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The centrality of (mis)trust in pandemic preparedness in Sub-Saharan Africa: a conceptual framework

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Abstract: Trust is central to pandemic preparedness and the degree to which the population has trust in policymakers and health authorities during an outbreak is based upon historical and social context as well as policy decisions. This paper aims to translate complex ethnographic knowledge into a conceptual framework to simplify multiple temporalities and spatialities of trust. This model is based on the literature, consulting experts and experience conducting research and providing technical assistance in a policy environment during the 2014–16 West Africa Ebola outbreak and the 2019–23 COVID-19 pandemic. Trust varies according to past and present decisions and realities and the model focuses on the complexities of trust depending upon populations' historical experience with medicine, (in)effective health systems, social context, colonial history, (dis)trust in public authority and social determinants of health. The world is increasingly interconnected and transdisciplinary and new approaches are needed to deal with these changes. A holistic, context-driven approach which forefronts the importance of gaining the trust of populations and addresses the new problems created during modern experiences of pandemics and epidemics is key to future preparedness efforts.

Keywords: Trust, Ebola, COVID-19, Africa, conceptual framework, transdisciplinary.

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Introduction

Research on trust has shown that it is important to gain a population's trust whilst preparing for and during a pandemic and this is not only about trust in medical providers, but is also bound up in trust in governments, communities and societies (Grant 2014, Leach *et al.* 2022, Storer & Simpson 2022). It is a complex issue and anthropologists have noted that a discourse of trust/mistrust can be deployed in a nebulous way to account for difficulties encountered in policy interventions (examples are given in Coates 2019, Leach *et al.* 2022, MacGregor & Leach 2022). It can serve as a vague proxy for a set of uncertain, complex, contextual and behavioural factors that hinder implementation. However, to fully discuss the concept we must first reflect on some of the key issues around understanding and discussing trust. Leighton and Roberts (2020) outline that too often the common-sense understanding that knowledge = trust dominates; this is that understandings of trust see it as a problem arising from a lack of knowledge or inappropriate calculation of risk, whereas in reality such framings are too reductionist. As Storer and Simpson (2022) argue, trust is a far more illusory and nebulous concept to be defined and resolved through simply providing populations with information in attempts to promote trust.

Understandings of trust need to be interrogated in order to be able to use the concept in practice. Though trust was central in classical sociology, for example in the works of Max Weber, Talcott Parsons and Gabriel Tarde, it was rarely interrogated directly, 'functioning instead as a sort of black box at the heart of social theory' (Carey 2017, Misztal 1992, Parsons 1970, Weber 1947). Trust is a precondition for collective human existence. Therefore each of human and social sciences separately insists on the importance of the presence of trust. For example, economists see trust as the foundation of all economic transactions and political science as the cornerstone of the legitimacy of government (Carey 2017). Indeed, trust does not imply a utopian vision but is rather a pragmatic concept and gives us a window not only into the empirical dilemmas of pandemic policy, but into wider questions of the context in which this exists and the interplay between these factors: for example care, social cohesion, stigma, inequality and freedom (Storer & Simpson 2022). This is the area this article will explore.

Whether trust is viewed as an etic (culture-general or universal) or as an emic (culture-specific) concept (Earley & Mosakowski 1996, Triandis 1994), the intersection of different levels or meanings of trust has implications for research into how context factors influence how policy decisions are reached and enforced in the outbreak climate. Lack of trust has been interrogated by Citrin and Stoker (2018: 50), who define mistrust and distrust as follows: 'mistrust reflects doubt or

skepticism about the trustworthiness of the other, while distrust reflects a settled belief that the other is untrustworthy'. Mobilising the concept of mistrust highlights the importance of transdisciplinarity in public health policies and practices to understand these interactions and how trust might be impacted in different contexts as trust is multi-faceted and complex, so needs to be considered beyond usual disciplinary boundaries. Biomedical science alone cannot 'end' epidemics, which are in large part socially driven and need to be viewed within the entire context in which they exist, and this article looks at the importance of trust within this (Bardosh *et al.* 2020, Blassnigg & Punt 2013, Darian-Smith & McCarty 2016, Gasper, 2010).

Mistrust during pandemics is associated with poor satisfaction with healthcare, lower uptake of medical recommendations regarding health behaviours or treatments, reduced quality of life, and worse health outcomes, and economists, epidemiologists and policymakers all recognised and wrote of its importance in recent outbreaks (Benkert *et al*. 2019; Birkhäuer *et al*. 2017, Leach *et al.* 2022, Storer & Simpson 2022, Thornton 2022). There must be 'trust between holders of knowledge, process facilitators and the eventual users of knowledge' for effective health policy to be well received by the community (Chambers 2006: 8, Storer & Simpson 2022). Trust is also self-referential in character—if only we had more trust, we could build more trust, then we would have more trust. However, despite its continual repetition in policy documents, trust remains an illusory concept and even scholars struggle to 'speak to the relational connotations of the concept' (Storer & Simpson 2022). Trust can also be used by policymakers to blame, exclude and stigmatise communities who are considered non-compliant: for example, by being vaccine hesitant (Leach *et al.* 2022). Trust is often taken for granted in healthcare policy, but building trust within communities involves tacit listening, acknowledgement, social support, and coalition-building. However, this is complex and a danger in some places is that exclusionary hierarchies might be enhanced, and vulnerable and marginalised populations further excluded (Sarafian 2023, Storer & Simpson 2022).

