Exploring medical mistrust:
from clinic to community

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Abstract: This introduction to the special issue, *Exploring Medical Mistrust: From Clinic to Community*, provides a conceptual framing of 'medical mistrust' from a critical social science lens. This special issue explores and unpacks the complex temporal, social and scalar relationships which are intertwined with contemporary manifestations of mistrust in medicine. We ask what social science and humanities disciplines can offer in relation to wider understandings of the processes driving resistance to and refusal of medical interventions, including but also beyond vaccines. We distil insights derived from diverse spaces of medical encounter, ambivalence and resistance that serve as arenas which generate mistrust. We bring this analysis to deepen an understanding of the frictions and affective relations which exist between vertical and horizontal relations which constitute health systems.

Keywords: medical mistrust, social science, anthropology, COVID-19, trust.

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Introduction

Prior to the COVID-19 pandemic, public trust in formal medicine and public health actors and authorities was often taken for granted within health policy. Yet, highly variable public responses to COVID-19 policies across global, national and local contexts have revealed how deeply medical technologies and practices are entangled with everyday lived realities of mistrust.

This special issue explores and unpacks the complex temporal, social and scalar relationships which are intertwined with contemporary manifestations of mistrust in medicine. We ask what social science and humanities disciplines can offer in relation to wider understandings of the processes driving resistance to and refusal of medical interventions, including but also beyond vaccines. We distil insights derived from diverse spaces of medical encounter, ambivalence and resistance that serve as arenas which generate mistrust. We bring this analysis to deepen an understanding of the frictions and affective relations which exist between vertical and horizontal relations which constitute health systems.

Within health policy vernaculars, trust and mistrust are portrayed as binary states related to individual choices to accept, or refuse, a variety of healthcare interventions (Storer *et al.* 2022). 'Medical mistrust' has been invoked by health policy experts and scholars alike as a term which serves to encapsulate disengagement with, and exists as a barrier to, a variety of clinical interventions, from low adherence to screening services and drug regimens, to avoidant patient–doctor relationships, to engaging in 'risky behaviour' (Benkert *et al.* 2019, Breakwell 2020, Powell *et al.* 2019, Williamson & Bigman 2018). Benkert *et al.,* based on a systematic review of the clinical literature, summarise that medical mistrust, 'is not the same as "no trust"; rather [medical mistrust] implies that a trustor's negative beliefs are that the trustee will go against the person's best interest' (2019: 86). In other words, it is not an outright dismissal of medicine's capabilities, but a more nuanced suspicion that medical institutions and professionals may have ill intent.

Whilst countless studies have correlated medical refusal with mistrust, left unanswered are the complex processes which generate supposed 'negative beliefs' that give rise to suspicions of malicious intent. Simultaneously occluded from view are trust's 'inner workings' and the 'outer', structural and historical drivers which equally drive mistrust in the present (Richardson *et al.* 2019). This narrow research focus may be used to legitimate forms of governance under which people are blamed for their behaviour (Bear *et al.* 2020, Douglas 1992).

In approaching medical mistrust, the contributions to this special issue explore the relationships which constitute the services and structures of health systems. Entries present health systems not as abstracted constructs, but as entities which

are not only pluralistic in their forms, but are sustained through human connections and bonds. This means attending not only to points of empathy and expertise, but also to an appreciation for dynamics of prejudice, dismissal and blame, which can enter into patient encounters with doctors, healers, therapists and medical scientists. In the same way, contributors call for understandings of national health services as shaped by global inequalities, which structure not only resources, but also the positioning of institutions within global flows of expertise (Crane 2013). In all, contributors call for understandings of medical mistrust which are grounded in realistic, social and humanistic understandings of health systems.

Based on situated discussions of trust processes within healing journeys, contributions to the special issue explore how trust, or mistrust, oscillates within doctor–patient power hierarchies. They foreground extensive quests on the part of doctors to get patients to trust them, and on the part of patients to get doctors to trust their own accounts of symptoms and suffering. Additionally, contributions explore possibilities to discuss trust at the level of the medical establishment; foregrounding the lingering afterlives of medical negligence, and histories of humanitarian biomedicine which have often lacked consent in the majority world. In all, the entries reveal a fraught terrain where cures are provided in contexts of changing scientific evidence, as well as place-based histories of biomedical and social exclusion.

We respond to recent calls to consider the socio-ecological lives of medical mistrust (Benkert *et al.* 2019), through offering contributions which centre patient and survivor experience. Considering how state–community relations cohere over patient bodies, we argue for understandings of trust and mistrust which 'emerge as complex, layered, contradicting, and simultaneous social intersubjectivities permeating … healthcare provision' (Sarafian 2023: np).

