misinformation are linked to reduced adherence to EVD preventive behaviours. Nevertheless, reported overall adherence to selected preventive behaviours was high, including avoidance of direct and physical contact and hygiene measures. This finding probably reflects the important local engagement efforts that have taken place since the beginning of the outbreak.

Using crude and adjusted analyses for all composite measures of trust, the adoption of preventive behaviour was positively correlated with higher trust. Increased EVD risk perception was associated with reduced odds of care seeking and vaccine acceptance among those who believed that Ebola is real. Although this finding seems counterintuitive, it is consistent with previous findings.<sup>22</sup> Possibly, as perceived risk increases, the likelihood decreases of respondents adopting behaviour that might ultimately expose them to EVD or be perceived to increase the risk of exposure.

Our findings on trust and EVD outbreak response align with the only previous quantitative study<sup>27</sup> on this issue done in Monrovia, Liberia, during the EVD outbreak in 2013–15. That study reported low levels of trust in the national government, although substantially higher than those we found in North Kivu, and the authors identified a correlation between trust in government and compliance with government EVD control measures. A qualitative study reported that a lack of trust, information, and ownership undermined contact tracing during the 2013–15 EVD outbreak in west Africa.<sup>28</sup> Other studies in various settings have identified an association between

distrust and reduced adherence to recommended public health interventions, suggesting that our findings fit well within the existing literature.<sup>13–16,29</sup> The general agreement around this issue across settings and methodologies reinforces our findings. Studies largely reaffirm the general principle of trust as an essential element for effective public health interventions, including outbreak control.<sup>30</sup> However, there are many questions that we are not able to answer with these data. For example, how does trust in governments and local and national institutions interact with and relate to trust in local and international non-governmental organisations, especially in conflict settings? What are the most effective tools for building trust? And should limited outbreak response resources be directed to rebuilding institutional trust?

Although the level of exposure to EVD information and knowledge of symptoms and transmission was generally high, belief in misinformation was widespread. As anticipated, belief in certain misinformation was associated with lower exposure to EVD-related information, which suggests intensive communication initiatives might effectively counter the circulation of harmful misinformation. The belief that EVD does not exist was linked to low adoption of preventive behaviours. Low institutional trust was associated with reduced levels of EVD knowledge (including transmission routes and clinical symptoms) and a greater likelihood of believing certain misinformation. The Liberia study<sup>27</sup> did not identify an association between trust and information about EVD and did not explore issues of misinformation. The reason for the different findings about information between the studies is unclear but might relate to study design, specific questions asked, or actual population differences.

There are limitations to this study. The survey was done in urban settings and findings might not reflect other affected areas, particularly rural areas. The survey explored trust in health workers regardless of their affiliation with government, private, or humanitarian and non-governmental service providers. Perceptions might differ on the basis of these affiliations. All data were self-reported, including behaviour changes. Social desirability bias (telling researchers what participants expect they want to hear, rather than what they actually do) can lead to over-reporting of adherence to prevention activities and there might be discrepancies between what people report doing and what they do.

There have been great advances in the response to many outbreak-prone pathogens over the past decade, but our understanding of the social dynamics and community perceptions related to behaviour during outbreaks require more research. The EVD outbreak in this study occurred in a highly insecure, densely populated environment, with attacks against civilians and a tense political situation, including delayed presidential elections. Attacks against health professionals, condemned by the UN, jeopardise the response to the EVD outbreak.<sup>31</sup> A lack

of institutional trust and widespread misinformation are, our findings suggest, additional factors that undermine control efforts. Engaging locally trusted leaders and service providers could help to build trust with Ebola responders who are not from these communities. If those involved in the EVD response are transparent and consistent in responding to the local needs to stop this outbreak, the trust established during this response could translate into long-term general trust in institutions. Until trust building is effectively translated into response strategies and communication protocols, the basic principles of intensive risk communication by trusted sources in a transparent, sincere, and consistent manner should be the cornerstone of the social mobilisation and community engagement efforts. Mediation (eg, by local and international peacebuilding organisations) and interactive dialogue between communities, community leaders, and local and international Ebola responders might address misinformation about the reality and politicisation of outbreaks, reducing the tensions between EVD responders and the community at risk.

#### Contributors

PV and PNP obtained the data with input from KKB, JB, and EJN for the study and questionnaire design. PV, PNP, and EJN analysed the data. PV, PNP, and EJN wrote the first draft. All authors contributed to data interpretation and reviewed and edited the manuscript.

#### Declaration of interests

We declare no competing interests.

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