Trust is often associated with doctor–patient healthcare encounters; however, the pandemic has refocused the role of trust in broader social contexts (Chan 2021). Bollyky *et al.* (2022) found that higher levels of government and interpersonal trust had large, statistically significant, associations with fewer COVID-19 infections. This corroborates findings of research done before COVID-19 that also found an association between trust and compliance with public health guidance (Gilles *et al.* 2011, van der Weerd 2011,). Therefore transdisciplinarity is key as it is problem-based and concentrated on the practical applications of knowledge in the real world where issues tend to be multifaceted and call for multiple analytical perspectives

(Darian-Smith & McCarty 2016). Transdisciplinary scholarship also considers how knowledge is constituted in the first place as a replication and outcome of particular worldviews, ideologies and cultural biases. According to Rosemary Johnston, transdisciplinarity 'overtly seeks ways to open up thinking to "maps of unlimited possibilities"... to create mindscapes that are unfettered by traditional patterns and procedures' (Johnston 2008: 229–30). For example, generally during a disease outbreak the world prioritises health protocols above environment and economic considerations (Grant *et al.* 2023). An example of the impact of not thinking in a transdisciplinary manner, and focusing on containing the outbreak is in Uganda where COVID-19 restrictions included many very restrictive and militarised lockdowns and forced hospitalisations, implemented in a context of political oppression surrounding national elections, and in which symptomatic Covid cases and local levels of mortality remained very low—thus damaging livelihoods and fuelling resentment and distrust amongst local populations (MacGregor *et al.* 2021, Parker *et al.* 2020).

A key issue when dealing with pandemics is that reciprocal trust (populations trusting authorities and vice versa) needs to be pre-existing amongst the majority of the population and be maintained with policies that garner adherence by the population. Securitisation, the use of military and harsh enforcements as well as war metaphors in political communications to the public appeared prominently during Ebola and COVID-19. For example in Malawi and Uganda, COVID-19 occurred alongside national elections and was layered with everyday mistrust in leaders, so people questioned whether health measures were connected to struggles for power, and open to manipulation by leaders seeking to avoid scrutiny or steal elections (Atuhura 2021, Grant & Sams 2023, Parker *et al*. 2020, Storer *et al.* 2022). If people do not already trust medical personnel and the government, it will be much harder, but still possible, to gain support for difficult policies, e.g. lockdowns. However, even with trust existing beforehand, if policies are not considerate of populations, they may lose trust (see Figures 1 and 2). Low public trust in sources of information among the population was linked to low societal compliance, and the involvement of local authority figures who command trust could lead to better community engagement (MacGregor & Leach 2022). In much of the world, public health is a local, community-based endeavour and so interpersonal trust (trust within communities) plays a large role (Bollyky *et al.* 2022).

This paper can begin to give insight into what needs to be put in place pre-pandemic and how to put trust at the centre of policy-making during pandemics. Fortunately, the author believes that trust is something that can be fostered, even in a crisis. Bottom-up community engagement which comprises cross-disciplinary collaborations and interventions, including true partnership with local communities,

giving voice to differing narratives and gaining trust, will lead to a true understanding of contextual realities and how to create policy for the situation. This can be useful in making context-specific policy decisions that are based on the lived reality of the population rather than using 'one size fits all' approaches or 'copy and pasting' policies from other contexts, which makes it harder for trust to be gained in a specific context (MacGregor *et al.* 2021). There has been learning between Ebola and COVID-19, but it could go further to ensure we are better prepared for the next pandemic and these findings can assist in attuning interventions to different contextual realities and therefore ensuring that they are proportionate, considerate to vulnerabilities and social inequalities and socially just (Leach *et al.* 2022, MacGregor *et al.* 2022). While there has been research in high-income countries showing the importance of trust in explaining individual precautionary behaviours related to COVID-19 (e.g., Borgonovi & Andrieu 2020, Ye & Lyu, 2020), few studies have addressed this in Sub-Saharan Africa (Yu *et al.* 2023).

Methodology

This research used in this paper is based on twelve years of experience working on research and policy on zoonoses and pandemics both as a researcher and providing technical assistance. Research projects the research was conducted in include the Dynamic Drivers of Disease in Africa Consortium (2011–16) and the Pandemic Preparedness Project (2019–23) and work providing technical assistance to policymakers included through the DFID Human Development Resource Centre (HDRC) (2011–12) DFID High-Quality Technical Assistance for Results (HEART) (2012–16), FCDO K4D (2016–19), the Ebola Response Anthropology Platform (2014–16), Social Science and Humanitarian Action Platform (2023–) and the Covid Collective (2023)[1]. During this work the author provided advice on how to engage with crucial socio-cultural and political dimensions of outbreaks, consulted and interviewed experts and used evidence to improve the impact of development policy and programmes. During the Ebola outbreak, the author went to policy meetings at the UK Department for International Development (DFID) and a report she wrote was used by the British Army and DFID when discussing issues of trust amongst local populations and how to incorporate these, showing increasing awareness of these issues (Grant 2014). It was recognised in the *Annual Review of Anthropology* that this report 'challenge(d) conventional wisdom by arguing that international experts'

[1]The dates given are the dates during which the author was involved, not the dates the projects and organisations existed for.

misconceptions about West Africans' responses to the epidemic were an important factor impeding the effectiveness of the response' (Abramowitz 2017).