COVID-19 and the ascension of trust

During the pandemic, trust became a ubiquitous term in UK and EU government policy. Against a response backed by scientific advice predominantly drawn from epidemiology and behavioural science, trust emerged as vernacular to simplify multiple and manifest human reactions to government-mandated health measures.

At different junctures of the emergency, trust—or mistrust—was used to explain: divergent rates of compliance with lockdowns and social distancing policies, variable uptake of vaccines and, latterly, to encapsulate aspirations for, or fears around, reconstruction in the post-Covid world. Subsequently, trust has been deployed by the EU, OECD (Organisation for Economic Co-operation and

Development) and WHO (World Health Organization) as a metric to compare citizen–state, and citizen–science relations (OECD 2021, WHO 2023). Within such contexts, trust has become self-referential in character; 'if only we had more trust, we could build more trust, then we would have more trust' (Storer & Simpson 2022: np). As feminist scholars Leighton and Roberts (2020) note, despite lacking a precise meaning, it has come to exist as a 'common sense' notion.

Whilst the trust boom has grown at scale, scholars have drawn attention to the need to bring context in. Wuerth (2023) noted that, during the pandemic, politicians attempted to instrumentalise trust that existed, or was imagined to exist, within local contexts, to ensure people accepted health interventions. Yet, as the effects of the pandemic in the UK become marked by raced and classed disparities, 'trust work' served to distract from the effects of austerity which fed into differential rates of mortality and socio-economic suffering. Communities who were being asked to trust—often members of historically minoritised communities bluntly categorised as 'BAME'—vehemently rejected being labelled as *mistrusting* by a state and healthcare system which had been a source of inequitable racialised provisioning prior to the pandemic.

Seeing through the performances of care which were momentarily performed by state actors towards minoritised groups, numerous forms of activism emerged to resist the erasure of inequalities. Often, efforts to bring attention to structural injustice took direct aim at histories of medical malpractice. Across many African American communities in the US, activist groups sought recognition of the historical violence rendered to communities through unethical biomedical practice; the example of the Tuskegee Syphilis trial was revived as a symbolic marker of recurrent deceptions(Manning 2020). During UK online public health briefings, Wuerth (2023) observed that community participants met calls to trust vaccines with furious chat messages about the genealogy of injustices which had distinguished communal vitality among minoritised groups, including the Windrush scandal and the Grenfell disaster. 'Trust briefings' presented a platform for groups to contest the denial of racism in the UK, made manifest in publications such as the 2021 Sewell Report. In Europe, Sarafian (2023) links widespread vaccine resistance amount Roma groups to a repertoire of injustice, which included taking Roma children into state care, forced sterilisation and segregating Roma women within maternity units.

In the wake of intense discrimination, mistrust related not to a simplistic enactment of non-compliance, but served as an active, communal response to intergenerational trauma (Benkert *et al.* 2019). Health providers were ill equipped to acknowledge and respond to the intensive discourse around prior injustice which resurfaced during the pandemic. Notions of 'misinformation' and 'conspiracy

theories' served only to inflame campaigns born from inequalities rendered through historic scientific and medical malpractice.

At the same time, complicating causal pathways between mistrust and behaviour, even in the face of these campaigns, many did not simply reject vaccines (Storer *et al.* 2022). Collective narratives of blame served to create perceptions of behaviour which disguised distinctions within groups. Yet, centring historical experiences, anthropologists and sociologists called for a centring of mistrust as the *de facto* mode through which many minoritised groups approach medicine. Throughout the pandemic, nodal figures in communities were visibly and continually invested in validating information relating to vaccine trials and their demographic inclusion criteria (Bear *et al.* 2020). The point being that historical inequalities project the need to *question* evidence; to either accept or refute the myriad dangers which could be associated with medical interventions (Storer & Anguyo 2023).

In sum, during the pandemic, activists and scholars, observing these struggles, urged for conceptions of trust which shifted the gaze away from 'transactional *trust in* institutions or supposed biomedical panacea' to relational trusts which are performed and enacted within kinship and neighbourly networks (Raschig 2022: np). Unpacking trusts' complexities was a task firmly located within an analysis which considered the ethical and social life of communities, where trust was being built in practice. In this special issue, we shift the gaze back. Building on these lessons, but considering the relationality within health systems, we ask how we can better understand the flows and functions of trusting/mistrusting relationships within the biomedical establishment.

Trust in context: history as a lens through which people view medical encounters and negotiate moral worlds

To read and frame the relationship with medical authorities, communities refer to and re-interpret history. Past experiences of discrimination, violence or racism are passed down and emerge as cultural repertoires for a subjective sense of identity bound in place and history and a reinterpretation of current relationships with health providers. These narratives of discrimination that may occur beyond the realm of medicine shape what is plausible and expected in a medical encounter in the present moment. Colonial domination was deeply intertwined with public health interventions (Vaughan 1991).

White (2005) understood 'dissent' in contemporary medical interventions as a way of assigning new meanings to specific colonial histories (2005) in the context of social and political dynamics. Thus, Fairhead and Leach (2012) warn us against

linear histories of 'trust' in which 'trust' is gained or broken down. Rather they say that medical trust or mistrust is produced in particular social and political configurations (e.g. neoliberal reform, postcolonial revolt).

Violence in medical settings is commonplace in particular contexts, as bureaucratic systems have different priorities to those of patients and healthcare workers themselves, and ignore the social nature of disease and the doctor–patient relationship (Jaffré 2003). Racialised and minoritised communities systematically experience discrimination and racism in health settings (Hamed *et al*. 2020). The medical relationship is shaped by expectations based on what is 'socially conceivable' (Chigudu 2019): the apprehension that might precede it and experience of it are shaped by people's historical experience of powerful actors, including health actors. Historical cultural repertoires of state violence or medical misconduct, such as the Tuskegee trials indicated above, shape what is considered plausible, and colours the medical encounter.

Political–economic context and power in the medical encounter

Theorists of trust have written that our current 'crisis in trust' is indicative of a wider crisis society in which we live today (Corsín Jiménez 2011) marked by declining faith in modernism and liberal progress and felt fractures in our neoliberal societies. How does this political–economic context manifest in medical encounters? In places like the United States where healthcare costs are exorbitant, there is often a lived reality that medical visits and hospital stays are marked by high bills and charges for everything. Much of these expenses are passed onto patients, who if uninsured or under-insured, will end up in medical debt. This corporatisation of for-profit healthcare in some ways underpins and drives medical mistrust, with the sense amongst many that hospitals, and by default medical providers, are profiting from these visits. In the United Kingdom, austerity policies and a lack of appropriate funding for the National Health Service (NHS) have led to highly public reporting of long wait times to see a general practitioner or specialist, low pay for doctors and other healthcare providers, and generally reduced service quality. However, these issues of under-funding and concomitant poor service quality are often not fully considered in the literature on medical mistrust.

Globally, structural adjustment programmes, austerity and user fees have created similar situations in public healthcare facilities at all levels, with costly laboratory tests at primary healthcare facilities or referrals to a private pharmacy to pay for medication when there are stockouts. Anthropological research during the Ebola epidemic in the Democratic Republic of Congo and western Uganda

demonstrated just that (Schmidt-Sane *et al.* 2020). There was a sense amongst many border communities in western Uganda that doctors are 'not to be trusted' because local clinics face stockouts and drug shortages, so the doctors 'must be selling those to make money'.

This political economy of healthcare, and in particular, a for-profit model, may indeed be irreconcilable with medical trust, particularly for marginalised communities. Power relations within a medical encounter, between provider and patient, complicate this. Many overworked medical providers may have only 10–15 minutes to spend with a patient, and so the encounter becomes distilled and transactional. There is no time to delve deeply into medical history nor a person's social circumstances. There is often a sense that patients must 'comply' with medical guidance, be it prescription or behavioural change.

Indeed, compliance is implied in much of the literature on medical mistrust. Is this the ultimate goal, to improve compliance with medical advice? Foucault's writing on biopolitics (e.g., Foucault 2008) and Agamben's writing on biopower (e.g., Agamben1998) come to mind here. Agamben notes how biopower is enacted during times of crisis, or states of exception, during which time crisis is used as justification to enact various policies—some may be good, but others may further exclude marginal or racialised groups. In the United States during COVID-19 and after, for example, this played out in terms of policies that negatively affected and took away from the rights of asylum seekers.

Biopower and cultural authority drive our normative assumptions that a doctor's orders must be complied with. How, then, does subversion or non-compliance potentially serve as a type of resistance? Do patients themselves view mistrust of providers as linked to wider socio-political resistance of power? At the centre of our modern health care systems is a nexus of power, trust and risk that cannot shift if structural features of healthcare do not shift first (Grimen 2009).