In addition to synthesising data collated through this immersive approach, experts were consulted to provide key papers and a rapid literature review was conducted according to the method outlined in Grant and Longhurst (2016). This approach was also used for rapid policy research by HEART and ERAP. Initial searches were done and then a snowball sampling approach was used, adding key-words as the literature was accessed and a reference list of key documents was used to find the most relevant literature. The initial key words used were 'trust', 'pandemic' and 'Africa'. Science Direct, Web of Science and Google Scholar were searched and the selection criteria included articles published between 2011 and 2023 focusing on Sub-Saharan Africa, and peer-reviewed journals were prioritised.

Drawing on this complex milieu of intersubjective and published experience, this paper will now present a conceptual framework showing how trust varies according to past and present decisions and realities, using the Ebola and COVID-19 pandemics as examples. It shows how trust was constructed or deconstructed depending upon populations' historical experience with medicine (e.g. Parker *et al.* 2022), (in)effective health systems (e.g. El-Sadr & Justman, 2020), social context (e.g. Schmidt-Sane *et al.* 2022), colonial history (e.g. Mutombo *et al*. 2022), (dis) trust in public authority (e.g. Parker *et al.* 2022) and social determinants of health (e.g. Ripoll *et al.* 2022). These contexts in turn influence how policy decisions are reached and enforced in the outbreak climate, the (in)efficacy of behaviour change communication, and how infodemics and social media (mis)information are contributed to and received.

Conceptual framework

The yellow section of this figure outlines the importance of the historical, social and economic context of the situation. Literature and experience have shown the areas highlighted in the model to be key to understanding how these issues affect current policies and realities (blue section). By feeding these issues (yellow section) into policy and involving multiple actors and narratives and considered community engagement, this enables policymaking that considers contextual realities and is attentive to social differences and vulnerabilities (the blue section of Figure 1).

Central in this model and emerging in the synthesised material is that key to increasing trust is that external actors undertake committed community engage-

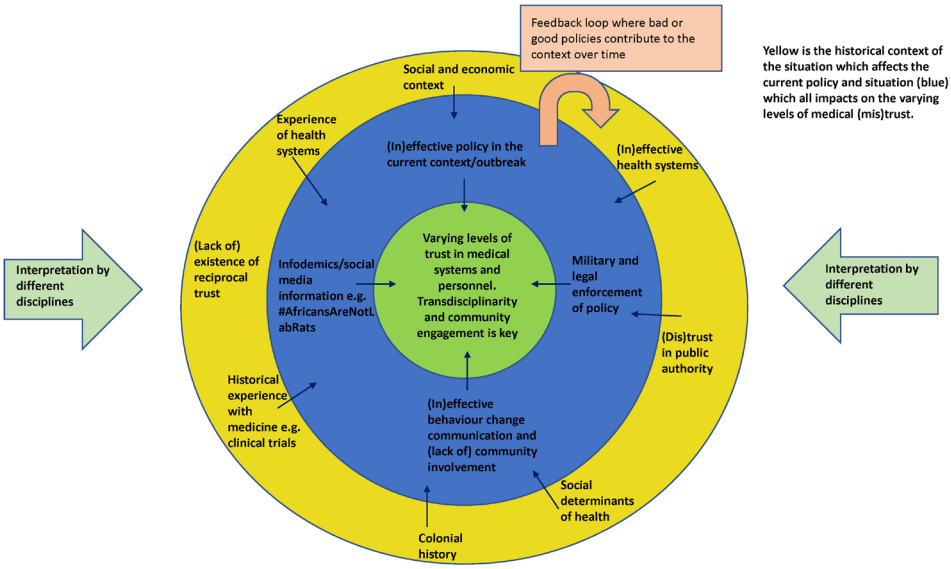

Figure 1: (Mis)trust in pandemics: a conceptual framework.

ment. This should comprise transdisciplinary collaborations drawing together all of these issues and harness mobilisation, knowledge and inventiveness 'on the ground', hearing from people about their priorities for and experiences of health and livelihood issues both current and historical (the yellow section of Figure 1). Doing this will release the pressure of disciplinary interpretation (green arrows), which are separately only able to consider part of the picture.

Taking this approach should increase the levels of trust in medical policy (green section of Figure 1) (Grant *et al.* 2015, 2016, forthcoming, Sams *et al.* 2022, Schmidt-Sane *et al.* 2022). There is also a feedback loop; poor policies impact on context over time and help contribute to and build histories. Figure 2 shows how the two layers interact with each other.

Each epidemic experienced has resulted in learning, but focusing on the centrality of trust in policymaking can ensure the design of the most effective preparedness policy (see Figure 2). Figure 2 shows the centrality of trust and how to analyse at what point trust has been lost in various contexts and whether long-term structural change or policy change is needed to address the issues and increase trust levels.

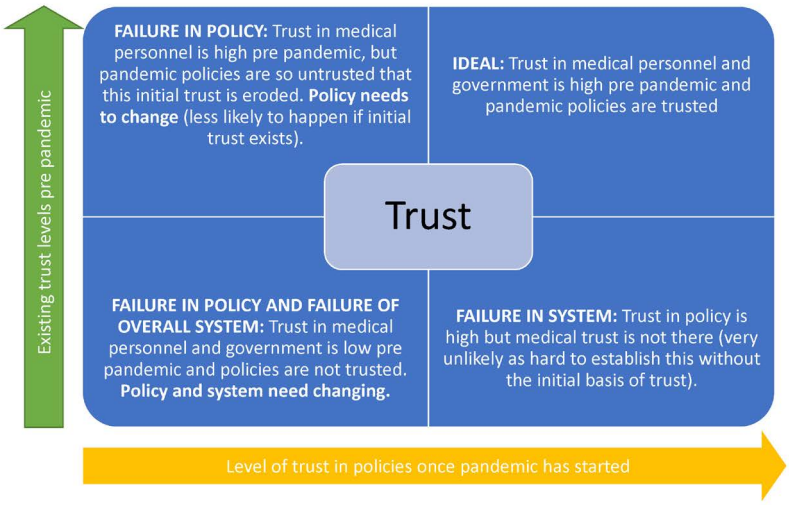

Figure 2: Conceptual framework on (mis)trust in policy-making and social contexts during pandemics.

Discussion

When analysing trust, the first place to start is to understand the long-term structural issues. This model points to a multi-layered production of mistrust in space and time and each section below discusses a different part of the model.

Part 1: Long-term structural issues (yellow section of the model)

Social and economic context

Historical injustices and socio-political issues inevitably shape interpretations of disease and trust in government, authorities and medical providers. This context shapes the ideology and narratives of a nation or region. For example, when epidemics circulate (through viral agents) in historically marginalised communities, widespread resistance has been reported, which has been interpreted as indicative of mistrust in response and a view of government, as either the cause of the disease, or a neglectful responder (Démolis *et al*. 2017, Ripoll *et al.* 2022). Fairhead (2016) also describes precarious 'social accommodations' that need to be made during a disease outbreak, that is, established norms of cooperation and coexistence that were violated throughout an outbreak: for example, the medicalisation of burials during Ebola when previously they were handled within communities and using important rituals which were interrupted by Ebola regulations on burials. Previous

research has also shown that corruption contributes to lower trust in government and social institutions, which might reduce compliance with public health guidance and policies (Bollyky *et al.* 2022).

An example of policy which did not account for these issues is when the Governments of Sierra Leone, Liberia and Guinea responded with bans and fines for burying, sheltering or treating suspected Ebola patients and corpses (Richards *et al.* 2020). People resisted the response teams to continue traditional burials, which fuelled the epidemic with some burials becoming 'super-spreading' events. However, the importance of burial practices cannot be overestimated, as they are closely controlled by the male and female societies who are central to local and regional politics (Grant 2014). Medical teams wishing to prevent traditional burials will likely be intervening in domains of power and 'secret' knowledge that lie at the centre of the socio-cultural context of the area (Wilkinson 2014). Mistrust is often cited by authorities as a way of pushing the biomedical, dominant culture against traditional beliefs, reinforcing histories of medical experimentation, injustice and oppression, and systemic racism; all too often, trust is expected before trustworthiness can be established (Jaiswal & Halkitis 2019). Further fuelling rumours was the focus on the biomedical crisis that COVID-19 had created without considering economic and livelihood issues. By instituting lockdowns without fully considering the economic impact on poor, marginalised and vulnerable people, public authorities lost trust among the populations (Grant *et al.* 2023). Another example of how these issues come together to manifest in reality is widespread reportage of vaccine fears. To give a couple of examples, in Guinea the pumping of disinfectant in markets was thought to be pumping virus, and when a COVID-19 vaccine was announced, rumours circulated about conspiracies to depopulate the world, starting with Africa (Grant & Sams 2023, Leach 2014).

By considering the whole context, including social, economic and livelihood, political and cultural, instead of only prioritising the biomedical crisis situation, more holistic and well-rounded policies can be developed, gaining the trust of the population as their lives and livelihoods are considered, not only their health (Grant *et al.* 2023, MacGregor *et al.* 2022). Unsettled national politics, distrust of foreigners fuelled by decades of extractivism and lack of respect for local cultures need to be considered when thinking about how to gain the trust of populations (Leach 2015).

When planning long term, these issues ideally need to be addressed on a wider structural level and, once they are, policy attentive to these histories and culture can be made to a gain the optimum level of trust in populations (Figure 2). There is no short-term fix to these issues, but improvements could be made by considering the four policy-making points (Figure 1, blue area) and considering local contexts

(Figure 1, yellow area) while ensuring effective communication and appropriate enforcement. For example, burial practices could be modified during an epidemic and people are generally open to these modifications, partly because indigenous protocols prescribe such modifications, for example adaptions to burials accepted during Ebola (Grant 2014). In this way, understanding and responding to local experience can be very effective and increase trust and positive responses (moving into a more positive box in Figure 2) (Hewlett & Hewlett 2008).