Grimen (2009) tells us that physicians are socialised to see themselves as beneficial helpers, but they are also gatekeepers and controllers, and he uses an analytic category of 'beneficial power' which is necessary to get medical work done. The nexus of power, trust and risk comes to bear on medical encounters in Western biomedical systems, which almost rely on that beneficial power and cultural authority. Medical encounters may be different with traditional healers. Sheldon's (2023) paper on one doctor's traditional healing methods (through 'nature cure') cohere with his patient's cultural worldview, focusing on a person's connectedness with the world rather than individual biology, thus engendering trust in their patient–provider relationship.

Social medicine as an interdisciplinary space offers us some answers for compassionate medical care and attention to the structural factors that shape ill

health. Paul Farmer's (2004) work on structural violence and the importance of providing equally excellent care to all has shifted notions in the medical field about how to be more trustworthy, rather than how to improve patient compliance. However, some of these lessons risk being lost, and they are lost in much of the dominant literature on medical mistrust. Instead, we need an understanding of medical mistrust-in-context, one which attends to those structural factors that drive ill health but also unequal relationships of power between provider and patient.

Moll's (2021) research in South Africa shows us how medical mistrust and health disparities result from interrelated problems of racism in healthcare provision. She describes how discrete historical events, such as the apartheid-era Project Coast and plans of biological warfare against the black population, are just one part of a longer story, which must include both enduring racial health disparities and a patient's experience at a clinic (Moll 2021).

This special issue includes papers from diverse contexts around the globe, and as such, explores the locally experienced and intersecting inequalities that shape medical mistrust. Relating to Farmer's and Moll's calls for improved care that attends to patients' lived experiences of structural violence and for clinicians to recognise *the biological effects of racism* and other forms of violence, the papers in this special issue explore new possibilities in clinical encounters and the consequences of *not* attending to or being aware of the wider social conditions that shape patients' everyday lives.

The special issue papers

The papers in this special issue come from a range of disciplinary backgrounds, diverse contexts, and medical issues and encounters within different spaces—from the clinic to the community. Sekhar and Jadhav's piece on 'negotiating trust' speaks about how trust and mistrust are fluid during times of uncertainty, revisiting material from the 1980s in the UK when haemophilia patients contracted HIV/AIDS from their treatment. Also taking a historical lens, Prates' work with Guarani indigenous people in Brazil show us how historical experience and conceptions of the body forged through outbreaks and trauma led Guarani people to question the COVID-19 vaccine. Based on work in Kenya, Muga and Igonya describe how the government's messaging on COVID-19 containment and prevention measures perpetuated mistrust and impeded people's ability to access sexual and reproductive health services. Grant's article conceptually situates trust in relation to pandemic preparedness in sub-Saharan Africa, arguing that medical mistrust is rooted in a

population's historical experience with medicine, (in)effective health systems, social context, colonial history, and a distrust of public authority.

Perkins' research on maternal health in Bangladesh focuses on the social, how medical (mis)trust is shaped by a wider moral universe of *dhora-dhori* (translated as mutual grasping or holding), or how people participate in an uncertain world. This patients' perspective shows how women act as embedded agents within their families and appeal to various social connections to tactically access services and resources, thereby collapsing distinctions between trust in personal relationships and trust in institutions, which are intimately entangled. Sheldon's work showcases a relationship between a doctor who uses traditional healing methods and his patient, whereby the doctor has to gain a patient's trust because there is a high level of uncertainty about alternative therapies. Frisone's article explores trust in the context of people with Alzheimer's disease, when declining cognitive abilities and the loss of autonomy undermine a patient's social identity and legal status. However, when caregivers preserve an unconditional trust in the permanence of the patient's subjective identity, that trust may be transmitted to clinical teams, thereby improving relationships and a patient's quality of life.

The future of theorising and operationalising medical mistrust

Taken together, these papers contribute to wider scholarly and critical attention to notions of medical mistrust and mistrust in public institutions. Much of the extant literature focuses on medical mistrust as an attitude or behaviour, with references to context, but less clear are the ways in which medical mistrust *is* context. This special issue's social science lens is both timely and imperative. What is lost when we rely on dichotomous, bounded notions of medical mistrust? What is missed when we seek to measure and 'improve' trust in medical providers, or when we understand it as behaviour? Through this special issue, we argue that critical social science literature must come to bear on these faulty and reductionist notions of medical mistrust. We hope to see future contributions that take these arguments further. We hope that these contributions will be read and acted upon in disciplines such as public health and medicine, and that future writing on medical mistrust will bring further context, nuance and complexity. Ultimately, a better and more imperative question is how do we make *medical providers more trustworthy,* rather than how do we improve *patient trust in* medical providers. That imperative requires better articulation between social science and public health scholarship and a more nuanced understanding of context.

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