Colonial history

For decades, people living in colonised states were subjected to coerced medical interventions that were in many cases neither safe nor effective (Lowes & Montero 2021). For example, Lowes and Montero (2021) analysed the effects of French colonial policies, which included forced examination and injections to treat and prevent sleeping sickness with severe, sometimes fatal, side effects, in Cameroon and French Equatorial Africa between 1921 and 1956, and they found that greater exposure to colonial policies significantly reduces present-day vaccination rates and trust in medicine. So, nearly one hundred years later, descendants still live with the effects of this historical trauma, resulting in less trust in modern times (Lowes & Montero 2021). Storer and Anguyo (2022) also make the point that successive historical deceptions have been practised by state and medical actors in some areas, bringing the issue into modern times. Kovacic *et al.* (2016) and Shaw (1997) suggested that involving elders in policy-making meant that decades later positive, trusting memories of approaches could be fostered. By considering these issues, the four policy areas (blue in Figure 1) should be considered carefully to ensure that policy-making is trusted as much as possible in this difficult context.

Resistance and mistrust must be understood through consideration of historical structural violence (Benton & Dionne 2015, Hirschfield 2017, Wilkinson & Leach 2015). Benton and Dionne (2015) argue that the transatlantic slave trade, the colonial period, 1980s structural adjustment programmes and civil wars in the 1990s were types of imperialism that helped create the context that intensified the spread of the 2014–16 West African Ebola outbreak. An example of this is Sierra Leone, which was used as a central port in the slave trade and then as a mining colony for the British Empire; therefore a substantial proportion of their encounters with outsiders were primarily extractive (Wilkinson & Leach 2015). This colonial history played out in the Ebola epidemic which took hold in Sierra Leone in 2014; reports were rife of instances of community resistance to medical intervention, mistrust and avoidance of healthcare centres, and stigmatisation of health workers and

survivors showing that memories of these histories last a long time, and therefore trust should be central to modern policies to begin to build better future relationships (Enria *et al.* 2016).

(Dis)trust in public authorities

Levels of trust will vary depending on the historical and social issues described above as well as public health paradigms. For example, public authorities[2] which historically have not held back from curtailing individual rights in the interests of protecting populations from infectious diseases will be viewed differently by the population and will need to consider different policies and communication methods to gain public trust (see Figures 1 and 2). Additionally, recent experience of policies and public authorities will shape trust levels. For example, questionable practices in the Ebola response in the Democratic Republic of Congo (DRC), including payments to security forces, renting vehicles at inflated prices, and corruption, may have jeopardised humanitarian operations and put lives at risk (Freudenthal 2020, Ripoll *et al.* 2022). The outbreak experience existed alongside existing complex protracted difficulties and many public figures and authorities tried to advance their own agendas, though this is often challenged by populations (Kirk *et al.* 2021).

Levels of trust in different public authorities may vary: for example, Lipton (2014) wrote about the situation in Sierra Leone during Ebola and found that while many people were proud of being law-abiding and respectful to authorities, there was a widespread mistrust of the motivations of the police and army, who are often badly paid and gain an income through bribes and fines. However, he found that in a crisis to survive people are forced to encounter and engage with certain actors and that policies were respected (Lipton 2014). Traditional practices such as secret societies are an institutional structure that people understand, and trust, and can be effectively used in times of crisis (Grant 2014). When thinking about gaining trust, these nuances need to be understood and used to ensure effective policy and communication of policy giving authority to trusted groups (Figure 1).

Trust can also be different in different authorities. Research findings showed that people had low trust and confidence in policing systems and state institutions and felt the state lacked a coherent plan, but they had more trust in public health offices, medical professionals and the emergency committee. (Collyer *et al*.

[2] The term 'public authority' refers to formal government and state instruments created by legislation to further public interests, such as the police, army and various sanctioned forms of local administration (Kirk & Allen 2021).

2021). They also found that preventative policies were more accepted if carried out in cooperation with local civil society organisations which were 'closer to the people', thus showing how policy can be adapted when context is understood (Figure 2).

Some examples of policies that have increased mistrust in public authorities and shown a lack of contextual understanding include padlocking churches shut in Uganda during COVID-19. People complained that 'people with authority have hidden our God from us. We would be going to church as we ask help from God about this disease. … But now God is hidden from us. You can see how it is a problem …' (Baluku *et al.* 2020).

Epidemic preparedness and response are not neutral, technical endeavours, but are profoundly shaped by geopolitical processes and by formal, hybrid and informal public authorities on the ground. These processes and authorities are likely to profoundly shape the future course of COVID-19 (Parker *et al.* 2020). A key lesson for preparedness is to decentralise, to trust local negotiations and to be flexible in implementation, responding to local conditions. This may help address the lack of trust people had in formal institutions because of the nature of an often predatory, autocratic state (Scoones 2023).

Historical experience with medical systems and personnel

Given violent and extractive colonial histories, often conducted under the guise of the 'greater good', there have been issues surrounding trust for decades ,with a particular concern around new treatments (Mutombo *et al.* 2022). Crane (2013) highlights the complexities of the HIV/AIDS epidemic in Uganda and how global health science both generates and relies upon inequalities, even as it strives to end them, when new treatments are disseminated to Africa. When COVID-19 vaccines were offered as a new solution, people questioned whether they were being used to experiment on or worse exterminate Africans and also wondered what the role of international actors was in this. This was discussed on social media, using hashtags such as #AfricansAreNotLabRats and raised in particular the question of trust in knowledge and how knowledge carries authority (Grant & Sams 2023).

Rumours such as these, whether originating online or in person, are articulations of mistrust, and produce more mistrust in the context of colonial legacies (Richardson *et al.* 2019). Rumours and mistrust can have huge impacts: for example, in 2003 three states in Nigeria boycotted the polio immunisation campaign because the political and religious leaders told parents the vaccines were 'corrupted and tainted by evildoers from America and their Western allies', believing 'modern-day Hitlers have deliberately adulterated the oral polio vaccines with

anti-fertility drugs and … viruses which are known to cause HIV and AIDS' (Jegede 2007).

Trust also seemed key for the COVID-19 vaccine, as in some places, there was evidence of mass absenteeism when the vaccination team arrived. In others there was an enthusiastic turnout. The variations seem to relate mainly to the existing state of trust in government medical services (Leach *et al.* 2022). Vaccine confidence also grew when the vaccines were delivered by trusted local providers, and local differences between villages in health service experience affected uptake (Leach 2022).) Community approaches in Africa have continually adapted throughout the post-independence period. Over time, responses have begun to include aspects of biomedical practice, giving hope to vaccines being increasingly accepted. Health policy is not imposed onto a blank canvas, but rather onto long-term attempts of populations to resist disease (Aluma *et al.* 2022).

(In)effective health systems

Trust in health systems is based upon beliefs and experience. Communities have diverse beliefs around disease, which can overlap or diverge with biomedical models, and this leads to health systems that have a plurality of health providers including biomedical, faith and traditional healers (Ripoll et al 2022). People may have very good reasons to mistrust the biomedical healthcare system, be it due to underfunding and structural issues or cultural beliefs. A study in Uganda found that distrust in the Ministry of Health is prevalent among frontline health workers; there is a lack of trust in the organisation's coordination role in service delivery and this affects healthcare delivery to patients, interrelations and provider cooperation (Akello & Beisel 2019).

Pre-existing ideas about health actors matter since this trust level is important during pandemics as it informs how people respond to new risks. However, levels of trust in health systems can change during outbreaks. Even if trust levels were previously high, heightened anxiety and a change in service levels can lead to distrust (Figure 2). So, when thinking about communicating and enforcing policies this needs to be considered. Fragile health systems were overwhelmed with the surge in cases at the peak of the COVID-19 outbreak, meaning essential health services (for example, reproductive health services) were disrupted in many African countries due to an imbalance in supply and demand (WHO Africa 2021).

Trust levels can also change due to fear during an outbreak. For example, in Sierra Leone doctors are generally respected, and people are normally keen to seek medical attention at pharmacies and hospitals if resources permit. However, during the 2014–16 Ebola outbreak, there was a widespread distrust of hospitals and

treatment facilities. People feared being wrongly diagnosed with Ebola, and either harmed by the treatment process or worried that they would catch Ebola in hospital. In part, this attitude stems from a distrust of the motivations and the capabilities of the government during the crisis, who many feel willingly benefit at the expense of ordinary people (Grant 2014, Lipton 2014). Field research in Uganda also showed that distrust moved across generations and outbreaks; people reported not trusting the government during COVID-19 vaccine campaigns because they had had experiences of the Ebola vaccine making them sick, so people avoided the vaccine (Baluku *et al.* 2020).

This experience goes back through the history of outbreaks. Trust levels can change and reflect experience of previous outbreaks. For example, Hewlett and Hewlett describe the situation in Gabon in *Outbreak Ethnography*. Local people were reluctant to talk about what had been happening or admit that people had died from Ebola due to a lack of trust in health policy and systems. Villagers, priests and local government officials supported the denial, even though laboratory tests indicated Ebola. Distrust of the international team was not surprising given local people's experiences with French and American teams during the 1996 outbreak, where blood was taken, but results not given, leading to rumours of blood or body parts being sold for profit (Hewlett & Hewlett 2008). Other communities in the 2014 outbreak also believed that, whenever international health teams visited, 'the communities [were] hit by illness' (UNICEF 2016, Fassassi 2014).

Despite colonial histories, most people want and value outside help, as long as feelings of mistrust are not amplified, but it is important to have a sense of the local institutional fabric and healthcare workers should make activities transparent and develop trust and rapport with local people. Working with communities could include regular community meetings to explain control efforts and walking in the community and acknowledging local people help. Social mobilisation is a key component because all stakeholders should be involved to enable pooling of resources and optimising the management of epidemics (Chippaux 2014). Past experience has shown that health education and social mobilisation efforts should target women and women's groups as they often care for the sick and perform burial practices (Grant 2014). Secret societies, which are male and female societies who are central to local and regional politics, are also often one of the most well-trusted institutions (Grant 2014). Collaboration with communities is needed to find solutions: for example, being creative with traditional rituals to identify new burial practices that meet cultural needs and infection-reducing protocols; and in how treatment units are located and designed (Leach 2014).

Social determinants of health

Different people and institutions will be trusted by different social groups, depending on the social and political histories of the affected communities (Figure 1, Ripoll *et al.* 2022). Different groups are affected differently by and are vulnerable to different infections, illness and levels of mortality by virtue of social roles and practices. Cultural logics refers to communities' own models of health and illness, explanations of epidemic emergence, as well as local capacities to respond. Mistrust may be a response to current and historical differences in healthcare and society as a whole and may play a role in COVID-19 inequities (Bogart *et al.* 2021). Vulnerability, power differentials and exploitation are involved in the concept of trust in healthcare (Bhattacharya *et al.* 1998, Fugelli 2001). Low interpersonal trust is most correlated with income inequality and government corruption, suggesting those who are economically and socially disadvantaged and confront a society stacked against them might be naturally less inclined to trust others (Abascal & Baldassarri 2015).

When considering how to make policy to deal with the context, it is important to consider that, while the centralisation of response may benefit coordination, decentralisation of response activities carried out by affected communities and promoted by local trusted actors can promote trust and increase the uptake of services. Understanding the political dynamics of a response and identifying how different response actors and activities are perceived by different social groups in a context is crucial (Ripoll 2022). For instance, in the 2018 DRC Ebola outbreak it was realised that local people felt uncomfortable engaging with external actors so they set up *comité cellules*—structures of locally elected, trusted community members who facilitated action plans at the local level (Oxfam International 2021, Ripoll *et al.* 2022).

Part 2: Outbreak policies (blue section of the model)

(In)effective policy

When a virus emerges with high potential for spread, governments must be able to convince citizens to adopt public health measures. Doing so often requires behavioural change, from mask wearing and physical-distancing rules to following quarantine policies (Bollyky *et al.* 2022). Policy can be ineffective if it does not understand the context, and the levels of trust in its populations. If levels of trust are low to begin with, it makes it harder to gain high compliance with policy. For example, a study on Ebola in DRC showed lack of trust in government was

associated with less compliance with government-recommended mitigation strategies, such as keeping physical distance and accepting vaccines (Vinck *et al.* 2019).

(In)effective communication and (lack of) community involvement

If the government and health teams do not take hold of the narrative on outbreaks and people are forced to work out the facts from the rumours and then decide the best course of action, they are more likely to ignore government directives rather than follow them. Especially if they risk greater difficulties, such as following lockdown rules to the detriment of their livelihoods (Baluku *et al.* 2020). Reinforcing knowledge networks that allow the exchange of validated information (not just from health sources) across communities and into the diaspora is important. These exchanges help build trust between different sources of expertise, avoiding anxieties such as those around vaccines (Scoones 2023).

An example of how misleading information can spread in the absence of trusted correct information is the misunderstandings of policies in Uganda, such as the emphasis on handwashing as a preventive measure led to rumours that the COVID-19 attacks and spreads through hands. This led to a belief that if washing with alcohol sanitizer is the remedy, then drinking a locally brewed gin would be a cure (Baluku *et al.* 2020)

When people are forced to make desperate and dangerous decisions to ensure the survival of their families and livelihoods based on media reports and whispers of information whilst still recovering from and facing the threat of Ebola, COVID-19 and other diseases, trust is eroded and a community already wary of the system, when faced with poor policies and poor communication, fall into the lower-left-hand box of Figure 2.

Military and legal enforcement of policy

Coercive government responses to epidemics lead to resentment and mistrust. For example, compulsory cremation in Monrovia at the onset of Ebola in 2014 led to mistrust in the response and the proliferation of secret burials (Abramowitz 2017). Also, during the COVID-19 pandemic, it has been argued that its impact had been exacerbated by military involvement: for example, comments from South Africa argued that the 'heavy cross' of COVID-19 had been made heavier by military involvement (Grant & Sams, 2023). Others referred to the COVID-19 pandemic as a ruse for increased control of the population. There were many examples of violent enforcement of lockdowns and other restrictive policies. For example, before there was any official communication or local experience of COVID-19, a Ugandan

village experienced extreme social unrest: 'this corona is making our people be beaten by the Army men' (Grant & Sams 2023).

During COVID-19, heavy-handed 'preparedness from above' forced people to 'prepare' in a way that impacted them negatively. COVID-19 measures in Uganda included a succession of restrictive and militarised lockdowns and forced hospitalisations, in a context of political oppression and national elections, during which time COVID-19 cases and mortality in Uganda remained very low (Parker *et al.* 2020). This damaged livelihoods and increased resentment and distrust amongst local populations, for example in rural areas market closures and people not being able to reach farms where they grew their food (Baluku *et al.* 2020, MacGregor *et al.* 2021). Village fieldwork discovered women being beaten, men being fined (and wondering if these are official fines or to line the pockets of the military) and facing extreme threat to their livelihoods (Baluku *et al.* 2020). These villages have a history of repeated externally imposed disease problems and to increase trust, an improved overall system and improved policy-making, communication and enforcement would be needed (blue section of Figure 1). This has happened in other epidemics: for example, stories of structural violence during Ebola helped explain why the epidemic became an epidemic of fear—of 'Ebola panic disease' not just Ebola virus disease and trust in agencies and communities were key to control efforts (Leach 2014).

When considering how to enforce policy, it is important to consider that the WHO model of response, and the way it has been enacted in developed countries, for example through lockdowns, can be experienced differently in different contexts. In Uganda, soldiers were the first prioritised group for vaccines, and allegedly there was 100% compliance. This only increased its association with a distrusted militarised state (Parker *et al.* 2019). Responses from below, supported by community-led communication, which make sense to people and are more ethical and humane, could change the experience of this, and future, disease burdens into something more manageable for these villagers, as there would be increased trust and compliance and less need for excessive enforcement of policy (Baluku *et al.* 2020, Grant 2018, MacGregor *et al.* 2022)

Infodemics and social media (mis)information

Once these policy considerations have been made, the challenge then moves towards replacing 'wrong' with 'right' information, in world that is increasingly connected by social media and technology, and restoring perceived lack of trust in public health institutions. A shift in the COVID-19 pandemic was the idea that the public face an excess of information and are vulnerable to mis- and disinformation

and there needs to be 'infodemic management' (Grant & Sams 2023, Sams *et al.* 2022). Whilst social media use was also widespread during previous outbreaks, for example, Ebola, Zika, and Nipah, the lack of human contact during the lockdowns made it an even more important connection (Grant & Sams 2023).

Technology and social media were used on an immense scale to keep people informed, productive and connected during the COVID-19 pandemic. Social listening and infodemiology can be used to make practical improvements by translating data into actionable insights based on community sentiment. Social media can have a role in amplifying and gaining access to unheard voices and narratives that emerge, especially during lockdowns, as usual social contact is halted. However, caution is needed, as the 'infodemic' also continues to undermine the global response and jeopardise measures to control the pandemic.

Social media has changed the way organisations communicate with their stakeholders as well as providing new opportunities for stakeholders to engage in direct dialogue both with organisations and with each other. Social media documents in real time the cultural and political–economic contexts, community responses and reactions. A deficit of trust in medical science, and/or in those developing or delivering technologies can be amplified during 'infodemia', but communication and engagement can strengthen and build trust (MacGregor & Leach 2022). This shows the importance of a transdisciplinary approach, looking from both a biomedical and social perspective, ensuring different actors work together (Grant & Sams 2023).

As mentioned above, rumours and mistrust can cause a real impact, such as the polio vaccine being banned in parts of Nigeria, and social media can amplify rumours such as viral tweets suggesting that the COVID-19 vaccine was developed to cause harm and reduce the world population (Grant & Sams 2023). Knowledge of these rumours can help plan a response. There is an opportunity to use social media, WhatsApp groups and other new technology and communication tools to communicate messages to communities, understand and hear rumours that are circulating and get access to real-time data on what conversations are being had around outbreaks.

Conclusion: the role of interdisciplinarity and social science in understanding how to gain trust and provide solutions

Research has shown that trust during pandemics is not only about trust in medical providers, it is bound up in trust in governments, communities and societies. This is tied up in arguments for transdisciplinary policy that understands that trust during pandemics, and indeed pandemics themselves are not just biomedical issues, but

social ones as well. De Ver Dye *et al.* (2020) recognised that 'COVID-19 is equally—if not more—a socially driven disease as much as a biomedical disease'. Even before COVID-19, researchers had long noted the connections between socio-economic inequalities and infections, and there is growing recognition that policy makers need to consider social, political and economic issues as key to pandemic preparedness and response (Bardosh *et al*. 2020).

The conceptual framework presented in this paper brings together all of these issues and shows the interrelationships between historical and social context and policy decisions and how trust is central to the interplay between these and the outcomes of epidemics and pandemics. Thus, showing that adopting context-blind approaches to epidemic response that ignore local realities and do not consider the levels of trust in government, policy, authorities, medical personnel and in wider society reinforces deep social and economic issues. This further inhibits trust in communities, leading to lower compliance with government policies and contributes towards a further destabilising of trust in that context for the future. To address these issues, policies should be sensitive to the historical and social context and be considerate of the choice of enforcement measures and how they are communicated and discussed. This allows communities to trust in the policies and the context creating reciprocal trust between authorities and communities and paving the way for increased compliance and buy-in in the future.

Controlling and reducing the human costs of pandemics, requires knowledge of social, economic, cultural and political processes, including drivers of trust, vulnerability and risks amongst different parts of the population. Of course, there are difficult decisions to be made: for example, when policies might be detrimental to trust but might be effective to save people's lives, for example during the COVID-19 lockdowns (Grant & Sams 2023). To advance the field, we need to use evidence to underpin inclusive, appropriate, tailored and responsive interventions which should be led by a range of actors and even emerge 'from below' (MacGregor *et al.* 2022, WHO 2022). A transdisciplinary approach looking at both biomedical and social drivers of disease with a focus on bottom-up community engagement, giving voice to differing narratives, would be more effective at preventing the spread of disease while mitigating other negative outcomes. Interventions can be attuned to different contextual realities, ensuring that they are proportionate, considerate to vulnerabilities and social inequalities and socially just. Hearing from people about their priorities, or concerns about other prevalent health and livelihood issues, is key to a proportionate and effective response that people understand and trust, alongside an approach involving multiple actors and narratives.

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